

Caring strategies in parents of children with cancer

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Abstract

Background: The increased prevalence of cancer in children influences the family as the main child caregiver. Regarding the spiritual dimension for increasing the life quality of parents and its effect on the management of the conditions induced by the disease, the goal of this study was to determine the strategy of care in parents of cancer children.

Materials and Methods: This study was performed with a qualitative method using the content analysis approach. Fifteen parents of the cancer children who were admitted to the Oncology and Hematology Wards of the Iranian Public Children's Hospitals participated in this study. First, the mothers were interviewed, then other participants, including fathers and mothers who had a special experience about this issue were studied through theoretical sampling. Data were analyzed using content analysis method.

Results: Data analysis led to the apparent main category of "intelligent rethinking" that included two subcategories: 1) "Cognitive confrontation" with the subsidiary categories of "effort to adopt" and "accept the disease" and 2) Optimism with the subsidiary categories of "hope" and "positive energy".

Conclusion: This study showed that spirituality has an important role in accepting and complying with disease by parents of a cancer child. This would lead to managing the conditions and achieving the hope, positive energy, and efficient management of the conditions. 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.

Key Words: Cancer, Nursing, Qualitative research, Parents, Spirituality

Introduction

Cancer is a common disabling disease that causes the child's death in different countries (1). When cancer is diagnosed in a child, it is as if the diagnosis is made for the whole family and all members of the family face the treatment (2). Cancer diagnosis in children not only affects the child's life, but also affects the mental health of the children (3, 4) and creates mental problems for them (5). Families who have cancer children, face, in fact, an upsetting experience, are shocked, and are forced to live with an additional burden of

disease. Child disease reduces the life quality of the whole family (6). Developing cancer is the most important and most serious problem which a person may face. In patients with the chronic physical problems such as cancer, the role of the coping or accepting the processes is very important for the health situation of the patient (7). Life-threatening diseases such as cancer, due to the effect of the cancer on the patient and his family, cause enormous changes in the structure and performance of the family. Since the childhood cancer is considered as a life-

threatening disease, the role of parents is increasingly important as the primary and main caregiver. Then, due to changes in the role of parents, they face various and complex problems. In addition to the cancer patients, the family has to be cared for (8).

Cancer is a disease with a strong impact on the patient, his family, and friends. Cancer patients need the long-term care at home. This changes the life routine. Since the child has to be admitted to hospital and be cared for at home, most mothers are forced to change their lifestyle. Fathers usually follow their previous duty and care for the other children and family in the absence of mother. In comparison to mothers, fathers' life does not change so much. However, the fathers also are affected by their child's disease. Therefore, all members of the family should organize their roles, interaction patterns, and internal and external relation, and attempt to adapt to the new conditions. Then, the performance of the family members and the performance of the whole family are affected by the disease (9).

Families coping with chronic diseases such as cancer, are different. The question here is: why is it that after being informed that one member of the family is affected by cancer, some families adopt an upsetting and boring life and surrender death, but other families cope with the disease stubbornly. Of course, this coping doesn't mean the complete remission, but these families experience a significant life by their innovative methods. What is the difference between these two groups? What factors can introduce the different behavior in facing the cancer? One of these factors can be the spiritual care in the families with a cancer patient (10).

Spirituality makes the patients compatible with the cancer and introduces a positive view of life and increases the life quality and sedation in patients (11). Spirituality makes the patients decide better and reduce their stress and unreliability (12).

Families referred to the importance of the role of spirituality and stated that spirituality plays an important role in conducting the decision-making, compatibility with disease, and death. Spiritual care requires understanding the spiritual beliefs and knowing the spiritual needs (13). Spiritual care influences decision-making and contribution of the patient in the treatment of the disease, and life quality of the patient and his family in the final stage of life and should be noticed as a part of treatment (14).

Offering spiritual care to the patient and his family can reduce the physical pain, increase psychological relief, reduce depression, reduce anxiety, increase the speed of healing, increase hope, induce deeper relationship between patient and nurse, and create a goal for life (15).

In fact, by reducing the cancer effect, the spiritual interventions can increase the life quality of the patients and their caregivers and create some positive outcomes (16,17). Given that the spiritual care is a mental phenomenon that is understood and experienced by persons, this study tried to interact with the participants and obtain their experiences with spiritual care and strategies which parents use to manage the situations.

