



Parents' experience of pediatric cancer: A qualitative study

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Original Article

Abstract

BACKGROUND: Suffering from life-threatening diseases such as cancer, due to its impact on the patients and their next of kin causes myriads of changes in the structure and function of the family. The objective of this study was to clarify parents' experiences of childhood cancer.

METHODS: This qualitative study was conducted through purposive sampling method. Semi-structured interviews were conducted with 20 parents whose children were diagnosed with cancer in the oncology department of Besat Hospital in Sanandaj City, Iran. Interviews were transcribed and analyzed through Benner's thematic analysis.

RESULTS: During data analysis, 4 main themes emerged including destroyer and terminator of life, horror and hope, disturbance of normal life, and gaining valuable experience.

CONCLUSION: Parental roles, routine care of a child with cancer, and facing multiple treatments and childcare problems threatened parents' compliance with the condition of the disease or treatment, and thus, parents sought social support. Therefore, more attention should be paid to the parents' probable reaction and different life dimensions. To make healthcare more effective, providing necessary psychological, mental, and emotional support and increasing parental hope is necessary. Parents of a child with cancer should be assisted in preventing some healthcare problems and coping with their child's illness.

KEYWORDS: Cancer, Qualitative Research, Parents, Diagnosis

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Introduction

Cancer is one of the leading causes of death in the world; thus it is called the new epidemic of our time after heart disease.¹ Among childhood chronic diseases, cancer has become the most important because it is prevalent and has a major impact on the life of the child and the family.² Cancer is the third leading cause of death in Iran after heart disease, accidents, and other natural phenomena,³ and the second leading cause of child death in Third World countries.⁴ This disease accounts for about 4%

of the deaths of children under the age of 5 years and 13% of children aged 5 to 15 years in the Iranian population.⁵

The development of life-threatening diseases such as cancer, due to their effects on the patient and his/her relatives, causes many changes in the structure and function of the family.² Today, the role of parents, especially mothers, is increasingly being addressed as a primary caregiver. Therefore, parents are faced with many complex problems due to changes in their parental role.⁶ For example, long-term exposure to cancer treatment in childhood causes stress and has negative impact on the quality of life (QOL) of parents.⁷ Cancer causes a disruption in the patient's life plan and that

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of every family member, and thus, challenges the entire family.⁸ The role of family members as caregivers has a positive impact on their adaptation to illness,⁹ and these caregivers play a central role in managing various aspects of the patient's care.¹⁰

When a child develops an illness, various factors in his or her family change. The daily activities of the family which were previously planned to meet the needs of the family change in order to meet the current needs of the child; therefore, family caregivers of patients are called hidden patients.¹¹ Caregiver personality traits, stressors, stress assessment, coping strategies, and social support affect the QOL of caregivers.¹²

Caregivers of cancer patients may face many physical, social, and economic problems in their care process, and their family life, marital affairs, occupation, health, and social life are negatively affected by caring for the patients.¹³ Cancer in children may have adverse effects on the parents' job opportunities,¹⁴ and causes a high socioeconomic burden due to its high fecundity, the high cost of treatment, long hospitalization, and psychological problems in the patient and his/her family.¹⁵

The mental and psychological effects of childhood cancer in the family are sometimes more disabling than the physical nature of the disease, and since parents are considered to be family pillars they must maintain family coherence through adaptation to the illness.¹⁶ In parents' experience of childhood leukemia, the main theme appeared to be the deadlock in the parents' life.¹⁷ Considering the abstract nature of this subject, the qualitative study of the experiences of parents can lead to a deeper understanding. Qualitative research provides a good opportunity to generate deep knowledge of nursing through the experiences of individuals¹⁸ and facilitates the collection of data which provide an understanding of the meaning of phenomena from the perspective of individuals. Indeed, this type of research

responds to the questions of individual experiences through the explanation of motives, attitudes, reactions, and perception.¹⁹

Other related articles have presented some aspects related to the effect of cancer on the family, but there is not adequate material regarding parents' experiences. Considering this lack of material and the heavy burden of this disease, the question that arises is "How is the first experience of having a child with cancer?" Considering this question, the most suitable method for this study was a method that could illustrate the nature of the phenomenon in its natural context, along with its structure and the factors affecting its formation. Therefore, the present study was designed in a qualitative way. This study aimed to explain parents' experiences of childhood cancer.

