

The Lived Experiences of Mothers Having children with Cancer: A Qualitative Study

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ABSTRACT

Background: There is the likelihood that cancer in children influences their growth and improvement. The mothers who have children with cancer and experience this hardness along with them play a highly significant role in this complexity. Researchers have considered these lived experiences in a limited way.

Methods: This qualitative study (phenomenology) was conducted in Mar 2019 among mothers who had children with cancer in Yazd. According to purposive non-random sampling, semi-structured interviews were conducted on participants, and 13 subjects were then selected in order to achieve saturation. The data were analyzed using Dikelmann's 7-step method and MAXQDA 10 software in order to analyze data.

Results: The concepts were first extracted and analyzed, 18 sub-categories were then obtained and eventually, 6 main categories including attitudes toward illness, desperation, psychical relief, multidimensional family problems, physician's attitudes, physical-psychological problems, were extracted.

Conclusion: Mothers experience pain along with the complex stages of their child who is seriously sick. Additionally, cancer bears many physical, mental, and psychological consequences for their children. It is possible to apply the results of this study in order to develop support strategies and provide services for mothers who have children with cancer as well as their children.

Keywords: Lived experience, Mothers, child, cancer, Phenomenology



Introduction

Currently, cancer is increasing in the world and identifying the disease in childhood is a traumatic experience for individuals who take care of these children (Masadeh, 2015). Cancer in children is an unpredictable stress factor that highly affects psychological phase of the child's life (Afshari et al., 2019). This disease impacts various aspects of a person's life physically, emotionally, psychologically, and socially (Mozafari et al., 2016). Additionally, this disease affects psychological and social aspects of life in the family thus appearing to be more serious than the physical damages caused by the disease (Khalili and Rahimi, 2014). Accordingly, diagnosing cancer in children provides unpleasant and painful feelings in parents involved with the disease (Cracoviensia, Cepuch, et al., 2013).

Additionally, diagnosing cancer in children is considered a psychological crisis for many patients, parents, and people around them, hence the disease in children significantly changes the parent's life situation (Norberg, Lindblad and Boman, 2005). If a child is hospitalized, the family and parents are continuously involved as first caregivers (Shields et al., 2003). In addition, treating the disease usually needs a long time and is painful so that the child with cancer and his/her family are subject to many difficulties (Paterson, Holm & Gurney, 2004). Research conducted by Syse et al. (2011) suggests that cancer in children adversely affects parents' occupational opportunities and reduces mother's income.

It is true that all members of the family suffer from this vulnerable condition, but observing and enduring a child's disease is a hard and unpleasant experience for a mother, especially when the child is affected with an incurable disease named cancer. It is likely for a mother who has a child with cancer not be able to perform well psychologically and socially and her capability to be in connection with the problem be reduced because of the need for addressing constant care, providing special conditions needed for these children, and coping with pressures such as observing the child's

suffering, following therapeutic interventions, and the unpleasant complications of chemotherapy (Khodadadi Sangdeh and Qomi, 2017). Although children who suffer from cancer tolerate many physical, mental, and psychological consequences and their disease significantly affects the family, the family is considered as the main system that socially supports children (Wong and Chan, 2006). Parents, especially mothers play significantly a role as the first and main caregiver. Consequently, the mother's psychological status is highly significant and can affect the child's behaviors and feelings (Alaviyan et al., 2016). To this end, the findings attained by Haghshenas (2017) explains that mothers who have children with cancer are significantly harmed due to feelings of anxiety and stress, and also anxiety and fear of their child's lack of recovery. Rodriguez et al. (2011) also conducted a study on the sources related to stress in children who suffer from cancer and their parents and concluded that mothers who have children with cancer report higher levels of stress compared to fathers. Masadeh (2015) conducted a study on parents who have children with chronic diseases and explained that stress and mental disorders in mothers who have children with cancer are higher than mothers who have normal children. Additionally, Asghari Nekah et al. (2014) in a study entitled "The state of the resilience of emotional damages in mothers who have children with cancer" explained that a high degree of depression, anxiety, and stress, and also their negative and significant relationship with resilience appear to be warning in mothers who have children with cancer.

