

RESEARCH ARTICLE

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Taking Refuge in Spirituality, a Main Strategy of Parents of Children with Cancer: a Qualitative Study

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Abstract

Background: Due to the rise in prevalence of childhood cancer the impact on family caregivers is increasing. Spirituality may be an alleviating factor for improving the quality of parent life. There is a lack of organized spiritual care in health care facilities, so that this aspect needs more emphasis. Thus this study aimed to evaluate the spiritual strategy of parents of children with cancer. **Materials:** This qualitative study was conducted with a conventional content analysis approach. Fifteen parents of hospitalized children with cancer at the Oncology and Hematology departments of governmental pediatric hospitals nationwide were purposefully selected. Semi-structured in-depth interviews were conducted for data collection and inductive content analysis. **Results:** Eleven sub-themes were extracted in the data analysis, which resulted in the generation of three themes: “spiritual strategy,” “spiritual escape” and “spiritual growth”. **Conclusion:** The spiritual approach of parents of children with cancer had a significant influence on spiritual care and consequently the acceptance of disease and coping with the associated conditions. Spiritual care clearly should be introduced into the health care system of Iran, particular for the parents of children with cancer.

Keywords: Cancer- content analysis- spiritual- parents- nursing

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Introduction

Cancer is a growing disease (Jabaaij et al., 2012) and as a common debilitating disease, is a leading cause of child mortality in developed and developing countries. Out of every 408 children born in America, a child gets cancer (Ward et al., 2014). It affects approximately 4 percent of deaths of children under 5 and 13 percent of children between 5 to 15 years in Iran’s population (Mehranfar et al., 2012). As the family is one of the main caregivers of child, the psychological, economic, and social pressures of the child’s disease have a profound impact on the family’s life and overshadow all aspects of life and health of the family (Masa’Deh et al., 2013). Families, who have children with cancer, face an uncomfortable experience in their families. They face shock and disbelief at the time of diagnosis and are forced to live with an excessive burden. The child’s sickness affects their family and reduces their overall quality of life (Khoury et al., 2013).

Spirituality means believing and communicating with a superhuman force; a force that gives people the power to appreciate the meaning of current and future life (Wong and Yau, 2010). Because of the life-threatening nature of cancer, the diagnosis of

this disease increases the spiritual needs of patients significantly (Pearce et al., 2013). Often when people are faced with difficulties, they are leaning to a higher power (spirituality) as a way to cope with their problem (Karekla and Constantinou, 2010). Families have expressed the role of spirituality as one of the most critical factors in palliative care and spirituality plays a vital role in guiding decisions in the final stages of life and coping with illness and death (Kassam et al., 2012).

In a study conducted by Balboni et al., (2013), they demonstrated that patients suffering from advanced cancer considered spiritual care as one of the effective factors in end of life cares. Moreover, the findings of another study in America indicated that spiritual-based care resulted in escalating the quality of life by promoting religious strategies of patients with cancer (Vallurupalli et al., 2012). The results of another study asserted that spiritual beliefs improved the quality of life for African Americans with cancer (Wenzel et al., 2012). Hence, paying attention to this important dimension in caring to achieve the suitable control and management of the conditions and accept the disease by parents is a necessity (Sheikhzakaryae et al., 2017).

A qualitative research in the Netherlands indicated that from the nurses’ perspective, although spirituality is

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one of the most significant areas in the care of patients with cancer, it was not practically well considered in the care of patients and their families (Van Leeuwen et al., 2013). The conducted studies assessed spirituality and the impact it has on the lives of cancer patients but its impacts on parents of children with cancer has not been investigated. Furthermore, no study regarding the experience of parents of children with cancer was found in Iranian context.

As the concept of spiritual care is a subjective phenomenon, which is perceived and experienced by individuals, it seems that to verify this fact, it must be searched in mind, and experience of people. Therefore, the epistemology of the researcher in this study is that in order to appreciate spiritual care, the researcher entered the study as an active participant and attempted to appreciate the spiritual approach of the parents of children with cancer through interaction.

