

Challenges of children with cancer and their mothers: A qualitative research

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ABSTRACT

Background: Cancer is one of the major causes of death in children and adolescents. About 4% of deaths in children of age less than 5 years and 13% of deaths in children of age 5-15 years are due to cancer in Iranian population. The disease can cause many problems, which are usually detected by a psychologist, for the children and their mothers. Therefore, this study aimed to identify the psychological challenges of the children with cancer and their mothers' experience.

Materials and Methods: This is a qualitative research conducted through thematic analysis approach. Semi-structured interviews were used to collect the data. Purposive sampling was conducted. The numbers of the children and their mothers participating in this study were 34 and 32, respectively.

Results: Data analysis showed that the problems faced by children with cancer and their mothers fell into five main categories. These categories included spiritual, psychological (such as aggression, anxiety, depression), communicational problems, inadequate knowledge (about the disease, its treatment, and treatment complications), and care-related problems.

Conclusions: The results showed that lack of awareness and spiritual problems were the most important problems of the patients and their mothers. If necessary knowledge about the disease and its treatment and complications is given to the children and their mothers at the time of diagnosis, and also, spiritual care interventions are administered during treatment, their psychological problems can be notably reduced.

Key words: Cancer, children, Iran, qualitative research

INTRODUCTION

Cancer is one of the major causes for mortality among children and adolescents. This disease accounts for about 4% of mortality among children less than 5 years of age and 13% of mortality among children between 5 and 15 years of age in the Iranian population.

^[1] Individuals diagnosed with cancer are prone to various degrees of stress and emotional suffering.^[2] A child diagnosed with cancer primarily suffers from its initial signs, which may be ignored and can affect his/her quality of learning and educational level. As a result of the disease complications, the type of treatment the child receives, and being far from his/her peers, physical, cognitive, and emotional problems may occur for the child with cancer.^[3]

There are studies on the methods to decrease such signs,^[4] but there is no qualitative study investigating the children's problems from their own viewpoints. Another point to consider is that research shows that diagnosis of cancer directly affects patients' and their caregivers' quality of life and changes their daily life through different methods.

From the very beginning of its diagnosis, cancer highly affects the physical, social, psychological, and spiritual dimensions of cancer patients and their caregivers, and puts them in a challenging situation. Especially, the mothers of children with cancer have a very disturbing experience in the family. They are shocked and seek denial and have to live with double pressure. The disease of their child influences their family, and consequently, their quality of life is diminished.^[5] Meanwhile, there is no study investigating the challenges faced by these mothers based on their own viewpoints. A proper treatment intervention for these patients is selected in such a way that the selected treatment meets all these needs of the mothers. Therefore, the best way to determine the intervention method is to know about the internal world of the individuals. This research aimed to detect the challenges faced by children with cancer and their mothers, in order to reveal their therapeutic needs.

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MATERIALS AND METHODS

The main aim of qualitative research is to deeply understand the reason and manner of phenomena. It helps to clarify the facts, norms, and values from the viewpoints of the participants.^[6]

With regard to the increasing incidence of cancer among children and a few studies conducted in the context of the challenges faced by the children and their mothers, the researcher decided to investigate these challenges with a qualitative approach to clarify these patients' needs to let nurses take a better care of these patients by knowing how they experience these problems.

In the present study, a qualitative method with thematic analysis and researchers' observations was used.

Sampling was done by convenient sampling, and the study population comprised children with cancer and their mothers referring to Seyed-Al-Shohada hospital in Isfahan in 2013. The participants were 34 pre-school and primary school children and their mothers ($N = 32$). Data were collected by semi-structured interviews.

Mean lengths of the interviews with the children and the mothers were 35 and 60 min, respectively. Interviews were recorded and the transcripts were noted word by word.

Based on the approach of Braun and Clarke, the sentences and paragraphs were considered as meaning units, and were coded and named based on their hidden concepts. The codes were compared based on their similarity and dissimilarities and the themes emerged. Data collection continued until data saturation in such a way that no new ideas, concepts, and themes were obtained in the last two interviews. With regard to rigor of the data, a part of the transcripts together with the primary codes were given to the participants to compare and confirm the consistency of the extracted codes with their own experiences as peer check. Member check was also adopted and the transcripts were reviewed by other co-researchers twice.^[7]

In the present study, it was tried to respect all ethical considerations. Therefore, a written informed consent was obtained from the participants before conducting and recording the interviews.

The participants were assured of their option of leaving the study at any stage with no effect on their treatment trend. They were also assured about the confidentiality and anonymity of the obtained data and their usage just in the direction of the research goal.

RESULTS

Based on the research goal, which was finding the challenges faced by children with cancer and their mothers, the obtained data and primary codes were detected. In primary coding, 752 open codes were extracted, and in constant analysis and comparison of the data, they were reduced to 124 codes. The codes were compared with regard to their similarities and dissimilarities and the themes emerged.