It is obvious that mothers who have children with cancer are engaged in such stressful situations; accordingly, they have many psychological problems. Hence, it is possible to call the long period of disease of children with cancer as the suffering and painful period of the life of these mothers. Incurable diseases have been studied, especially in children for many years, and the psychological damages and various problems related to mothers who have children with such



diseases such as cancer have been less considered and examined. Therefore, this study aims to examine thoroughly the lived experience of mothers who have children with cancer using a qualitative approach and interpretive phenomenological strategy.

Methods

The interpretive phenomenological strategy was applied in this study in order to explore the lived experience of mothers who have children with cancer, since phenomenology is associated with lived experience and daily life more than other strategies, and enables us to achieve a more extensive understanding of people's experiences. In fact, phenomenology is to describe the cases that appear in our knowledge and awareness (Hariri, 2017). The research sample was selected among mothers who have children suffering from cancer in Yazd province using the nonprobability snowball sampling method and the interviews were performed with several mothers who were interested in collaborating in the research by attending a clinic special for children with cancer. Then, the mothers were asked to introduce some other mothers who had children with cancer and additionally were desired to participate in the interview. Accordingly, some mothers who had children with cancer were interviewed most of whom suffered from leukemia, and after interviewing with 13 people, data saturation was occurred. The inclusion criteria were mothers who had 3 to 10 years old children with cancer and were enthusiastic to participate in the study. The data were collected using a semi-structured interview and it was attempted to examine their life experiences by conducting interviews with these mothers. The research was conducted in such a way that the relevant questions were first designed, and the objective of the research was explained briefly to all the participants so that they became convinced that participating in this research would not have unfavorable consequences for them. Mothers had also the opportunity to cancel their participation and cooperation at any stage.

The interviews were lasted in 30 minutes to 1 hour. The data were analyzed using Dikemmann's 7-step method by MAXQDA 10 software in order to analyze data. To this end, the text of the audio file of the interviews was transcribed word by word in the first stage and all the texts of the interviews were examined in order to gain the whole sense. Then, an interpretive summary for each interview was written in the second stage, the texts of the interviews were then analyzed in the third stage, and their themes were also extracted. It was referred to the text of the interviews again in order to explain and classify the concepts after extracting the significant phrases related to the research in the fourth stage. In the fifth step, it was started to compare the texts of the interviews in order to identify and determine the common categories. The basic models that established the relationship between the categories were extracted in the sixth stage and eventually a draft version of the categories was sent to other colleagues in the seventh stage to provide their final suggestions. Findings were evaluated and validated using four criteria of credibility, consistency, conformability, and transferability. The researcher kept her continued contact with the environment for credibility and observed the environment frequently and deeply in order to ensure the depth of the participants' experiences. All the details as for collecting the data, list of the participants and their information, the recorded interviews, the items extracted from the interviews, and the researcher's notes were stored in order to observe the consistency criterion. The results were then compared with the original raw data in order to achieve the credibility and consistency of the results with the data. Additionally, the researcher's mental thoughts were recorded during collecting and analyzing data in order to trace and control the entered perspectives in the research. This study is also confirmed by the Ethics Committee of Yazd University with the code IR.YAZD.REC.1400.006.



Results

Table 1 projects the demographic information related to the participants.

A major category, 6 sub-categories, and 18

sub-sub categories were extracted after analyzing the data that shows the mothers' lived experience who had children with cancer. Each category has been explained in the following part (Table 2).

Table 1. Demographic information pertinent to the research participants

Participant	Gender of child	Age of child	Number of children	Order of birth	Disease duration
۱	Son	Four years	۲	Second child	Two years
۲	Son	Four years	۲	Second child	Two years
۳	Daughter	Seven years	۳	Second child	Six months
۴	Daughter	Four years	۲	Second child	Four months
۵	Daughter	Eight years	۲	First child	Three years
۶	Son	Five years	۲	Second child	Seven months
۷	Daughter	Three years	۳	Second child	One year
۸	Daughter	Six years	۲	Second child	Five years
۹	Son	Eight years	۲	Second child	Four years
۱۰	Son	Six years	۲	Second child	Six months
۱۱	Daughter	Eight years	۲	Second child	Four months
۱۲	Daughter	Ten years	۲	First child	One month
۱۳	Son	Eight years	۳	Second child	Three months