Materials and Methods

In this study, in order to clarify the experiences of a spiritual approach in parents of children with cancer, a qualitative approach with Conventional content analysis was used. Participants were 15 parents of children with cancer with the highest diversity of demographic factors. The setting of this research was oncology and radiotherapy wards, governmental oncology clinics and pediatric hospitals nationwide.

The data were gathered from January 2015 to Jun 2017 and using purposeful sampling. Participants, with maximum variation in sampling, continued the study until reaching to data saturation. Participants were chosen from parents with a child with any type of cancer who had been ill for 6 months from their childhood disease (Until the stages of shock and dismay caused by the diagnosis of the disease have passed) and have children up to the age of 12 (before adolescence). The first participant as the key participant was the mother of one of the child's suffering from cancer. The selection of contributors was the choice of people who were rich in information and can volunteer and participate actively in the study. Therefore, for the first participant to choose a mother with a child with cancer who had enough experience in this regard and tended to express their experiences in this field. Continuous data analysis, comparison of the events, differences and similarity of the data all gave the researchers the opportunity to find novel participants. Data collection was done until data saturation was achieved. Semi-structure interviews, notes and reminders were used and to record the interviews a recorder was used. The interview started with this question: "would you please tell me your experience of your child's cancer?" "What did you do after your child's disease?" How do you approach this situation?" and the probe questions were asked according to the interviewees' experience. The interviews were conducted in appropriate space and time and favorable places to the participants. After listening to the interviews for several times, they were transcribed. Interviews time was 30-90 minutes. Extracting of data led to the appearance of themes, and sub-themes. The process of data analysis was based on Lundman and Graneheim,

which means that the interviews were transcribed after listening several times. Then, the texts were read line by line, phrase by phrase and paragraph by paragraph and basic codes were obtained from these concepts. Next, the codes were compared based on their similarities and differences and were classified under more abstract classes. Finally, by comparing different categories with each other and in-depth reflection on them, the hidden contents in the data were extracted as the theme of study (Graneheim and Lundman, 2004). MAXQDA version 10 was used to facilitate the process of commuting, table of contents, classification and frequent comparison of data and recovery of quotes in the process of analyzing data.

Ethical code was obtained from Shahid Beheshti University of Medical Sciences, (Ethical code is IR.SBMU.RETECH.REC.1396.1287) and eligible individuals were identified. Obtaining informed consent from participants, the confidentiality of interviews, personal data and the freedom of participants for non-compliance or withdrawal from the study were emphasized in all parts of the study by the researchers. They also assured them that all interviews would remain confidential and trust will be respected.

Results

Participants in this study were 15 parents of children admitted to the pediatric oncology wards and clinics. Eleven mothers and four fathers attended with maximum diversity in terms of age, occupation and education. By data analyzing, three themes of "spiritual strategy", "spiritual escape" and "spiritual growth" with 11 sub-themes were obtained for spirituality approach (Table 1).

The theme of the study clarified the fact that although parents had unstable and distressful mental status after the diagnosis of their child's cancer, they attempted to boost their own spirituality which helped them in reaching to composure and getting along with the disease's conditions.

One of the emerged themes was "spiritual strategy" which included five sub-themes of "appealing to God", "Trust", "esteem of god", "thanksgiving" and "remembrance of God".

Participants used a number of strategies, which were religion based and rooted in their religious beliefs in order to coping with the child's cancer-related stress. One of these strategies was "Appealing to God". The participants stated that by means of appealing to God or asking the prophets and saints who had a high position in the history of their religion to intervene for them or conducting religious ceremonies and following God's orders, they asked God to cure their sick child.

