

“Parents a dead end life”: The main experiences of parents of children with leukemia

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ABSTRACT

Background: The quantitative studies show that due to the widespread prevalence, high death rate, high treatment expenses, and long hospital stay, leukemia influences the families and their children to a great extent. In this regard, no qualitative study has been conducted in Iran. So, this study was conducted in Arak in 2011 with the aim of expressing the experiences of the parents whose children suffered from leukemia.

Materials and Methods: Using qualitative research approach, by applying content analysis method, 22 participants were interviewed in two educational hospitals during 2 months. The study was started by purposive sampling and continued by theoretical one. The data were analyzed based on the content analysis method.

Results: Data analysis showed that insolvency, knapsack problems, cancer secrecy, trust on God, self-sacrifice, adaptation, medical malpractice, and hospital facilities were the level 3 codes of parents' experiences and “parents a dead end life” was the main theme of this study.

Conclusion: In this study, the experiences of the parents whose children suffered from cancer were studied deeply by the use of qualitative method, especially by the use of resources syncretism rather than studying quantitatively. “Parents a dead end life” emerged as the main theme of this study, emphasizing the necessity of paying further attention to the parents. On the other hand, making more use of parents' experiences and encouraging them helps make the treatment more effective. It is suggested that these experiences be shared with parents in the form of pamphlets distributed right at the beginning of the treatment process.

Key words: Blood cancer, children, Iran, parents' experiences, qualitative research

INTRODUCTION

Statistically and epidemiologically, cancers occurring before the age of 15 are called children's cancer and the most widespread type of cancer in children is leukemia,^[1] which makes up about 30% of children's cancers. In fact, leukemia is the result of virulent changes of blood cells, which is divided into four types including chronic lymphocytic leukemia (CLL), acute lymphoblastic leukemia (ALL), acute myeloid leukemia (AML), and chronic myelogenous (or myeloid) leukemia (CML) based on the cell type (either lymphocytic or myeloid).^[2,3] Among the different types of cancer, ALL is seen in 80% and AML in 20% of children.^[4] On the other hand, researches show that because of its high death rate, high treatment expenses, long hospital stay, and psychological problems in the

patient and his/her family, leukemia causes a heavy social and economic load^[5] for the family and deeply affects all aspects of family life and the parents physically, mentally, spiritually, and socially.^[6,7]

Most of the families tend to participate in all processes of child's hospitalization and they mostly describe such participation as effective and influential, especially when the child is suffering from leukemia.^[8,9] Sise *et al.* state that cancer in children, because of long treatment period, heavy load of life, and high expenses, may have horrible effects on children's future vocational opportunities.^[10] Considering the heavy load of this disease and based on the other related articles which describe the various effects of blood cancer on family, it was observed that very few of them refer to parents' role in and influence on the treatment process. However, no qualitative research on parents' role has been done till now. Hence, the question of what the experience of having a child with blood cancer might be like was raised, and the best way to study this is by a method which can show the nature of the entity in its natural setting along with its structure and factors influencing its formation, in other words, a qualitative study. A qualitative research will enable the researcher to understand the real world of personal and everyday work

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life of the people and lets the researcher to feel the facts as they really are and describes the social world. In this study, content analysis was used as a qualitative method. This method is used in social sciences in order to study the content of communication (speech, written texts, interviews, and images).^[11] On the other hand, all the researchers have many years of experience of working in the oncology ward, especially in pediatric oncology unit. Therefore, they tried to explore the experiences of the parents whose children suffer from cancer, in order to highlight the parents' role in children's treatment.

MATERIALS AND METHODS

This study was done with the aim of expressing the experiences of the parents whose children suffer from leukemia. Considering the question in the study and the interactive and social nature of perceived needs, a qualitative design based on the content analysis approach was used.^[12]

Participants and settings

Twenty-two participants selected based on convenience sampling method during 2 months (April and August) were interviewed inclusively in 2011 in two educational hospitals of Arak University of Medical Sciences, Arak, Iran. The participants included 22 parents (18 mothers and 4 fathers). The educational levels included elementary ($n = 5$), high school ($n = 11$), and bachelor or higher degrees ($n = 6$). The mean age of parents was 32 ± 8.7 years. Nineteen parents were married and three were divorced. The children were 22 people (13 boys and 9 girls) with a mean age of 7.32 ± 4.7 years (maximum 12 years and minimum 2 years of age); 60% suffered from ALL, 35% from AML, and 5% suffered from others. The history of disease showed a duration of at least 6 months up to 7 years. The study was conducted in a quiet room of the hospitals.