Materials and Methods

Considering the research question, this qualitative study was carried out using phenomenological methods.

Through purposive sampling method, 20 mothers and 4 fathers whose children were diagnosed with cancer in the oncology department of Besat Hospital in Sanandaj, Iran, were selected and participated in the study. The study inclusion criteria were parents' willingness for participation, ability to communicate, age of more than 18 years, and having a child with cancer who was newly diagnosed and undergoing treatment. The newly diagnosed treatment course may vary in different individuals and cancers, and usually, in different studies, the duration of stress disorder is considered 2-3 months after the diagnosis of the disease.²⁰ Therefore, in this study, parents of children who were diagnosed with and treated for cancer during the last 3 months were selected as participants in the study. This study was conducted in 2017.

The main data collection method used was in-depth semi-structured interviews. The researcher referred to the oncology ward and

interviewed the participants after obtaining informed written consent. All interviews were recorded on tape, and immediately after completion of each interview, the text was fully transcribed. In some cases, informal interviews were also used. The interview began with a general and simple question about the diagnosis of a child's cancer and ended with more specific questions. The duration of each interview was 45 to 70 minutes, depending on the situation. In order to keep the identity of the participants confidential, they were given a number from 1 to 20. Moreover, to increase the credibility of the findings regarding the correctness of the interpretations and the coding process, a number of faculty members familiar with the method of analyzing qualitative research were consulted with.

The thematic analysis method was recommended by Benner²¹ as the method of data analysis. In this method, first, data analysis should be started, and then, having effective flexibility at all stages, each stage of the development of work should be guided.²² However, in general, information management includes classification and ranking of primary data, modification and moderation of categories, integration of both initial and meaningful themes, presentation to an expert group, extraction of main themes (general), re-presentation to the expert group, and ultimately, the explicit and unambiguous expression of the underlying structure of the phenomenon, i.e., the parents' experience of their child's cancer in the studied subjects. To obtain a general understanding of the text of the interviews and the transcribed information, they were read several times. In this method, the comprehensive comprehension of the text is more important than understanding sentences, paragraphs, and metaphors. A regular and continuous movement from the components to the whole text, and vice versa, is imperative and emphasized in order to create a general perception of that text.²¹

The information coding steps included the following steps.

1. Classification of raw data by reviewing and retrieving texts transcribed from the interview tape, written descriptions of the participants, and other available documents in order to achieve a general perception of the concepts and phenomena examined
2. Extraction of important data and determination of the similarities and differences between meanings and primary raw texts
3. Setting the meanings and concepts extracted in the previous steps
4. Classification of meanings and concepts in the primary categories

This study was approved by the research committee of Kurdistan University of Medical Sciences, Iran (no.1394.97). This study was approved by the Ethics Committee of Kurdistan University of Medical Sciences, with the code of ethics no. IR.MUK.REC.1394.97. All participants were volunteers, and written consent was obtained from each of them in which the voluntary nature of the participation was mentioned. The participants were assured that they could leave the study at any time even after they had signed the consent form. They were assured that their care would not be affected if they chose not to participate in the study. They were also assured of data confidentiality; this meant that their names and other significant details, which might reveal their identity, would not be published in the study report. All the participants' names were changed into codes during the transcription of the interviews, data was locked in separate locations and the coded information was used for data analysis and discussions.

Results

In order to explain the experiences of parents of children with cancer, similar sentences and phrases were first extracted from the responses, and then, were classified in terms of concepts and themes.