Regarding this issue participant number 10 stated

"Saying prayer or for example, there was a praying ceremony on Tuesdays in the prayer room and we participate in more religious ceremonies. We said the prayer over the head of our girl with my husband and we trust in God and then the prophets and saints"

With regard to trusting God, the participants believed in this issue that by leaving things to God, they can accept the created condition caused by the disease of

Table 1. Themes and Sub-themes of Spiritual Approach Extracted from Interviews with Parents of Children with Cancer

Theme	sub-theme
Spiritual strategy	Appealing to God
	Trust
	Esteem of god
	Thanksgiving
	Remembrance of God
Spiritual escape	Lack of communication with God
	Religion desertion
Spiritual growth	Spiritual attitude
	Spiritual tendencies
	Transcendent beliefs
	Providence of God

their child. Human should consider God as the main reason of all events and the fact that nothing would be accomplished without his will. Concisely, let your destiny to God's hands.

Participant number 9 stated

"In that condition, when you feel that you cannot do anything and there is nobody to help you, you remember God who is the only person that can help you. Human should trust God and accept that he needs to accept that crisis and there is nobody better than God who can help human".

The participants stated that their children's sickness and tolerating its related hardships had made them closer to God because they believed that in such a condition the only person who makes them calm is God.

As the participant number 11 expressed that

"I feel that I have become closer to god during this time, and I have more connection with God. I feel I have become another person and away from religious and prayer issues, I always like to help other people because I feel like that God would help me the same way. These spiritual issues change my feelings."

Some of the participants stated that we have to be thankful of God under any circumstances. Otherwise, God would punish us and some worse events may occur.

Participant number 15 explained in this regard

"I always say prayer that now God is testing us this way, I hope I would have the capacity not to be ungrateful and my toleration would not be finished."

Furthermore, the participants stated that their relationship with God had increased in the course of their child's disease. Different issues such as religious or non-religious ones, which helped the parents to accept the disease and have hope and composure, boosted this relationship.

Participant number 9 explained

"I found this relationship with God, not that I had not had such a relationship but it increased. You know, in hard conditions human remember God more and talk

with him. Nowadays, I always talk with god while doing my prayers. It puts me in a good mood. Of course, I talk with god not only while saying prayer but also when I am walking, driving and almost always."

The other theme is "spiritual escape" which included the sub-themes of "lack of relationship with God" and "religion desertion".

Although all of the participants unanimously agreed on the significance of spiritual care in their cancer, they stated that they sometimes stay away from God and spiritual issues due to mental and psychological pressures caused by the disease.

With this regard, participants stated that the psychological and mental pressures made on the parents due to the disease of their child had made some negative mental state in them and had made them far from God. For instance, the participant number 3 stated that:

"Some of them become really pagan and deny the existence of God and hate God entirely. If they were saying prayer earlier, they quit it. They say why God has created this problem for me. They were angry at God."

Likewise, turning away from religious issues is one of the other consequences created due to the sickness of child. As the participant number 8 explained:

"I always say that if something happen to my son I will lose my belief in God"

The third theme of this study was "spiritual growth" which consisted of the sub-themes of "spiritual attitude", "spiritual tendencies", "transcendent beliefs" and "providence of God".

Spiritual attitude originates from the depth of human consciousness and cognition and results in the promotion of human lifestyle and mental health. The participants stated that spirituality is like a superior force that a person can connect to it.

Participant number 3 expressed

"My experience of spirituality is non-material things, such as soul, God, prayer,"

Moreover, participant number 8 stated

"Spirituality is not just repeating the sacred words; spirituality means trusting and leaning on a superhuman force."

With regard to the spiritual tendencies, as we know, the origin spiritual inclinations of human is in his nature and somehow clarifies the man's relationship with God in the realm of moral and spiritual strategies. Being in the path of spiritual growth is the path to perfection and happiness, which is the want and consent of God for every human being and it, is the desire of perfect humans.

Participant number 2 explained

"Spirituality is something personal and we cannot make somebody do something against his will. Parents usually do such things because such things are in human nature and in these conditions, they are converted from potential to actual and these critical conditions act as a stimulant to manifest these issues in them."