Materials and Methods

To answer the question: "what is the strategy for the parents of cancer children in facing the disease?", this study used the qualitative approach and qualitative content analysis method. Fifteen parents of children with cancer were selected with maximum diversity in terms of demographic information for this study. The study environment included the departments of Oncology, Radiotherapy, and Oncology Clinics of the public hospitals. The data were collected in 2016 using the purposive sampling method. Sampling was continued until data saturation. In the purposive sampling method, the participant who was the mother of one of the cancer children who

had sufficient experience, and was inclined to participate in the interview, was first selected as a key participant. Then, other participants including fathers and mothers of the children with cancer were interviewed based on the information obtained from previous participants and data analysis. The parents of cancer children who were younger than twelve years of age (before adolescence) participated in this study. A personal semi-structured interview and field notes were used to glean the required data. A recorder system was used to record the interviews. The interview started with a general question: "Please present your experience with your child's cancer" and then other questions were followed in terms of experiences. The questions differed from one participant to another. Duration of the interview was averagely 60 minutes.

In this study, the data analysis process was based on the Lundman & Graneheim method. In this method, after performing the interviews, the researcher immediately listened to the interviews several times to get a general understanding of the content. Then, the interviews were transcribed verbatim. Next, the text was read in details and the initial codes were obtained. Then, the researcher compared these codes. Subsequently, the similar codes were classified into a more abstract category, and finally by comparing the classifications and their careful consideration, the content hidden in data was introduced as the major theme. Also, the MAXQDA software (version 10) was used to analyze the data.

After getting the code of ethics from Shahid Beheshti University of Medical Sciences under code number of IR.SBMU.REC.1395.11, the researcher identified all qualified persons and performed interviews after obtaining informed written consent. The researcher explained the research goals and procedures. She also observed all ethical issues in the study including principles of anonymity and information confidentiality.

Moreover, the participants had freewill to cooperate or withdraw from the study in all steps of the study.

Results

The participants were 15 parents (11 mothers and 4 fathers) of cancer children who were admitted to the oncology wards and clinics with maximum diversity in terms of age, job, and education (Table I). The results obtained from data analysis formed the main category of "intelligent rethinking" that included the subcategories of "cognitive confrontation" and "optimism" (Table II). The first theme of the study was the Cognitive Confrontation. Due to changes in the conditions of life routine and pressure introduced by the child disease, parents need some interventions to adapt and cope with the situations. When the current behavior of the person is not sufficient to cope with the situations and the person should change the behavior, the person uses the adaptation approach. In adaptation, a person changes their cognitive built to cope with the new situation. In other words, adaptation is a process of changing the cognitive built to adapt to the new understandings.

Participants stated that they tried to adapt and comply with the new conditions and reduce the stress induced by the child's disease using the different methods.

Participant number 9 stated: "I participated in the psychology class. There, anyone was asked to show his/her emotions. They were asked: what was your emotion, mother? Say the memories of your child. Abreaction creates a better mood."

Participant number 1 stated: "I thought it was what happened. If I lose my hope, I couldn't perform a useful work. The spiritual issues make me hopeful. I'm sure that this problem will have a happy ending. The hope made me to adapt to the new conditions."

This led the participants to adapt quickly. Participant number 5 explained: "Familial support is very important. If you have a

good husband (or wife) and don't have the family problems, you can better adapt to this problem. This support helps to solve the problem".

Participant number 14 said: "Talking to other families who are in a similar situation is very useful and helps us about the treatment process, follow-up, and the end of the treatment",

The second theme obtained from the study was "optimism". One of the issues that was referred to by the participants, was hope. Hope is a state created as a result of expecting in humans and leads to peace, contentment, and confidence.

Participant number 11 stated: "Other parents that are here and have a similar situation, help us very much. When we talk together and we understand they had a child with cancer, similar to our child, and had the same situation, and now their child is improving, our hope increases and we are encouraged to continue treatment. They say: Don't worry. We also endured

such hard situations. The spiritual atmosphere that is dominant there, influences us and increases our hope."

In addition, participant number 6 stated: "Religious activities and confidence in God were very promising for us. We hoped for future. I thought if God wants it, my daughter will be surely treated".

Moreover, participants referred to the role of optimism. Optimism means having an optimistic attitude, thinking, and behavior in life. Optimism helps people to adapt to the situation in the best way. Optimism means considering the positive issues in life and not regarding the negative aspects of life.

In this regard, participant number 7 stated: "now, I enjoy life more than previous. The wealth is not important to me. This problem drives me to try to enjoy what I have and try to maintain them, not to try to obtain what I don't have without appreciating what I possess. This gives me a positive and good mood and feeling."

Table I: Demographic characteristics of the participants

| Characteristic | Frequency |
|------------------|-----------|
| Gender | |
| Female | 11 |
| Male | 4 |
| Age | |
| 20-29 | 3 |
| 30-39 | 4 |
| 40-50 | 8 |
| Education | |
| Diploma | 6 |
| Associate degree | 4 |
| Bachelor | 4 |
| Master | 1 |
| Job | |
| Employee | 4 |
| Housekeeper | 8 |
| Others | 3 |

Table II: The main category and sub-categories of the strategy of the parents of cancer children facing the disease

| Main category | Subsidiary categories | Subsidiary subcategories |
|------------------------|-------------------------|---|
| Intelligent rethinking | Cognitive confrontation | Effort to adapt Admission of disease |
| | Optimism | Hope Positive energy |

Discussion

After data analysis, the final category of "intelligent rethinking" with two sub-categories of "cognitive confrontation" and "optimism" were extracted. Parents are considering ways to deal with child disease and its problems. Spiritual care leads to parental re-thinking for effective control of conditions, which is called intelligent rethinking in this study. The first theme of the study was "cognitive confrontation". Parents stated that using spirituality is one of the ways to adapt to the disease.