Data collection

The data were collected using semi-structure interviews with open-ended questions to allow the participants to explain their own points of view and experiences in depth using a conversational style. The opening questions for each interview were: "Please explain about your experiences on having a child with blood cancer" and "Please explain the problems, feelings, and conditions you experienced in your life when you found that your child suffered from cancer." Subsequent questions evolved depending on the information provided by participants. The interviews lasted approximately 60 min. The family members were given the opportunity and were encouraged to talk about what was in their mind about the topic under study. The data collection and analysis proceeded concurrently by the authors in

order to develop themes related to the reality of the parents' viewpoints and experiences of their needs of having a child with cancer. Once the themes were identified and information saturation was achieved, the interviews were discontinued (for some codes, data saturation occurred when 16 participants had been interviewed and for the other codes, interviews continued up to 22 participants, during which data saturation occurred completely). Data saturation is the level at which no further information was obtained from the present interviews and data.^[12]

Data analysis

The interviews were conducted in Farsi language and then translated into English. Every interview was recorded and transcribed verbatim and then was analyzed using the conventional content analysis method.^[13] Data analysis was started simultaneously with the data collection, and the data were analyzed before the next interview. At first, the wholeness of the interviewed context was considered as a unit of analysis. Then manifest content and latent content were determined concisely. It proceeded using line-by-line coding; primary codes were freely generated during repeated discussions between the researchers. Statements not related to the study were eliminated. Secondary codes or subcategories with similar meanings were grouped into categories or level 3 codes [Table 1].

The coding process was interactive and categories and themes evolved (added, deleted, and merged) as re-readings were completed and analyses progressed [Table 2].

Data credibility

The researchers independently analyzed the data by identifying and categorizing codes for the subjects' responses to each question. Then, the two authors' codes and their latest analysis development as themes were compared. In areas where the two did not agree, definitions were clarified

Table 1: Example of analysis process

Story	→	Primary codes	→	Secondary code or subcategory	→	Category or levels 3 codes
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Table 2: Example of theme emerging process

Categories or level 3 codes	Theme
Insolvency	"Parents a dead end life"
Knapsack of the problems	
Cancer secrecy	
Trust on god	
Self-sacrifice	
Adaptation	
Medical malpractice	
Hospital facilities	

and discussions continued until consensus was reached. The coding process was interactive, and the categories and themes evolved (added, deleted, and merged) as re-readings were completed and analyses progressed.^[13] By using a semi-structured interview format and seeking multiple sources of perspectives from different family members, the accuracy of data was enhanced. Trustworthiness and data credibility were established through member and peer checking, and a prolonged engagement in the research field. A strategy was used to ask the participants to review the elicited themes and categories and then to incorporate their comments into the evolving data analysis. Furthermore, the confirmability of findings was verified through presenting various sections of stages to the faculty members and experienced staff in reports and journal clubs and then comparing their opinions and interpretations; the outcome indicated great consistency. Maximum variance sampling (selecting parents belonging to various age groups, gender, and cultural and socioeconomic status from two general and specialized hospitals) during data collection and sampling conferred greater transferability to data.^[12] The researchers ensured the depth of the content and its authenticity by thoroughly identifying diverse and novel data. The analysis was finalized by identifying a number of subthemes and a theme that emerged to describe the parents' viewpoints and experiences regarding having a child with cancer.

Ethical considerations

This study was approved by the Medical Research Ethics Committee of Arak University of Medical Sciences. Official permissions for conducting the study were obtained from the research councils of the two teaching hospitals in Arak, which had evaluated the proposal. The following points were explained to the participants: (i) objective of interview; (ii) confidentiality and anonymity of information; and (iii) destruction of all recorded data after the end of the study (1 year). The participants were informed that they may refrain from interview at any point they desired. A written consent was obtained from all the participants and all the interviews were recorded after obtaining the written consent.

RESULTS

The data of this study are the results of interviewing parents whose children suffered from cancer, which are reported scientifically by the use of qualitative methods. In continuous and circular data analysis, 595 primary codes were extracted and later by considering their areas of overlap and merging them, 174 secondary codes (subcategories) were extracted. After doing more analysis, eight categories or level 3 codes were extracted from the parents' experiences, including insolvency,

knapsack of the problems, cancer secrecy, trust on God, self-sacrifice, adaptation, medical malpractice, and hospital facilities. "Parents a dead end life" was the main theme of this study. What follows is a description and an explanation of the main theme and the categories.