Moreover, with regard to transcendent beliefs it could

be said that belief is the sense of certainty, choosing, and superiority and it refers to the features and beliefs of people leading to perfection and *happiness*. For example, participant number 7 stated that:

“When I faced with this issue, I asked my friend to make a charity organization for children with cancer. I know the well-known Mahak Charity Organization exists in Iran but I wanted to help the unprivileged children who are living in other provinces where Mahak Charity Organization is not working there.”

Participants considered religious beliefs as any belief that has a religious origin. They accepted anything, which was happening by attention and thought and according to the religious rules, was religious belief. In this regard, participant number 5 explained:

“As we are Muslims, parents get help from the prophets and saints and bring green cloths to fasten on their children’s beds or wrists. They say prayer. Sometimes, they make Yassin necklaces for them. It is likely that these beliefs make them calm.”

Another issue that the participants emphasized them was the providence of God, which referred to the willing and wants of God. It was having tendency toward something that leads to wanting that thing. With regard to God, providence means creation and the existence of object. Participant number 8 explained:

“I say, maybe, something worse was supposed to happen and God had mercy on me from this way. Maybe he wanted to come back because my son’s disease is inactive now”.

Participant number 7 stated

“Human is an autonomous creature and the only creature which is given the authority is human which is not separated from the God’s willing. I mean that when something happens, it is the providence of God that event occurs. If I don’t accept that event at first, later on I would accept it and I would be silent. When I accept it and I become silent, it is actually the time when the miracle happens and what I want comes true”.

Discussion

Three themes of “spiritual strategy”, “spiritual escape” and “spiritual growth” were extracted. In other word, although spiritual escape existed, the participants attempted to reach a spiritual-based approach to accept the disease by means of devising spiritual strategies and spiritual growth.

The first theme of the study, which was spiritual strategy, indicated that the participants believed conducting religious activities is a means to achieve composure, have hope in future, and tolerate hardships and critical conditions related to the disease. They could have the power to accept their hard condition by connecting to that super human power. Religion and spirituality plays a key role in the acceptance of disease for cancer patients and it provides hope and relief (Molassiotis et al., 2009).

Hamilton et al., (2015) found that religious beliefs and activities such as prayer was the power source for participants. The participants of Hamilton et al., (2013)

stated presence of God throughout their lives and his control over their survival will cure their disease. In the study conducted by Hekmatpou et al., (2013) one of the emerged themes was trust in God and the parents of children with cancer pointed out its positive impact in their lives. In addition, Hunsberger et al., (2014) showed that in families of patients with cancer religious issues during the course of the disease increases. The participants in the study carried out by Abdolli et al. believed that their disease was God’s want and they believed in the destiny that God had chosen for them. This belief in God resulted in the acceptance of the disease by them (Abdoli et al., 2011). Harandi et al., (2009) claimed that their participants believed in God’s will in conducting issues and their disease and they had accepted their disease by leaning on spirituality. The participants in the Ebadi et al., (2009) asserted that spiritual tendencies had resulted in creation of meaning for life during their disease and it had increased the quality of life.

In another study carried out by Falah et al., (2012) religious issues such as prayer, Appealing to God and forgiveness had been effective in their compliance with the disease. Hassankhani et al., (2010) expressed that religion plays an essential role; the participants stated that spiritual values as a source for coping with their problem and disease and hope in future had increased in them.

Iran is a Muslim country; spirituality in Iranian culture is according to the orders of God and regulations of the Quran. This issue could create composure in the individuals and help them make spiritual growth (Ahmad et al., 2011). It is believed that Spirituality is a source of support (Hashemi et al 2015; Mollica et al., 2016) and coping resource in facing the problems (Bonomo et al., 2015; Reutter and Bigatti, 2014). Spiritual care can reduce tension, depression, lowliness of patients and by creating positive and enjoyable feelings; it promotes the quality of life (Sankhe et al., 2016). In Iranian culture and society with regard to religion, people believe in fatalism and their disease was God’s will (Sadati et al., 2015)

Therefore, the analysis of the participants’ speeches in this study indicated that issues that were used by the participants with regard to religion were Appealing to God, trusting God and saints, relationship with God and feeling intimacy with him, believing that the child’s disease was due to God’s will. All of these issues led to calming the child’s parents and hope to the recovery of their child and better acceptance of their disease which in turn could result in strengthening their spirituality ultimately.

