

Original Article



Explaining the Process of Spiritual Adjustment in Parents of a Child with Cancer: A Qualitative Study

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Abstract

Introduction: Having a child with cancer impacts the family members and reduces their quality of life. Considering the fact that spirituality creates tranquility, hope for the future, and acceptance of the disease, this study aimed to explain the process of spiritual care in parents of a child with cancer.

Methods: This study was carried out using a qualitative method and grounded theory approach. The setting of this research was oncology and radiotherapy wards, governmental oncology clinics and pediatric hospitals. Using purposive and theoretical sampling method, 22 participants (eight mothers, three fathers with childhood cancer experience and 11 individuals working in oncology departments of different Iranian pediatric hospitals) were selected and individual and semi-structured interviews were conducted.

Results: The data analysis led to the creation of a core variable of "bridge towards spirituality" which included five main categories of "unstable situation", "spirituality," "crossing rocky path", "multi-dimensional support", and "rethink".

Conclusion: Due to the significant impacts of a child's cancer on parents and the fact that people's spiritual needs increase in critical and stressful situations, paying attention to the spirituality process is essential for managing the conditions created by the child's disease and help parents through developing a comprehensive program of spiritual care in health care centers. Spiritual care is currently absent in the health care system of Iran, which necessitates attention to this issue in the parents of children with cancer.

Introduction

Cancer is one of the most challenging health problems that a person may face. Despite recent advances in the treatment of different types of cancer, still the concept of such a disease means the end of life for many people.¹ Having cancer, suffering from severe treatments, and the resulting fatigue affect the physical, functional, social, and psychosocial status of patients and their families and it triggers the feeling of disability in them.²

Families are more exposed to cancer-related pressures than others. In other words, since the family is the main caretaker of the child, the psychological, economic, and social pressures of their child's disease have a profound impact on all aspects of the life and the health of the family members.³⁻⁵ Families face a distressing experience when their child is diagnosed with cancer. They experience shock and disbelief; and have to live with a double burden, and consequently, their quality of life is reduced.⁶

Due to the life-threatening nature of cancer, the diagnosis of this disease significantly increases the

spiritual needs of patients.^{7,8} Often, when people are faced with the difficulties of life, they tend towards a superior power (spirituality) as a way of coping and adaptation⁹; as a result faith in God increases in patients with cancer.¹⁰ In order to prevent the negative impacts of cancer on various aspects of the life of the individual and his family, the need for spiritual care is the main objective in the care of these patients.¹¹ Since cancer diagnosis, as well as its invasive and long-term treatments, eliminates the patient's ability to enjoy life in many cases, it often causes patients to suffer from a lack of purpose, value, and meaning in their lives. Therefore, it is necessary to pay attention to the spiritual needs of these patients and their families during rehabilitation because it can affect the quality of life of both patients and their families.¹² Families have expressed the importance of spirituality since it plays an essential role in guiding decisions in the final stages of life, adaptation to disease, and death.¹³

Due to the major role of spirituality in improving the health of cancer patients, helping to meet the spiritual

needs of these patients and their families is considered as a vital element of clinical care. In order to provide comprehensive care to patients, it is necessary to pay special attention to the spiritual dimension as one of the important and effective dimensions of human health. Therefore, considering the importance of this issue and the lack of a similar study in Iran, we focused on investigating spirituality in parents of children with cancer.

In this study, the researchers attempted to identify the views on spirituality by entering into the world of minds of families of a child with cancer as well as those who are related to these patients, such as medical personnel. The researchers used the statements and interpretations of the people involved in the research, to understand the phenomenon and the interactions that occur during spirituality adjustment. Also, given the spirituality adjustment in the context of society and in interaction with people, the researchers used grounded theory approach for this study. In addition, using the grounded theory approach, one can have a deeper appreciation of the complex phenomenon of spiritual care and its hidden aspects in the social and cultural context of the Muslim community. In addition, describing and revealing the processes of mutual interaction between individuals in one social context; would ultimately lead to the provision of foundations related to spiritual care. Accordingly this study aimed to explain the process of spiritual care in parents of a child with cancer.