The themes that emerged from the participants' responses obtained were categorized into five main domains including spiritual, psychological, communicational, knowledge, and care-related problems. There were 11 subthemes in mothers' group and 11 subthemes in children's group.

Spiritual problems

As presented in Table 1, the subthemes of children's and mothers' spiritual problems were similar, although they were extracted from different concepts. This category is divided into three subthemes in the children's group as follows.

In the subtheme of "why me", one of the participants who was a 6-year-old girl with ALL (Acute Lymphoblastic Leukemia) said:

"I am a good child and follow my dad and mom, why God made me sick?"

Table 1: Obtained themes and subthemes of the challenges of the children with cancer and their mothers

| Subthemes of children's group | Themes | Subthemes of mothers' group |
|--|--------------------------|---|
| Why me Connection with God Divine punishment | Spiritual problems | Why me Connection with God Divine punishment |
| Anxiety/fear Depression Aggression | Psychological problems | Anxiety Depression Aggression |
| Being spoilt and demanding too much from the relatives Communicational problems due to treatment (alopecia) | Communicational problems | Familial disputes due to the child's disease Paying too much attention to the diseased child and depriving other family members from attention |
| Inadequate knowledge about the disease, its treatment, treatment complications, and disease prognosis | Knowledge problems | Inadequate knowledge about the disease, its treatment, treatment complications, and disease prognosis |
| Lack of cooperation in medication due to boredom Lack of cooperation in nutrition | Care-related problems | Mother's loneliness in taking care of the child Lack of trust on nurses and continuous attendance in hospital |

In the subtheme of “connection with God,” a 6-year-old boy with diagnosis of osteosarcoma said:

“why doesn’t God listen to me? I pray so much but I am not yet healed!”

Another female, a 5-year-old participant with diagnosis of AML, (Acute Myeloid Leukemia) said:

“They say God loves the children, why doesn’t he love me and doesn’t heal me?”

In the subtheme of “divine punishment,” another 6-year-old boy with diagnosis of AML said:

“As I disturbed my mom, God made me sick, I promise not to disturb my mom anymore. Perhaps, as I lied, I got sick!”

Another 5-year-old boy with diagnosis of ALL said:

“Hamid is yet a bad boy, why doesn’t he get sick?”

Spiritual problems in mothers’ group were categorized into three subthemes of “why me”, “connection with god”, and “divine punishment”. The participants mentioned the following issues in these subthemes.

One of the participants who was the mother of a 10-year-old girl with diagnosis of rhabdomyosarcoma and was in “why me” category said:

“I always wished everybody the best, I was punctual with my pray and fasting, I always helped charities, why should my child get sick?”

A mother of an 8-year-old boy with diagnosis of ALL (another participant), in relation to “connection with God” said:

“From the time my child is sick, I do not pray anymore. It has no use. God has forgotten me!”

Another participant who is the mother of a 7-year-old girl with Hodgkin’s lymphoma, in relation to “divine punishment” said:

“God punished me as I was not thankful. When I got pregnant, I always asked what this child was for. I wished I had had an abortion”.

Another participant who was the mother of a 6-year-old boy with diagnosis of a brain tumor said:

“I broke my father’s heart when I married my husband. Now, God made my child sick instead”.

Psychological problems

With regard to psychological problems, the subthemes of the mothers and the children were similar, although they were extracted from different concepts. This category is divided into three subcategories, which have been obtained through researchers’ observations in the research environment of the

hospital and the clinic. The subcategories of psychological problems in the group of children included anxiety, depression, and aggression. With regard to “anxiety and fear”, one of the participants who was a 7-year-old girl with diagnosis of lymphoma said:

“How many more times I should have injections and serum therapy? I scare to die with injections and serums!”

She also asked thus:

“How long does the treatment last? I am concerned and anxious”.

With regard to “depression”, the researchers observed the children who left their favorite activities. For instance, an 8-year-old boy with diagnosis of rhabdomyosarcoma avoided eating and making communication with others. He even did not like to watch cartoons anymore. With regard to “aggression”, avoidance and screaming during the medication time were among the children’s problems. They, even after medication, they talked with the treatment team and their parents with violence. They would scream and empty themselves, when something was not their favorite.

For instance, a 7-year-old girl with diagnosis of ALL would frequently leave her bed and go to other rooms. She would cry and scream and say *“I hate serum, leave me”*. When they would take her back to her room, she would hit her mother and cry.

The subcategories of psychological problems in the group of mothers included anxiety, depression, and aggression. With regard to “anxiety”, one of the participants who is the mother of a 5-year-old girl with diagnosis of AML said:

“What happens to my kid? Will the treatment be successful?”