Table 1. Categories and subcategories

Primary code	Subcategory	Category
Life terminator	Life destroyer and terminator	Destroyer of life
Life destroyer		
Terrible and invincible	Terrible and invincible	
Horror of death	Horror	Horror and hope
Desperation		
Hopelessness		
Huge shock		
Hope for God's mercy	Hope	
Trust and faith in absolute divine power		
Huge problem	A mountain of problems in life	Disturbance of normal life
The ill child's problems		
Family problems		
Neglecting of ordinary life	Neglecting life	
Self-neglect		
Neglecting other children		
Gaining experience for compatibility with the present problems	Gaining experience for compatibility with problems	Gaining valuable experience
Gaining experience for compatibility with future problems		

The participants included 20 women and 4 men aged 27 to 53 years with the mean age of 40 years, and their education level ranged from illiterate to undergraduate degree. Finally, they were interviewed, and the 4 categories of destroyer and terminator of life, horror and hope, disturbance of normal life, and gaining valuable experience emerged as main themes with 40 primary codes and 8 subcategories (Table 1).

Most of the participants who had a child newly diagnosed with cancer stated that cancer was an enervating disease and for those suffering from cancer, the probability of death is high. Participant number 3 stated: "Cancer is like a black plague that destroys everyone who gets it." Another participant also said: "Cancer is a crippling and destructive creature" (P13). Another participant said: "I have always been horrified by cancer. I thought of it as a scorpion or crab in my body eating and destroying the organs, and it reminds me of a black and dark way" (P5). With regard to the horrified and invincible subcategory, participant number 11 declared: "Cancer seems to me like a very big and horrible monster that

is very powerful and difficult to defeat." Another participant also stated: "I am horrified by this terrible disease and I see it as a competitor who cannot be defeated. Treatment is very difficult and long, and it is impossible to defeat it" (p6).

One of the other main categories that the participants acknowledged was horror and hope. Horror had 4 subcategories of huge shock, desperation, horror of death, and hopelessness. The shock caused by the diagnosis of a child's cancer, which is a severe blow, affects not only the parents, but also the child and all other family members. Participant number 5 affirmed: "The news of our child's cancer was the worst shock to us". Participant number 10 said: "When I discovered that my child had cancer, it was as if the whole world had crashed on my shoulders. It was really a very difficult moment. It was painful." Participant number 8 also said: "The news of my child's cancer was the worst news I had ever heard, I was shocked, and it was as if my world had been damaged."

With regard to fear of death and desperation category, most of the participants

stated that they felt frustrated with the diagnosis of their child's cancer. Participant number 14 stated: "When the term cancer is used, the first thing that comes to everyone's mind is the idea of death and dying and feeling desperate and frustrated." Participant number 7 stated: "My heart was squeezed to such an extent that I felt that the world was small for me and that my child was dying. It made me crazy." Participant number 11 stated: "The news of my child's cancer was equal to a sense of worry, disappointment, and loss of my dearest." Participant number 9 also stated: "It is a very serious danger that you cannot cope with. You lose all hope, and you think your dearest will disappear due to this great danger and he cannot survive."

Hope for God's merci and trust and faith in absolute divine power were the sub-themes of horror and hope. Participants reported that on hearing that their child was diagnosed with cancer, based on religious teachings, they asked God to solve their problem because he was the supreme authority and they should trust him. Furthermore, most participants noted that the child's illness increased their hope and trust in God. Participant number 7 stated: "I had lost my heart at the beginning, but I soon realized that I had to do all I could by trusting in the merci of the Lord to help heal my daughter." The hope for God's mercy in most of the participants' statements was in the form of the need for words of hope, noticing God's merci, strengthening the morale of the child to continue treatment, and accompaniment and empathy in care and treatment. Participant number 11 explained: "I believe that the pain that God gives, will also be healed by him. Therefore, I ask for my child's health from God." Participant number 1 also stated: "My child's relative recovery is due to God's grace. He is omnipotent, and his kindness is given to everybody and this feeling makes me calm and gives me hope".

Another major theme of the study was

disturbances in the normal routine of life, and most parents in the study acknowledged that their child's cancer caused them to encounter many problems in different aspects of life. This theme consisted of the 2 subcategories of a mountain of problems in life and neglecting life.