Materials and Methods

Using a grounded theory method, this study was carried out based on the Corbin and Strauss (2008) approach, with four steps including data analysis for concepts, field data analysis, linking data analysis process, and class composition.¹⁴

The setting of this research was Iranian oncology and radiotherapy wards, governmental oncology clinics, and pediatric hospitals and data collection was performed from January 2015 to June 2017.

After clarifying the objectives of the study, an informed written consent was obtained from the participants. The researchers considered all the ethical issues in the research including the confidentiality of interviews and anonymity of private information. Moreover all participants were free to leave the study at any stage. The participants of this study were 22 people including 11 parents with a child cancer (eight mothers and three fathers), four nurses, two psychologists, two instructors, and three doctors working in the oncology and hematology departments of state hospitals Tehran. The first author conducted face-to-face interviews in the oncology units and clinics, and purposeful and theoretical sampling was used for data collection.

Individual and semi-structured interviews were conducted. Initially, general questions such as "State your experience when your child was diagnosed with cancer"

were addressed and other questions were asked according to their follow-up experiences. Firstly, the sampling was done purposively and we asked some questions from the mother of a child with cancer, who had adequate experience in this field. Then, the rest of the participants entered into the study from the third interview by theoretical sampling and this continued until data saturation. Each interview lasted for 30 to 90 minutes. For example, the following questions were asked: What happened to you when you found out that your child had this disease? Describe your experience when you heard the diagnosis of the child's illness. Tell us about your experience working in pediatric oncology. Data collection and data analysis were performed simultaneously. In this study, after holding 22 interviews, there was no new, and this meant data saturation. MAXQDA10 software was used to encode the data and Corbin & Strauss approach was used for data analysis.

In order to determine the validity of data, the method proposed by Corbin & Strauss was used, which included the appropriateness of the data for the research team and participants, the applicability of the findings, the organization of concepts for their understanding, and the use of reminders.¹⁴ Member check and peer check were used for accuracy and robustness of data. To determine the validity of the data according to the method by Corbin and Strauss, which included data fit for the research team and participants, for use the findings and organization of concepts and understand them we use of memoing. To judge validity and reliability of the data, credibility, transferability, dependability, and conformability suggested by Guba and Lincoln were used.¹⁵ To provide the above mentioned criteria, researchers carried out long-lasting contacts with participants to assure them, used interview instructions, allotted adequate time for interviews, assessed and compared the obtained data and their categories to find similarities and differences, double-checked the data with participants, and presented data analysis and research characteristics in detail for the readers.

Results

The participants of this study were 22 individuals with an age range of 22-50 year and different education levels (from a high school diploma to a specialty in medicine). Eight mothers, 3 fathers, 4 nurses, 3 doctors, 2 psychologists, 2 university instructors working in the oncology department participated in the study. Data analysis were showed of experience of participants in spiritual care (Table 1).

When the researchers raised questions about the participants' experiences, most of them pointed out that the child's illness caused various reactions, including denial, anger, depression, and the like. These conditions could have an effect on their compatibility with the disease, the acceptance of the created conditions and elimination

Table 1. The categories and subcategories of spiritual care in parents of a child with cancer

Core variable	Category	Subcategory	Sub-subcategory	
A bridge to spirituality	Unstable situation	Mental desperation	Exhaustion	
			Mental pains	
			Mental concern	
		Inefficient support	Inadequate support	
			Insufficient awareness	
			Religious beliefs affected by society	
	Spirituality	Spiritual adherence	Resort	
			Trust in God	
			Divine glory	
			Thanksgiving	
			Existential acceptance	
			Remembrance of God	
	Crossing rocky path	Lack of supportive resources	Spiritual attitude	
			Spiritual desires	
		Family affection	Spiritual beliefs	
			Belief in divine providence	
		Multi-dimensional support	Emotional support	Social support failure
				Emotional support failure
			Care and treatment support	Parental relations changes
				Family mood failure
			Social support	Family sympathy
				Acquaintance sympathy
	Rethink	Cognitive confrontation	Health care team support	
Acquaintance support				
Optimism		Governmental centers' support		
		Private centers' support		
Loss of family life quality	Spiritual support	Spiritual teaching		
		Need for spiritual presence		
	Parents' support with the help of the child	Mental support		
		Physical support		
Loss of family life quality	Cognitive confrontation	Attempt to adapt		
		Acceptance of disease		
	Optimism	Hopefulness		
		Positive energy		
Loss of family life quality	Spiritual challenge	Reduced communication with God		
		Religion escape		
Loss of family life quality	Loss of family life quality	Family disorder		
		Changes in life		