Insolvency

In this study, not finding any solutions means complete failure and absolute hopelessness of the parents. Nearly all the parents admitted that after having heard about the child's cancer, they were overly desperate.

In this regard, Participant 1 said:

"After hearing about my child's illness, my whole body began to tremble and I felt as if the whole world was crumbled down on me because I had had the experience of losing a dear one because of cancer before. To me, cancer and death were equal and life seemed totally worthless. I was really distressed and did not trust the future...."

Participants 13 and 6 said:

"When the doctor said that my child was suffering from cancer, I could not see anything anymore. I couldn't talk to anybody. I neither ate food nor slept and life seemed completely meaningless. I said to God, 'if my child does not get well I would not want to continue this life anymore.'"

Knapsack of the problems

All the parents talked about having problems after having faced their child's cancer. These problems were numerous and varied.

Participants 10 and 6 said:

"Because the hospital was far from our house and because the treatment process took a long time, my child and me were both exhausted. On the other hand, because I was busy with my child, I was fired from work and faced lots of financial problems."

Participants 7 and 18 mentioned thus:

"I have two children, one who is sick and the other one is a newborn baby. When I am in hospital, my baby is at home crying, so I have to come home from hospital several times a day to take care of them both and this is really hard."

Participants 5 said:

"I have lots of problems in making money for the child's expenses and while my husband is unemployed and sick, I cannot pay any of the expenses."

Cancer secrecy

Concealing child's illness means that at first, the parents did not want to talk about the illness and tried to conceal it.

Participant 1 said:

"After the final diagnosis, I tried to conceal the illness from my child. Although I told many of my close relatives and friends about the illness, I tried to hide it from others and talked to those who could understand me."

Participants 6, 5, and 12 said thus:

"I hated the idea that other people get to know about my child's illness and I did not like to tell anybody. However, after chemotherapy and his hair loss, nearly all my relatives found out about it."

Trust on God

Almost all the participants claimed thus:

"Based on religious trainings in difficulties, we have learnt that we should ask God to solve all of our problems. If he is really kind to us, this incurable disease will get well."

In this regard, Participants 22, 1, and 18 said:

"When all of the doctors said that the treatment of my child was almost impossible, God only could help me. I entrusted my child to him and asked for his well-being. He is the omnipotent and the Almighty. I decided to help the poor and contribute to the charities in case my child gets well, and if he does, I would pay them all."

Participant 15 said:

"After I found about my child's difficult disease which is dangerous and may cause his death, my connections with God improved and I take part in religious ceremonies more than before and I use every moment to participate in religious ceremonies. I pray all the time and ask God for his well-being."

Self-sacrifice

Devotion means parents' continuous care and attention. They all talked about their non-stop and overall care in order to support the child psychologically. They also claimed that they were very careful about the child's sanitary and eating program and about providing his needs.

In this regard, Participants 2 and 4 said:

"Before the chemotherapy, I cut my child's hair so that she would not understand the loss of her hair. I also bought a wig for her after she lost her hair so that she does not feel depressed. I was careful about the time of her medicine and tests, too..."

Participants 9, 14, and 17 said:

"The most important role I have had in my child's treatment is my emotional support. I always buy his favorite toys so that he does not feel down."

Adaptation

Although the parents were severely shocked after hearing about their child's cancer, they could face the situation by adjusting their status and by others' feelings of empathy.

Participants 11, 9, 14, and 1 said:

"At first, I thought I could never cope with my child's disease, but when in hospital I saw that other children's situation was worse than that of my child and their parents were more hopeful, I became also more hopeful and relaxed."

Participants 3 and 5 said:

"In my adaptation with my child's disease, my husband's and my sister's warm support were absolutely important and my relatives' presence in the hospital was really relaxing to me. I feel I am not alone and my colleagues also support me at work."

Medical malpractice

Before the definitive diagnosis of the child's illness, most of the parents had talked to doctors about their child's pale face, anorexia, and loss of weight, but because of carelessness and incomplete tests, the illness was not identified at early stages, and thus, many treatment opportunities were lost. Other treatment errors included lack of hygiene, inappropriate physical condition, long wait time, and lack of hospital beds.

Participants 17, 9, 4, and 6 said:

"Physician's carelessness and late diagnosis caused time loss and thus the progression of the disease."