With regard to the mountain of problems, participant number 5 stated: "After my child developed cancer, we had a lot of problems. We had to leave the village and come to the city. My husband was a farmer and now he is unemployed. The cost of hospitalization and treatment of a child is very high for us, and besides the sadness of the child's illness, we have many problems in terms of the cost of the treatment and our life expenditure." Moreover, participant number 3 stated: "After the diagnosis of my child's cancer, our life was destroyed, our priorities changed, and all of our future plans were forgotten." Another participant (p9) said: "After the child's development of cancer, the parent feels like he/she is stuck in a hole full of problems, that he/she is lonely and there is no one to save him/her." Participant number 11 also said: "In addition to my sick child, I have two other children at home that are impossible to handle and I practically do not take care of them; my mother and my sister occasionally take care of them."

Neglecting life was the next primary theme about which participant number 2 stated: "My daughter's illness paralyzed the normal course of our life." Another participant stated: "All my life, priorities, and future planning were destroyed" (P14). In this regard, participant number 12 said: "We were always partying and traveling, but this interrupted everything. My husband's job has been closed for the past 3 months; when I was in the hospital, he was at home with my other children. We are constantly commuting between the house and the hospital." Participant number 6 explained her experience in this regard as: "All our connections with friends and relatives have been broken. Most of the time, my wife and I

do not have the time to talk to each other, there is no pleasure left in our life."

In general, limited social activity due to looking after the child was one of the problems that the participants experienced in the form of loss of occupational status, a reduction in the duration of their work, limitation in social activities outside the home, such as reduced contact with family and friends, and recreational activities and sports. This subcategory especially emerged among those parents' who had the assistance of other family members or close relatives in looking after their other children or immigrated here from their village and town.

The last theme was gaining valuable experience for parents of children with cancer which consisted of the 2 primary themes of gaining experience for compatibility with present and future problems.

Most of the participants acknowledged that having their children be diagnosed with cancer was a valuable experience for themselves and their children in the face of future problems, for example, participant number 12 stated: "In the face of future problems, we have learned to be more patient in comparison with those who have not had such experiences." Regarding the same issue, another participant affirmed: "It was a valuable experience, but experiencing such a thing was really difficult" (P15). Another participant stated: "Children with cancer become weaker, more agitated, and more restless due to long and hard treatment. Parents should be patient and calm so that they can help their children relax and tolerate the pain of treatment. In this experience, you will become more and more patient than the past, but the cost is the difficulty and suffering of this experience" (p16). Another participant also said: "I am sure if my child survives, he will be a very strong person in any problem. He could be unaffected by any problems and he can cope with any problem that occurs in the future" (P3).

In conclusion, the parents' experience of their child's cancer was that they considered cancer as the destroyer of life and believed that they had a disorder in their normal life. Although they were afraid of their child's treatment, they considered the experience as valuable.

Discussion

In this study, the destroyer of life emerged as one of the main themes and was confirmed by all the participants. The most common concerns of parents were identifying a child's cancer and having many problems, and challenges posed to the child's life and death. Moreover, the life-threatening nature of the disease was one of the most important concerns and one of the concerns of parents after the diagnosis of the child's cancer, especially the sense of imminent death and the close proximity of their child to death. The results of this study are similar to the results of a qualitative study by Jadidi et al.; they reported parents' complete helplessness and absolute frustration in continuing to live after hearing of their child's cancer and that they considered cancer equal to death.¹⁷ These findings were also in agreement with that of the study by Streubert et al. which showed that the most notable concern of mothers of children with cancer was death.²²

Similarly, a qualitative study reported that mothers of a child with cancer are exposed to a destructive experience in their families, and when the disease is diagnosed, they suffer from shock and disbelief and are forced to live with the extra burden on their shoulders.²³ Having a child with cancer changes the lives of parents and their mothers and families experience many physical and psychological stresses. The identification of the mothers' concerns by healthcare staff and planning for therapeutic interventions based on their needs and concerns is necessary. Therefore, in order to adapt to these problems, it is necessary for mothers to be supported by more family

members and nurses. Support from professionals ensures the parents confidence in conducting therapeutic and caring measures.