The second theme of the study was spiritual escape, which clarified that the stressful conditions of the child’s disease had resulted in lack of faith in God and aversion from spiritual and religious issues in some of the participants. Schreiber and Edward, (2015) claimed that the participants experienced that God is involved but distant. However, staying away from God, the weakening of religious faith and unwillingness to do religious activities were listed as the reasons for spiritual escape. Moreover, Taylor et al., (2015) stated that feeling helpless and seeking for support were seen more than anything else in the youths and elderly suffering from cancer; they have seen that these patients were suffering

from a sort of spiritual vacancy. In this respect, Sankhe et al., (2016) asserted that the spiritual needs of cancer patients often involves finding meaning and hope, access to spiritual resources and extracting meaning from life because these patients and often their families were suffering from lack of purpose, value and meaning in life due to their physical injuries.

Belief in life after death was one of the things that the participants referred to in the study by Khramimarkani et al., (2012) did not achieve such a theme, which could be attributed to the fact that parents did not accept the death of their child in the recent study (khoramimarkani et al., 2012)

In this study, the participants claimed that in some cases the mental and psychological pressures of their child's disease had made them far away from God and spiritual issues. However, despite this spiritual escape, parents had reached the necessary spiritual uplift with regard to spirituality.

The third theme of the study, which was spiritual growth, showed that participants had diverse strategies in terms of spiritual matters, belief in God, a superior force, spiritual matters. They are personalized, which could be variant considering every one's culture, and the belief that helping others, generosity and devotion will strengthen the spiritual dimension in human can be helpful in creating peace in individuals.

Spirituality during suffering from cancer could lead to the understanding of God as the supreme power and an opportunity to increase faith and acceptance and continuation of treatment of disease. The patients consider cancer as an opportunity to reform spiritual beliefs in life and getting closer to God by which they could overcome their fear of death. In addition, by appreciating God's power as the supreme power, they understand their own power in overcoming disease and consequently provide them with an opportunity for spiritual growth and development (Abrams et al., 2016). As Kumar et al., (2017) Participants stated that cancer disease increased their faith in God and changed their perspectives. Schreiber and Edward, (2015) claimed that the participants experienced spiritual uplift during suffering from disease, cancer was seen as an opportunity for their spiritual growth, and faith in God is stronger. In addition, Sun et al., (2015) stated that cancer improved the spirituality in families of patients with cancer (Sun et al., 2015). Peterson (2014) observed in his study that cases like feeling protected, feeling of connection to an extraterrestrial force is effective in the spiritual and psychological distress of children with cancer. The researcher suggested that children with cancer and their families must be assisted in finding out the meaning of life, creating hope in them, and meeting their spiritual and psychological distress. Cancer induces psychological problems in parents, which may serve as factor that drives them towards spiritual affairs (Sheikhzakaryae et al., 2017).

Due to the spirituality is a vital element in the search for meaning and purpose of life and disease is a chance for spiritual, therefore it is necessary to consider the spiritual needs of patients and their relatives should according to their culture (Delgado-Guay, 2014).

Findings of this study showed that spirituality is personalized and it is a personal issue, which is different from each person to the others. Each person can develop spirituality within himself according to the spiritual approaches and his needs beliefs and experiences.

In conclusion, the results of this study indicated that spirituality led to compliance with disease and increased the hope in future and composure. Therefore, the necessity of paying attention to this topic in the nursing education programs, in-service training courses for medical staff as well as holding training classes for parents of children with cancer can be noted.

Sampling from different regions of the country and choosing participants with variation in age, gender and experiences are strengths of this study. This study was conducted on Muslim participants, so the results may not be generalized to non-Muslim patients. It is recommended that similar studies be conducted on participants with other children chronic disease and other religious and ethnicities.

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