Participant 2 said:

"One of the problems of the hospitals is the long wait time for chemotherapy."

Participant 8 said:

"The servants are not careful about hygiene. After the chemotherapy and because of the blood cell loss, the child gets infections. They wear masks, but because of non-isolated rooms in the blood ward, the patients cannot be separated."

Hospital facilities

The term "hospital facilities" refers to the availability of facilities to the patients and their families, experienced and friendly nurses in the blood ward, and effective communication between parents and the staff.

Participants 19, 7, 3, and 2 said:

"Because of long treatment process and the patients' need for kindness, the hospital has employed the best and most experienced nurses in this ward. The nurses are so kind"

and friendly and they understand us and treat my child so nicely. Blood ward is considered as parents' second home and the staff's good behavior is really influential."

Participants 10, 5, and 1 said:

"I always used to sleep on a chair at nights and of course, I could not sleep at all, but after the hospital has provided us with folding chairs which can be changed into a bed at night, we can sleep better to take better care of the child the next day."

Parents a dead end life

As a matter of fact, after data saturation, the main theme was emerged by all data. In this regard, after continuous and circular analysis of the data and considering all of parents' statements, "parents a dead end life" was identified as the main theme of this study. All the participants claimed that all aspects of their lives had been affected by the child's cancer in a way that the basis of their lives was being ruined. They said that absolute hopelessness and fear of future had overwhelmed them and they deeply felt the meaning of pain and distress in a sense that could not be described. They emphasized that thinking about the image of their child's death is intolerable.

DISCUSSION

Insolvency, knapsack problems, cancer secrecy, trust on God, self-sacrifice, adaptation, medical malpractice, and hospital facilities were identified as the eight categories or level 3 codes of parents' experiences and the influence of child's blood cancer on their lives. In this study, "parents a dead end life" was the main theme that all the participants referred to. In this section, all the existing data are described.

Insolvency

All the parents admitted that their life had been totally ruined by their child's disease and that they were bitterly hopeless and could not find any solutions. In all the interviews, the parents talked about absolute hopelessness about their child's survival and because of having a negative image of cancer and its equality to death, they had no hope in continuing their life. In Wills's study conducted in Hong Kong, the first reaction of the parents was "a very imminent death" and a dominating horror in their soul.^[14] In the Islamic Iranian culture where family dependence and bonds are much stronger, the stress that the parents face is much more severe and greater and because cancer is equaled with death, and parents wish their own death rather than that of their child. Dongen-Melman *et al.* stated that the feeling of a child's loss is the worst and most severe problem for the parents.^[15]

Knapsack of the problems

The parents talked about the socioeconomic and family problems in the child's treatment process. Hadi considers the socioeconomic burden of cancer really heavy, and points to high expenses, long hospital stay, and psychological problems.^[5] Syse *et al.*, in their study conducted in Norway, refer to the negative effects of the child's cancer on occupational opportunities of the parents and reduction in the mothers' income.^[10] In Wills's study, parents' and children's tiredness caused by long treatment period was considered as one of the most important problems, while the Iranian mothers never complained about tiredness.^[14] Also, Wu's study reported parents and children to have the highest level of tiredness^[16]. In Rice's study, hair loss was the most important problem of children and anorexia was the major problem of parents.^[17]

Cancer secrecy

In this study, the parents did not say anything to the child about his/her disease and never used the word "cancer" when the child was present, and called it as anemia, anorexia, or infection. The main family members, including grandparents and siblings, were told about the disease, but the disease was usually concealed from other relatives. Wills writes that in China and Hong Kong, none of the doctors used the word "cancer" to describe the child's disease. Seemingly, not exactly knowing the disease is very important to the child and in different cultures, the idea is the same because knowing about the disease only disturbs the child and endangers his psychological health. In a study conducted in China, grandparents and siblings were told about the disease, but the child was asked not to say anything at school as others would humiliate the siblings. In this study, because all the fathers and 50% of mothers worked full-time, they told their colleagues about their problem so that they could arrange the tasks in advance, but none of them told their neighbors in case they asked. In one case, the mother did not say anything to the neighbors since she thought they would say that the child would bring bad luck to the family and relatives.^[14] Therefore, the consequences should always be considered before anything is told about the disease, since it affects the parents', children's, and his/her siblings' psychological health seriously.