Mothers of a child with cancer noted fear of losing a dear child on the one hand, and belief in God and the mercy of God on the other hand as their experiences. The results of this study were similar to that by Bjork *et al.*,²⁴ Neil and Clarke,²⁵ Yeh,²⁶ in which the primary response of parents after a definitive diagnosis of blood cancers was fear and horror because they considered cancer as imminent deaths. In the Iranian-Islamic culture, which is more family-dependent, parents of a child with cancer are more likely to be affected by stress. Losing the child was reported as the parents' worst and biggest problem. All of the parents of a child with cancer were frustrated by their complete disbelief in the child's survival because of their negative perception of cancer, which was equal to death in their perspective.²⁷ Anxiety and fear of the future in the event of a recurrence of illness and the loss of a lovely child were expressed as parents' experience. Uncertainty of treatment is an important and recognized issue in the clinical and experimental literature. Because the parents' exposure to the diagnosis of their child's illness is an acute and stressful incident, it causes some symptoms in them. Since all of the participants in the study were Muslim, it is likely that using some strategies such as religious strategies can reduce their level of stress and concern. Patience is one of the most valuable beliefs of Muslims that helps them overcome difficult situations, and they see it as an action that gives value to human performance.²⁸ Nurses can use some coping mechanisms, such as supportive religious beliefs to reduce the harmful effects of cancer in parents.

One of the other aspects emphasized by the parents was God and seeking help from him for recovery. During this period, feeling hopeful and the search for meaning and

purpose in life have a religious basis and faith and prayer are important sources of strengthening it.²⁹

In the current study, the results showed that when the status of the child was getting worse, parents were more hopeful of God's help. The expression of trust in God and the belief that God is a superior and absolute force without any condition made all participants communicate with God and trust in him at the time of diagnosis and throughout the treatment process. To explain these findings, one can say that hope allows humans to overcome stressful situations and enables them to make a lasting effort to achieve their goals. The hopeful human does his best to achieve more goals.²⁴ Trust in God, which meant trust and reliance on his power, was a hard and unconditional support in difficult times. With faith, recourse, and trust in him, solid steps could be taken to tackle this massive problem because relying on God's power strengthened the will and decreased the effect of psychological stressors and made them more capable of achieving harmony and balance.^{30,31} Tartaro *et al.* also talked about God, praying, and gaining power from God as the most common defense mechanism to deal with stressful situations.³² Considering the results of this research, nurses can emphasize the importance of the role of prayer in maintaining health and enhancing effective coping strategies in life-threatening illnesses, such as cancer in children. Considering the Iranian people's belief in the hypothesis of prayer and its effectiveness, it is desirable to use this treatment method as a complementary treatment in combination with other kinds of therapies. Since this method may still be unknown to some and, as is the case for the presentation of any new method of therapy, its experimental stages and effectiveness must be institutionalized in the healthcare system. Thus, further studies on the efficacy of prayer, especially in chronic patients, are

recommended. Another concept emphasized by the mothers was disruption in the normal routine of life. Having a child with cancer caused many changes in both parents' lives and many psychological and social problems.

Most of the parents involved in the study pointed out that when they became aware of their child's cancer, they became conscious of serious family problems, the disintegration of their family, and their sense of helplessness and loss of life. They stated that they lost their normal life, had a sense of disability which disturbed the relationship between parents, they could not look after other family members, and they discontinued family and social relationships. In addition, it disrupted their occupational, social, and experiential experiences. All of these were in line with the findings of Bjork *et al.*,²⁴ Neil and Clark,²⁵ and Kars *et al.*,³³ which resulted in harm to the family and the marital relationship.