In relation to “depression,” the mother of a 9-year old boy with ALL said:

“I am worn out; I am not in a mood for anything or anybody. I do nothing for myself. I have also totally left the household affairs”.

In relation to “aggression”, the mother of a 10-year-old girl with rhabdomyosarcoma said:

“I am not in mood for anybody, wherever, someone talks to me, I shout at them”.

Communicational problems

In the context of communicational problems, the subcategories of the mothers and children were different and were obtained from various concepts. This category is divided into two subcategories as follows.

The subcategories of communicational problems in the group of children included being spoilt and demanding too

much and the communicational problems resulted from treatment complications.

“Being spoiled and demanding too much” was one of these subcategories, as a 6-year-old boy with AML said, *“If I let them shave my head, they (his parents) should buy me a tablet”*, or a 5-year-old girl with ALL said, *“I am sick, my mom should always stay by me”*.

“Problems associated with treatment complications (alopecia)” was another category of communicational problems. In this regard, one of the participants who was an 8-year-old girl with ALL said:

“I am bald now; my friends do not play with me anymore. I do not like to go to school”.

Children reflect this problem by painting their heads. The subcategories of communicational problems in the group of mothers are as follows.

One of the subcategories was family disputes due to the child’s disease. In this regard, the mother of a 5-year-old boy diagnosed with lymphoma said:

“From the time my child got diseased, I have lots of problems with my husband’s family. Everybody prescribes something! I am out of my mind now”.

Another subcategory was “excessive attention paid to the diseased child and depriving the other family members of attention”. The mother of a 6-year-old girl diagnosed with osteosarcoma stated:

“My two other children and my husband are angry now. There is no way. If I am not here, she never eats anything with anyone else, except my sister who is busy with her own life. I am really alone”.

Problems related to inadequate knowledge

As presented in Table 1, the subcategories of inadequate knowledge were similar in the groups of mothers and children, and they included lack of knowledge about the disease, treatment stage, and its complications, and the disease prognosis.

In mothers’ group, the members required knowledge about the overall disease and its treatment trend from the very stage of diagnosis. For instance, the mother of a 10-year-old boy with ALL said:

“In early stage of my son’s disease, I knew nothing about the blood-borne diseases and their treatment. I would refer to hospital and the related physician for any problem. When I would come to hospital, they would say, ‘Don’t worry. This is a complication of the treatment’. I wish, they would tell us what the treatment complications would be like”.

The mother of an 8-year-old girl with AML said:

“I wish they would explain to us about the disease, its reason, treatments and disease trend as well as treatment complications at the time of diagnosis. When one does not know what happens, it is very worrying”.

In the subcategories of inadequate knowledge problems in the group of children, a 9-year-old boy with ALL said: *“I want to know how long I should come to the hospital. What are these medications? Why I take them and what is wrong with me?”*

An 8-year-old girl with ALL said:

“I do not know why I take these medications? Will my hair grow again when I lose them?”

Care-related problems

With regard to care-related problems, the subcategories of mothers and children were different and had been extracted from different concepts. This category is divided into two subcategories in both the groups of children and mothers. The subcategories in children’s group were:

“Lack of cooperation in taking medication due to boredom,” which has been extracted from researchers’ observations.

Based on the researchers’ observations in the hospital and clinic environments, one of the problems of the children with cancer is lack of the child’s cooperation during injection and his/her screaming and restlessness, especially among pre-school children. The other subcategory is “lack of cooperation in nutrition”. The children avoided eating food due to nausea and vomiting, and this was one of their care-related problems. Once in a while, the children taking corticosteroid containing medications develop edema that is mistaken as obesity; therefore, they avoid eating. For instance, a 7-year-old boy with ALL who faced such a problem and avoided eating said:

“I am yet strong even if I do not eat. Look at me, I am so fat.”

The subcategories of care-related problems in mothers’ group included the following items:

“Mothers’ loneliness in taking care of the child” is one of the problems faced by mothers as the child gets so dependent on his/her mother and does not let her take care of the others.

The mother of a 10-year-old girl with rhabdomyosarcoma said:

“I am quite unaware of my life; I am always in the hospital. If I go home, my heart is here. I do not know what to do? My daughter is comfortable just with me, but my son also deserves care. I do not know what to do”.

“Lack of trust to staff nurses and continuous attendance in hospital” is another subcategory.

In this relation, the mother of a 10-year-old boy with ALL said:

“If we do not supervise, the nurse may make a mistake in medication. For example, the nurse may connect chemotherapy before the antibiotic is finished”.

The mother of a 7-year-old girl with AML said:

“They pay no attention to the child. For example, they do not mind what to do after the serum is over. Honestly, the nurses face a load of work, but I wish they would take time a bit more, or at least would tell us what to do”.