of their calmness. Participants stated that they used every way to calm down and control the conditions. Therefore, the main concern of the participants was 'the challenge of relaxation'.

Regarding the first category

For example, the participants stated that:

"I felt very bad and shocked and I can't even accept it

now. I have no idea of life and all I am thinking of is my son. Life does not mean anything to me. I don't know how to express my feelings but when I say nothing is meaningful, it means it is the end of the way of my life." (Mother, 45 years old)

"When I just found out that my son has cancer, I had a feeling...I was feeling confused and I felt I was not in this world. I had a lot of mental problems and I was saying why

should this happen to my child." (Mother, 48 years old)

In this study, parents had tense experiences and were under the influence of the contextual conditions, which was spiritual despair, this would result in a sense of threat to their child's life and uncertainty about his/her recovery. The main goal was to create calmness and tranquility to overcome the stressful conditions. Therefore, actions, feelings, and interactions were toward achieving this goal, which was called the "spirituality" and included the strategic patterns of "spiritual adherence" and "spiritual growth."

Since awareness of the disease and the process of treating a child with cancer caused many mental and psychological crises for the parents, they used different patterns to manage changes and problems associated with the disease, including the spirituality. Parents were trying to do spiritual affairs to relax and reduce tensions. The use of these strategies help parents; to accept the disease and cope with the conditions created by it.

Regarding the second category

"Wherever I am, I say prayer for others and then for my own kid. When I chant the religious words, I do it for all the kids in the oncology ward. I read Quran every day because it gives me calmness and serenity; I chant the religious words a lot. I ask the prophets for help and I trust them." (Mother, 42 years old)

"God has wanted to examine us. People are examined differently but some of the exams are really hard such as this issue. God wants to examine parents by their kid's disease. We are saying prayer and asking God to give us the power to tolerate this burden." (Father, 43 years old)

In the meantime, a number of factors were considered as barriers to the acceptance of illness and serenity in the participants, which included "lack of supportive resources" and "family affection", which ultimately led to the main category of "crossing rocky path".

Regarding the third category

One participant said:

"My husband has a bad mental status, so he can't help me in this situation." (Mother, 45 years old)

"We even had bad fathers who were addicted and said a thousand insults and misdeeds and did not support them at all." (Nurse, 45 years old)

The existence of a series of factors as facilitator played a major role in the process of compromising with the disease and eliminated the main concern of the participants, which was the "multi-dimensional support" category including "emotional support", "care and treatment support", "social support", "spiritual support", and "child support".

Regarding the fourth category

For example one of the participants stated:

"Acquaintances and relatives come and look after the

kids for a few hours so that the parents could take a rest or they look after the other healthy kids at home so that the mother could look after the cancer child in more relaxing conditions." (Physician, 35 years old)

The set of strategies that parents of a child with cancer used to deal with the concerns resulting from the illness creates the context for the incidence of consequences in people. In this study, the parents eventually reached to the "rethink" which due to the problems caused by child's cancer and its impact on the family. Considering the ways in which they were prepared to accept and compromise on the disease, the consequences included the creation of "rethink" that included the subcategories of "cognitive confrontation", "positivism", "spiritual challenge" and "loss of family life quality".

Regarding the fifth category

In this regard, two participants stated:

"After a while, I managed to control the situation and accept the illness; the situation was as before again because, in my opinion, no one can manage the situation like a man at home. Of course, my wife was right next to me and she was giving me emotional support; she wanted to pacify me." (Father, 50 years old)

"I've prayed so much, but the results of the medical tests are not good and even I do not have anyone to listen to me. They say that there is a God that will help, but is it possible that I beg so much and God does not reply? These issues make me lose my belief." (Mother, 45 years old)

After the initial codes were extracted, similar codes were placed in a category and the corresponding subclass was written. Then the sub-classes were placed in a category according to their similarity and formed a sub-class. In the same way, according to similarity and style, the subclasses were placed in one category and the main class was abstracted.