Table 2. The main and sub-categories taken from examining the mothers' lived experience who have children with cancer

Major Category	Sub-Categories	Sub-sub Categories
Suffering from disease	Attitude towards the disease	Curability of the disease
		finish line
		God willing
	Desperation	Denial
		Helplessness - confusion
		Questioning mind
		Vitality
	Spiritual relief	Positive reinforcement
		Accompanying and helping those around you
	Multidimensional family problems	Financial and pharmaceutical problems
		Mental and psychological problems
		Traffic problems
		Family problems
		Accompanying the doctor
Attitude of the treating physician	Non-accompanying physician	
	Compromise and isolation problems	
Physical-psychological problems	Extreme cuteness	
	Physical problems	

Attitudes toward the disease: Participants frequently reported different definitions of cancer and had various attitudes toward the disease. Some of them believed that cancer can be treated, and used terms such as a curable disease, whereas others called it a long cold for example, the participant number 1 stated that "Cancer is a

disease that can be treated and it is highly required to observe, and if you observe it, it is not a serious disease" (No. 1). Mothers sometimes recognized cancer to be the end of life and used terms such as the last stage of life, the end of life, and the bitter end: "Cancer is a highly dangerous disease that does not frequently ends in a good result" (No. 12).



Some mothers recognized the influential will and authority of God in this disease and considered it as a divine test: "I think that we should not name it cancer; I believe that cancer is a divine test" (No. 8).

Desperation: Participants reported various ideas about the way to react to their child's cancer, but finally, all of them experienced reactions such as disbelief, confusion, and helplessness. Some mothers asserted that they originally refused to accept their child's disease and did not believe the truth: "At first I said everyone was lying, I always thought the doctors are wrong" (No. 7). Many mothers stated that they reacted with anxiety, helplessness, and confusion at the time of hearing about their child's cancer: "I did not understand and realize the situation at all, the physician was talking to me and I just saw that his/her lips are moving without hearing his/her voice at all." (No. 4). Some mothers stated that they had reasons in their minds and asked themselves and God why my child has developed the disease in response to the news of their child's cancer: "The first thing that obsessed my mind was, God, why me? Why my child?" (No. 8)

Spiritual relief: Participants usually introduced different methods and strategies for a child's mental relief. Some mothers strived to apply strategies such as creating a pleasant and happy environment, fun and entertainment, and preserving their spirit as high in order to help their child to continue with hope: "I have constantly tried not to behave as if being upset in front of my daughter, tried to laugh in front of her and did not allow her to see me sad at all." (No. 12). Other mothers additionally used positive supporting techniques to preserve his/her spirit in various forms such as giving a gift, promising, and praising, and employed these ways to help their child to keep his/her spirit high: "If you are to be a good child and listen to our words, we will buy you a percent" (No. 6). Mothers who participated in the study expressed phrases such as accompanying others and providing supportive tactics about the role of helping others in providing

psychological relief: "Our relatives and people around us were extremely sympathetic, highly supportive and helped us in problems." (No. 5)

Multidimensional family problems: All the participants explained that they are fighting with many problems after developing their child into cancer. They had a lot of critical difficulties the most significant ones of which were financial and drug problems including drug shortages and high expense of treatment. They said "We all have problems with preparing medicines, that is, they are scarce and we cannot afford them; moreover, we are required to travel to other cities to find these unavailable drugs" (No. 4). Several mothers also referred to some psychological problems such as a lack of psychological support, mental problems, and the continuing struggle with their child's disease: "there is no psychologist or psychiatrist in access to offer consultation to us every day, or for example, to have a psychological file there in the office for myself or my son" (No. 9). Another problem that some participants suffered from was commuting and travel problems including transportation and accommodation: "We have so many problems to attend the hospital as we live in another city and we do not have any place to stay here" (No. 3). Also, other families had various family difficulties due to their child's cancer, such as parental disputes, disruption of life process, paying no attention to other children and vulnerability of other family members. "Our family problems, they stated, have been increased, we have disputes that we had not previously experienced at all, I have also another son that I am not informed of his situation since I came to the hospital and I do not know about his daily life because of my problems here" (No. 11).