DISCUSSION

The present study investigated the challenges of the children with cancer and their families. The first theme of this study showed that not only the children but also their mothers face spiritual problems when exposed to cancer. Spiritual problems are divided into three subthemes of “why me”, “connection with God”, and “disease as a divine punishment”. No research was found concerning these issues among the children with cancer and their mothers. Only in one study, some children with cancer stated that they had stopped praying God as they were so much affected by their disease. It reported that a child had said thus: *“I tried to pray, but it had no use! So, I do not believe in God anymore”*,^[8] which is in line with the theme of the “connection with God” obtained in the present study. However, no more reports were found for comparing our results. Most of the studies investigated the effect of spirituality on patients’ health. Pierce *et al.* indicated that spirituality gives hope and love of life to the family caregivers of the chronic patients. They also indicated the importance of nurses’ attention paid to patients’ spirituality, and regulation of the interventions for the accompanying persons in this context.^[9] Another study showed that spiritual care is among the very important aspects of holistic nursing care.^[10] With regard to the results of the present study revealing that spiritual problems were one of the main categories of the challenges faced by children with cancer and their mothers, the need for such a care, given to the clients, is highly felt. It is suggested to educate the nurses in the context of spiritual care including active listening to the patients, facilitation of their emotions and expression of thoughts, helping them with disease acceptance, and highlighting hope.^[11]

The second theme obtained in the present study showed that both the children and their mothers face psychological problems when exposed to the disease. Its subcategories included anxiety, depression, and aggression both for

children and their mothers. In a study conducted in 2005, fear, loneliness, and irregularity were reported as the complications of taking care of children with cancer, which is consistent with the present study to some extent.^[12] The findings of a study conducted in Sweden showed that anxiety and depression levels were yet high, even up to 2.5 years, after diagnosis of the child’s cancer,^[13] which is in line with the present study. With regard to the children, the findings of a study conducted in 2012 showed that children with brain tumor developed insomnia causing tiredness and a reduction in their function.^[14] In the present study, depression, anxiety, and aggression were reported to be common among the children with cancer.

Third theme of the present study showed that both children and their mothers face communicational problems when exposed to the disease, which is consistent with Lee *et al.* reporting that these patients face problems in their interpersonal communications due to the disease affecting the body image of the children and adults.^[15] This finding is also consistent with another study in which children with cancer were reported to have problems in communication with their friends as they were at the center of attention due to their disease, although this problem should be different with respect to two different cultures.

Kamper *et al.* argue that peers pay extra attention to the patient because of his/her disease, which impairs his/her interpersonal communication; but in the present study, peers isolated the patient because of his/her disease, which reveals the necessity of education in this context in schools.^[8] One of the subcategories of this theme was children being spoiled and demanding too much, which is consistent with a research conducted in 2008 reporting that parental excessive support lowers children’s behavioral and social adaptation.^[16] In the subcategory of family, two themes were obtained. One was familial disputes due to the child’s disease, which is consistent with that reported by Pai who reported that the mothers of the children with cancer face more familial conflicts.^[17] Another subcategory was paying excessive attention to the diseased child and depriving the other family members from attention. This excessive attention was also reported in Collette’s study.^[16] The fourth theme showed that both the children and their mothers face inadequate knowledge when exposed to the disease, which is in line with the report of Gibson (2010) who argues that lack of knowledge leads to children’s concern about their present time and future.^[18] The findings of another study on the effect of postoperative self-care education among the patients with esophageal cancer showed that the education improved patients’ quality of life.^[19]

Fifth theme of the study showed that both children and their mothers face care-related problems when exposed to

the disease. In the subcategory of familial problems, two basic concepts were obtained, which are mothers' loneliness in taking care of their diseased child and lack of trust on staff nurses and permanent attendance in hospital. Also in a research conducted in 2011 about the experiences of Syrian women with breast cancer, the researchers referred to care-related problems among their basic findings under main category of "need for a lot of special care" with sub-categories of "short time of hospital care" and "a higher need for psychological care".^[20] No research was found in relation to the subcategories of care-related problems in the group of children (lack of cooperation in medication due to boredom and lack cooperation in nutrition).

CONCLUSION

The results of the present study showed that the main category in relation to the challenges faced by children with cancer and their mothers was inadequate knowledge, which influences other categories like psychological problems such as anxiety and social communications in such a way that when patients' family members know about the disease and its complications, they face fewer conflicts. In the category of care-related problems, lack of trust on health care team and lack of children's cooperation in care programs can be due to their lack of knowledge about the disease, its treatment, and its complications.

As patients' education is among the duties of nurses, it is suggested to educate nurses in this field to be able to educate the patients and their families. In this way, an efficient step can be taken toward reduction of the challenges of the children with cancer and their mothers, as the more peace and comfort the patients and their families have, the more conveniently the treatment personnel can work for the patients.

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