Self-sacrifice

Parents' 24-h stay at hospital and near the child's bed and mothers not sleeping at night in order to take better care of their children and providing all their needs are the signs of compassionate and total participation in the treatment process, which show the greatest devotion. In Wills's study, the mothers stayed awake close to their children's bed and the fathers came to see their children after work.^[14] In Ames

et al.'s study conducted in Canada, parents were present at the intensive care unit, blood ward, and oncology section all the time.^[18] In Iran, parents' devotion cannot be described, but it is understandable and makes the parents feel useful and relaxed, though it does not have a definite structure and is not guided through the treatment process. In other countries such as Canada, parents' presence in the form of a kind of participation is organized by trust in the treatment team. Parents are the people who understand their child better than anyone else. In Wah-Lam's study conducted in China, parents prepared themselves for a long stay at hospital and were very much interested to cooperate in the treatment process.^[19]

Trust on God

Since all the parents considered "relying on God" when facing problems, it can be said that the only strong feeling of support is provided by God and that by praying to God, many of the obstacles can be removed. In Rezaei *et al.*'s study, parents' religious grade was higher than their existential grade^[20] and the reason is Iranian people's belief in God and the connection they have with God which makes the tolerance of hardships easy. Akhavan Kazemi quotes Allama Tabatabayee, "safety in all aspects is based on having true belief in God." In his interpretation, every anxious soul is comforted and relaxed when remembering God.^[21] In Wills's study, the parents had been reported donating free drinks and food after they found about the disease. Preparing such religious ceremonies encouraged the parents and made them feel better.^[14] Relying in God's endless power and making him pleased by praying and sacrificing can give hope to parents, so that they engage in the treatment process with more readiness.

Adaptation

With the passage of time, parents could adjust themselves with the conditions by the help of relatives, friends, and the treatment team, as well as by praying to God. In Wills's study, although parents denied their child's disease at first and thought that their child was not suffering from cancer, they got used to the new conditions slowly. Talking to other parents whose children suffered from cancer helped them to a great extent; fathers mostly talked to the physician and by gaining more information, they could gradually face the situation.^[14] Relatives' kindness and emotional support along with their financial support were indicated in this study and also in Wills's study. At times, parents helped each other by buying food and beverages and taking care of each other's children.

Medical malpractice

Errors in treatment, which means those errors which result in illness or its getting worse, and also missing opportunities

were claimed and approved by most parents. Most parents considered this disease as accidental and did not blame their family for it. In Wills's study, most mothers blamed themselves because of undergoing radiography at the time of pregnancy and nannies were also blamed because of not having enough supervision. None of the fathers blamed their wives for the disease. Only one father thought that his own gene had caused the child's disease.^[14] In this study, the parents considered most of the errors resulting in child's aggravating conditions. The main fault was the doctor's lack of proficiency in diagnosing the disease at early stages (especially in private centers), which resulted in child's worsening condition and at times his/her death. However, the conditions at educational and medicinal centers were not as bad and in most cases, better results were obtained mainly because of doing experiments such as complete blood count (CBC), flow cytometry, and coloring, which resulted in diagnosing ALL and AML.^[22]

Hospital facilities

The findings which emphasize hospital facilities, including welfare and instrumental, as well as good relationship between parents and staff are completely in line with helping the parents and increasing their satisfaction and suggest development in hospital services. In this regard, Fisher and Broome suggest in their study three-dimensional relations among parents, physicians, and nurses.^[23] Karimi *et al.* also suggested that parents need help in order to satisfy their needs and such needs are answered only to some extent.^[8] Hence, the mutual collaboration between parents and the treatment team based on parents' needs is essential to accelerate the treatment process.

Existence of diversity in culture, personalization, socioeconomic status, and many other dimensions which affect the parents' moods may be the limitation for having more related codes.

CONCLUSION

In this study, the experiences of parents with children suffering from cancer were obtained by a qualitative method in which syncretism of resources was done, and thus, more profound results were obtained. On the other hand, "parents a dead end life" was the main subject of this study and also the most important finding of this research, which emphasizes the need to pay thorough attention in all aspects. Also, by using such experiences and increasing the hope of parents, the treatment process would be more effective. Therefore, it is suggested that these results be distributed in the form of pamphlets at the beginning of the treatment process. On the other hand, these findings should teach a ll nursing students and nurses who are working in pediatric

oncology wards. It is also recommended that the findings be considered as a basis for conducting interventional studies for these parents, with the goals of adapting more with the situation and having a suitable quality of life.

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