Attitude of the treating physician: The mothers who participated in the study had different comments about the response and support of their child's physician. Some of them were satisfied with the attending physician's kindness and support as a person who is a good listener, and noted also the physician's caressing: "My child's physician has

fancy labels and gifts and gives them to such children. My child hopes that when he/she refers to the office, he/she will not return without a gift" (No. 2). But some mothers also explained that the physician does not collaborate with us, he/she is serious, irresponsible, and has a hard spirit: "Rarely, the physician talked to the child or joked; he/she just examined my child or asked us if the child had eaten anything. We also had to respond to the physician's question" (No. 8).

Physical-psychological problems: Cancer has diverse physical, psychological, and adaptive consequences, particularly on the child and family, and mothers mentioned these various consequences. Most of them explained the child's adaptation and isolation problems such as restlessness, irritability, petulance, and tendency to isolation as the most significant consequences of this disease: "He/she is not on speaking terms with his/her friends at the time of playing, or if we go somewhere, he/she will ask us to come back to our house, as he/she says, mom, I do not like here" (No. 5). Other mothers stated about the consequences of their children being extremely pampered and recognized that over-support and over-attention to the child during the disease would make him or her spoiled and exigent: "Because everyone supports the child and give the right to him/her and sympathizes with him/her, accordingly, he/she becomes a little selfish and spoiled" (No. 8). Participants also mentioned the physical consequences caused by cancer and its treatment such as the side effects of chemotherapy, weight loss, hair loss, as well as the child becoming a picky eater. "When he/she is treated with chemotherapy, he/she makes a lot of noise as his/her bones become painful, and when he/she goes to the hospital, he/she does not eat anything" (No. 7).

Discussion

The major objective of this research was to explore and describe the lived experiences of mothers of children with cancer. Regarding the information obtained from mothers' interviews,

many factors such as mother's attitude to illness, physical and mental problems of the children during the disease and even the way the physician treats them can play a significant role to create or reduce suffering for the patients and those around them, especially the mother. Meanwhile, some mothers had a negative perspective on the impacts and consequences of this special disease where as others showed a more promising view of cancer. Comparing these findings with the results of Rezaie et al. (2018) on the quality of life of mothers of children with cancer indicates that these mothers reported a favorable condition due to positive adjustment to their child's disease. Furthermore, the results of Van Schoors' (2015) study, which concentrated on resilience of families after hearing about child cancer, revealed that most families were resilient and adapted well to the cancer diagnosis crisis. Most of the participants indicated desperation and helplessness reactions considering hearing about their child's cancer after being affected with the disease. Almost all of them had experienced the reactions of confusion, denial and humiliation at the beginning of their child's diagnosis. In this regard, Jadidi et al. (2012) in a research entitled "Explaining the experiences of parents of a child with leukemia", concluded that breaking off with life means helplessness, and complete frustration of the parents as for continuing their lives after hearing about child cancer can be seen in the vast majority of parents. Wong and Chan (2006), in a research on the qualitative experience of Chinese parents having children with cancer indicated that the first reaction of mothers to their child's cancer diagnosis was shock, denial of reality and concern, but they quickly accepted the reality.

Furthermore, in line with the methods of spiritual relief by themselves and those around them, participants noted that they were promising, creating happy and entertaining environments and activities like gifting for instilling hope in their child. Hence, Benzein and colleagues (2001) indicated that the spirit of hope is a dynamic experience and, if strong, results in a positive



reassurance in the sick child. One of the factors which decreases stress and psychological tension in mothers of children with cancer is companionship and help of those around them. They create hope by comforting and accompanying them. In this regard, the findings of Jadidi et al. (2012) also demonstrated that parents of children with cancer, although after realizing their child's illness, had severe shock, however, by matching their situations with others and consolation and help from relatives, they were able to cope somewhat with their child's disease.