In order to determine the core variable, the main concern of the participants was determined and then, the core variable that links all these categories was determined. Cancer, a chronic and debilitating disease, is a crisis for the family of a child with cancer, and parents as the caregiver of the child are affected by the complications and consequences of the disease.

Parents also enter the healthcare environment for the treatment of their children, and they are faced with a situation that reflects the inadequate support of the treatment and hospital staff in terms of their mental, and spiritual health. Moreover, the nurses and other staff do not have enough knowledge in this area, and there is no related systematic care. In addition, considering the culture of the Iranian Muslim community and the teachings given in this regard, religious attitudes and beliefs are created in their minds at the time of birth born.

Discussion

The results of this study showed the "bridge towards

spirituality” which included “unstable situation”, “spirituality”, “crossing rocky path”, “multidimensional support”, and “rethink”. As the results of this study indicated, the diagnosis of the child’s cancer had led to shock and disbelief, rejection of the disease, and psychological and behavioral symptoms in the parents and they suffered from diverse mental reactions.

In current study, the participants sought to blame someone for the illness of their child. For example, they blamed themselves, others, or the health care team, which led to distress and criticizing themselves or others. However, the parents stated that they had been able to accept their child’s illness. Another study showed the necessary compromise and adaptability with their trust in God and doing religious affairs.¹⁶ In one study on the experience of parents of a child with cancer, parents said that the diagnosis of their child’s cancer was very difficult and shocking for them, and the participants stated that this caused discomfort and mental problems for them as well.¹⁷ In addition, anxiety and fear of death caused by the disease reduced the quality of life in the families of people with cancer.^{17,18} Performing religious affairs could reduce anxiety and depression in mothers of a child with cancer.¹⁹ In current study, the participants stated that by trusting God and conducting religious affairs, they had gained the ability of adaptation to the disease, and the higher the level of spirituality in people, the higher the ability to face the stressful conditions of life. Thus, as the spirituality increased in participants, their mental health increased as well.²⁰

The results of another study from the perspective of families and caregivers, showed that spiritual affairs and beliefs could affect the quality of life and mental health of the patients and families and decrease depression and anxiety.²¹

In a study, Reisi et al investigated the relationship between spirituality and anxiety and depression in cancer patients, which showed a significant relationship between them.²²

In current study, the participants used different spiritual strategies such as trusting God, depending on God, and remembering God; they had created the background for spiritual growth and reached themselves to real peace that was connection to a higher power. In one study, the participants believed that performing religious affairs was a mean to acquire composure, hope in future, and tolerate the hardships and critical conditions of disease. They had achieved the ability of peace and adaptability with the disease by connecting to a higher supernatural power. Religion and spirituality played a pivotal role in the adaptability of the patients and provided comfort and hope.²³ Issues such as being supported and the sense of connection to a supernatural power were effective in the spiritual and mental disorders of families having a child with cancer. This can help the child with cancer and their families to find the meaning of life and to create hope in

them to relieve spiritual and philosophical disorders, and to increase their spiritual growth.²⁴ Ultimately, in current study, the participants could achieve the ability to manage the conditions and gain adaptability with the current conditions. They stated that the hope for future increased in them and they had achieved the positive energy for efficient management of situations.