Religious practices are considered as a key factor in the treatment. In fact, religious beliefs become important during disease more than ever and help the patient to adapt to the disease and increase the ability to cope with disease and improve the treatment process. Disabling and chronic diseases cause the patient face the challenges about the goals of life. Generally, religious activity is a reinforcing resource for patients that increase the treatment rate (18).

In a study by Hildenbrand et al., (2014) performed on the parents of the children with cancer, parents stated that they used different methods to adapt to the disease including cognitive organization, admission, relaxation techniques, practical strategies, support based on the problem, expression of the emotions, obtaining information about disease and exploring the solution, and spiritual or religious adaptation. Parents stated that believing in God and God's presence in life eases

enduring of the disease and conditions (19).

In a study by Hexem et al., (2011) performed on the parents of the children with cancer, the participants stated that belief in God is the cause of peace and is effective in adapting to the disease (20).

Mollica (2016) found in his study that spirituality makes a better decision-making in the patient with cancer and is an adaptation resource for them that reduces their stress (21).

Hexam et al., (2011) performed a research about how parents of children with cancer who received palliative care, could use the religion, spirituality, and life philosophy in the hard moments. This research was performed qualitatively using the method of grounded theory in which the main category was "religion, spirituality, and philosophy of life". These parents have reported that spirituality and religious activities help them in their decision-making about treatment of their child. In addition, this increases their control on the existing situations and conditions (20).

The second theme was "optimism". The participants stated that a hope for the future and a positive feeling were introduced by different methods of adaptation and performing the spiritual activities leading to hopefulness and peace for them.

In different studies, it is shown that spirituality increases the good feeling in the patient with cancer (22). In Perez & Smith study (2015), it is shown that spirituality and religion make the people

adapt to their cancer, and then a good feeling is introduced (23).

Bekke-Hansen (2014) carried out a study on the patients with heart diseases, as a chronic disease, and showed that belief in God increased during the disease. This belief made a positive impact on their quality of life (24).

Also, Kumar (2017) found in his study that spirituality makes the patients with cancer adapt to their disease. This creates a positive outlook of life and increases peace in the patients (25).

In the study by Pedersen et al., (2013) performed on patients with cancer, they observed that increasing the belief in God increases their life quality (26). Also, Tsai et al., (2016) concluded in their study that the religious belief makes a mental support for patients with cancer (27).

Pedersen et al, (2014) studied the spiritual care of the children with cancer. This study demonstrated that spirituality is a vital dimension of a child's experience at the end of life. Issues such as being supported and a sense of connection to extraterrestrial forces are effective in improving the mental upsetting of these persons. The results of this study indicated that to admit and cope with disease, the child and his family should be helped to show emotions and reinforce their relations. The cancer children and their family should be supported to find the meaning of life, find hope, remove the spiritual distress, and optimize mental growth (28).

Hamilton et al., (2015) conducted a qualitative study on patients with cancer. According to the participants' opinions, they found that the religious belief and belief in God create peace and hope in the patients (29). The study by Stebra et al., (2014) focused on religiosity and spirituality among the cancer survivors in America and South Africa and their caregivers. The results showed that the more the spirituality, the more optimism in the patient with cancer (30).

Conclusion

The findings of this study performed with the goal of explaining the strategies of parents of the children with cancer, showed that the parents of children with cancer, due to the created mental stress, use spirituality as a method to admit the disease and control and manage the situation. Spirituality causes the patients acquire hope, positive energy, and effort to adapt to the disease. This study can be a basis for more interventional studies to evaluate the effect of spiritual care on the strategies of the parents of the children with cancer.

Limitations and suggestions

This study suffered from some limitations that constrained the generalizability of the results. This study investigated the experiences of parents of children with cancer. These experiences may be effective for other people coping with the disease. Then, we suggest that future study be performed about this issue. Also, we suggest that other research be performed about the parents of children with single cancer disease. With regard to the clinical situations and shortage of the human resources, the common curative care in the health centers focuses on the physiologic symptoms and less attention is given to parents. Therefore, it is necessary to train the treatment team about studying the needs of the parents of children with cancer, offering the correct information and spiritual care and religious beliefs to parents, and improving their abilities in this field.

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Conflict of interest

The authors declared any conflict of interest with respect to this article.

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