In addition to individual issues, cancer also triggers various family problems. Some parents are less likely to show up in public because of their child's illness and spend most of their time in the hospital with him/her. Also the findings of Borjaliloo et al. (2016) underlined that parents of children with cancer bring a change in their daily lives. Moreover, their lifestyle and daily activities such as career life are changed, communication with other children and family members becomes less and their social life becomes more limited. One of the problems which mothers frequently noted was the vulnerability of family members and lack of attention to other children. In a study on the siblings of cancerous patients, Parchal and Lendlot (2012) reported that siblings of children with cancer faced the problem of inaccessibility of parents and also reported impaired life progression and academic achievement. Moreover, the findings of Maarefvand et al. revealed that parents of these children apply emotion-focused strategies more, and continuous stress and burnout due to child disease as well as financial issues can reduce the caring potential of children with cancer. Another concern of this disease relates to financial and drug problems and most of the mothers participating in this research unfortunately encountered with. The high cost of the drug and its shortage were part of these mothers' complaints. The findings of Rahimi et al. (2014) on parents of children with cancer also indicate the costs related to treatment and

unemployment being very significant concerns of such parents.

Considering the way the physician and the medical team treated the patient and his companion, the vast majority of mothers maintained the good attitude, responsiveness and accountability of their child's physician, and noted that humor, good mood of the physician, his information giving, patience and appeasement of the patient are efficient in the morale of the child as well as the mother. These cases are consistent with the findings of Jadidi's et al. (2012) study in describing the experiences of the parents of children with leukemia. Affability of physicians and nurses, communication skills of medical staff as well as presence of experienced and good-natured nurses decreases the suffering of patients and their parents and grant them a sense of empathy and peace of mind. Borjaliloo et al. (2016) in a study entitled "Determining information requirements of parents of children with cancer" also indicated that the requirement for medical information about cancer and treatment methods of care as well as physical and educational health is the most concern of such parents. Meanwhile, some of the mothers participating in the research believed that the physician or other members of the hospital's medical team did not associate with the sick children and their companions as they must in terms of emotion, empathy, reassurance and kindness. The attitude of this group of physicians (involving a small number of course) can be derived from personality or individual problems.

Considering the outcomes of cancer, statements showed that cancer bears several consequences on children with cancer. This disease and its complex impact on children results in the formation of children with characteristics such as isolation, as well as physical, and mental fatigue. In line with these results, the findings of Wu et al. (2010) on Chinese children also proved that cancer-related fatigue is a common matter for children with cancer and this fatigue has negative impacts on these patients both physically, and psychologically

and also influences their family, school and social interaction. Furthermore, based on Hechler's et al. (2008) research on parents of children with cancer, fatigue and loss of appetite were the most important symptoms that these children showed from the point of view of their parents. Such behaviors were observed in hemodialysis patients and children with autism (Farnia et al., 2016; Ebrahimi et al., 2016).

The pivotal category of the study, i.e. super-category, means that the suffering of the disease refers to the reality that the disease is suffering and thus it induces suffering for the patient, as well as those around him/her, especially mother as primary caregiver, and in the meantime, chronic diseases like cancer more contribute to the creation of suffering for the patient and those around him, especially the mother, in all physical, mental, and social dimensions. Furthermore, since this is a qualitative study, we should be cautious in generalizing its results. Other limitations of this study involved lack of domestic qualitative research background in the realm of experiences of mothers of children with cancer compared to quantitative research, and regarding that the research was conducted in the form of individual interviews, the process was slow and time-taking.

Conclusion

On balance, it can be mentioned that from the findings of this research, that the significance of this problem is conceivable, that is, such mothers have a constant requirement to be paid attention to in the areas of material, spiritual and social assistance. Regarding the impacts of this disease on mothers of these children, it is recommended that in the country's macroeconomic health system and mechanisms, in addition to supporting the patient, the issue of support and service-providing to the patient's companions, especially mothers of affected children be predicted and designed. Regarding that this research was conducted on mothers of these children, it is recommended that similar studies be conducted on fathers of children

with cancer to achieve a deeper understanding of lived experience with a cancer child.

Conflict of interest

There is no conflict of interest among the authors.

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Authors Contribution

Conceptualization, Z.D.; Methodology, Z.D.; Formal Analysis, Z.D and H.Z.M.; Investigation, Z.D.; Writing -Review & Editing, Z.D and H.Z.M.; Supervision, H.Z.M; Writing -Original Draft, Z.D.

All authors read and approved the final manuscript and are responsible about any question related to the article.

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