In one study, the researchers analyzed how the parents of a child with cancer who had taken palliative care used religion, spirituality, and philosophy of life in the hard moments of life. This study was qualitative and had been conducted using the grounded theory. The core categories were “religion, spirituality, and philosophy of life”. These parents stated that spirituality and religion helped them in the therapeutic conditions and decision-making situations. Moreover, it increased their control over the current conditions.²⁵ Religious beliefs and belief in God created calmness, comfort, hope, and acceptance of illness.²⁶ Spirituality increased, optimism, positivity²⁷ and adaptability, and at the same time reduced anxiety,²⁸ it also improved the quality of life in cancer patients.²⁹

The results of the study by Rajati and colleagues regarding cancer have confirmed the positive effect of religion and prayer in this disease.³⁰ In one study on cancer patients, the participants initially felt frustrated and fatigued and believed in fate and prepared themselves for bad events. However, religion and religious affairs had created hope and power in them, and had contributed to adaptability and gaining a new meaning in their lives.³¹

As stated, in current study, the participants referred to a number of factors as facilitators of the spiritual care process, such as the support of the community and the treatment team, the charity, and the hospital, which helped them in spiritual care process. Other factors such as lack of supportive resources, family problems, and reduced contact with God were among the factors that delayed their attainment of calmness and adaptation with a disease, and played a deterrent role in the spiritual care of parents. In another study, the presence of the parents in the hospital along with the sick child had led to problems and contradiction in doing their jobs. Leaving their job had pushed them under many financial burdens.³² Some studies showed the nurses did not give them any positive energy and paid attention just to their physiologic needs. They did not consider the patients’ concerns and did not allocate time to sympathize with the patients. In this regard, the participants asserted the high workload of the nurses, lack of time, and fatigue as the barriers to their spiritual care. Moreover, the participants stated the necessity of the presence of staff that could help them in doing their religious activities. They claimed that there was no clergyman or religious consultant in the ward to relieve their concerns.³³

In current study, the fathers provided the necessary support for the mothers and made their relationships closer to their spouses. For example in one study claimed

if fathers help their wives at home and, by dividing their responsibilities and Collaborate with them, they can tolerate the conditions created by the disease better.³²

Paying attention to the personal and social problems of patients and their families would lead to better compliance by patients and their caregivers by providing social and economic support.^{34,35}

In addition to patients and their families, spirituality has a positive role in the nursing care behaviors. Spirituality played a positive role in caring behaviors in nurses and it made them provide better care services for the patients and their families.

This study, had some limitations negatively affecting the external validity of the findings. Since this study was conducted on Muslim participants, the results may not be generalized to other conditions with non-Muslim patients.

Conclusion

In this study, the parents of a child with cancer pursued different spiritual strategies such as trusting God, resorting to God, and doing religious and spiritual activities. In the meantime, the presence of factors such as lack of support from the community and acquaintances and the problems caused by the disease led to a change in the lifestyle and the relationship among family members. In some cases, their relationship with God was dimmed due to the psychological stresses of the disease, which was an obstacle to the spiritual development of individuals. There were other factors such as acquaintances' support, which included emotional and caring support as an aid to the parents. On the other hand, the supports provided by the medical staff or the charity and hospitals, as well as spiritual support of others people (e.g., clergymen) could create calmness and lead to their spiritual growth. Finally, by practicing the spirituality approach, parents acquired the ability to accept the disease and adapt themselves to the conditions caused by the illness, and the hope for the future increased in them.

It is recommended that similar studies be conducted on minority religious ethnicities to attain externally more valid results. This study investigated the experiences of the parents of a child with cancer; these experiences may be effective for other people coping with the disease. For example, sister or brother. Hence, we suggest that future studies this issue.

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Author's Contributions

SSG; Interview: MIB; Coding data: NSHZ; Writing and editing and interview: MSH; Interview: SZ; Coding data. All authors have read and approved the manuscript.

Research Highlights

What is the current knowledge?

Cancer is one of the diseases that causes a lot of stress to those around the patient, and efforts are being made to understand the different aspects of the impact of this disease on caregivers.

What is new here?

In this qualitative research, various aspects of the impact of cancer in children on caregivers from the perspective of different people who are in contact with the child have been discussed, and from this aspect, this research has novelty and innovation.

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Data Accessibility

The datasets are available from the corresponding author on reasonable request.

Ethical Issues

The Ethics Committee of Shahid Beheshti University of Medical Sciences authorized the permission to conduct this study (ethical code: IR.SBMU.REC.1395.11).

Conflicts of Interests

The authors declare no conflict of interest in this study.

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