Miedema *et al.* stated that when a child is fighting cancer, all of the family gets involved in the issue, it disrupts life patterns, and the healthy children of this family also experience issues in facing the needs and wants of their sick sibling.³⁴ Syse *et al.* also argued that cancer significantly reduced the job opportunities and income of the parents and increased their psychological stress and caring responsibilities.¹⁴ It has also been reported that with the diagnosis of childhood cancer, a major change occurred in the QOL of the family,³⁵⁻³⁷ causing marital problems and divorce among parents of children with cancer. According to Cohen, economic problems among parents of children with cancer increased their psychological problems (stress) and affected the continuation of the treatment of the child from the financial perspective.³⁸ Similarly, Brown *et al.* stated that the existence of financial stress, job losses, and various other economic problems among cancer families has been proven.³⁹ One of the themes achieved from the results of a study on the experiences

of parents of children with cancer in Lebanon was increased responsibilities of parents and the consequences for the family.³⁵ This study also found that fathers' experiences are largely related to financial problems and mothers' experiences are related to fatigue and the feeling of guilt for leaving their other children at home.³⁵ Therefore, during the treatment of the child with cancer, parents needed support and advice from the healthcare team and family members. The presence of family nurses and psychological counselors, and participation in groups with parents going through similar experiences can help in this regard because today only physical care is provided in many healthcare centers. Therefore, it is suggested that centers be established for mental counseling for the parents so that parents and patients can better cope with sickness and obtain the ability to get back to normal life.

Gaining valuable experiences in dealing with problems and the increased suffering and responsibility of parents was another theme that increased the tolerance of both parents and the affected child. In this study, the changes resulting from cancer treatment and its implications were described as a continuous battle against cancer by the participants. This was also noted in the study by Behrman and Field, in which the parents of the affected child believed that the diagnosis of cancer in the child needed fighting.⁴⁰ The family's system was challenged with a new experience, and, on the whole, the child's illness was considered as a battle which required a continuous fight; they stated its consequences, and expressed hope for the future and planned for it.⁴⁰ As a result, as nurses are aware of the family's problems, they should help them reorganize roles, interactive patterns, and relationships within and outside the family to help them adapt to the new situation. Performing parental roles, routine care of the affected child, and confrontation with multiple childcare treatments threatened parent's

compliance.⁴¹ Parents were seeking social support and, when their child was in the hospital, meeting the parents of other children with the same diagnosis, and who had gone through psychosocial problems, and were more experienced helped them become much more relaxed. In the present study, receiving emotional support and sympathy and empathy with other parents of a child with cancer in the hospital have been reported by the participants. Owens et al. also argued that parents of a child with cancer used parents with similar experiences as a supportive source⁴² which was consistent with the results of the study by Jadidi et al.¹⁷ Abu-Saad³⁵ and da Silva et al.³⁶ also acknowledged that the vast majority of mothers, although initially denied it and believed that their children did not have cancer, they finally came to terms with the issue and talking with other parents of a child with cancer helped them. Parents helped other parents through caring for other children with cancer and purchasing food for each other. Pediatric oncology nurses can provide parents with information about childhood cancer and child care methods. Through parental meetings and encouraging parents' participation in these meetings, these nurses not only provided them with the necessary information, but also helped parents to share their life stories and experiences with others. Perhaps through this method they will be able to meet the needs of their sick child in a more comfortable way.

Limitations and Recommendation: One of the limitations of this research can be the psychological state of the participants when responding to the researcher, which was beyond the control of the researcher. However, the researcher tried to overcome this limitation by providing a suitable and safe atmosphere for the parents. The other limitation was that the study was conducted in only one medical center in the capital of the province to which patients from different cities were referred for treatment; the long distance from home could

affect part of their experience. Therefore, further studies on this issue with similar participants are recommended.

Conclusion

In this study, the experiences of the parents of a child with cancer were deeply analyzed with a qualitative approach. The 4 major themes of destroyer and terminator of life, horror and hope, disturbance of normal life, and gaining valuable experience were extracted. Issues such as various philosophical questions (life and death, faith, and hope) and being socially supported were parents' major concerns irrespective of advances in treatment. Childhood cancer was a severe emotional stressor for parents. Therefore, their possible reaction, as well as their different life dimensions should be addressed in order to increase parental hope. Spiritual, mental, and emotional support will make the healthcare services more effective, and help parents avoid some health problems and deal with illness and death. Nurses, physicians, psychologists, and mentors are required to train and enable parents to care for children with cancer.

Conflict of Interests

Authors have no conflict of interests.

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