RESEARCH ARTICLE

Caring for a Child with Cancer: Impact on Mother's Health

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Abstract

The life of a mother undergoes a dramatic change after a child is diagnosed with cancer. The present study aimed to determine effects on the everyday life process and health status of mothers with children suffering from leukemia. This qualitative study was based on a grounded theory approach with sixteen mothers. The results indicate that after onset of disease in their children, they marginalized their own health and tied their identities to taking care of the child and keeping the child healthy by ignoring themselves, becoming imprisoned in a taking-care-of-the-child position, and trying very hard for seek balance and stability Enduring physical pressures on the one hand, and constantly attempting to achieve balance and stability in family processes on the other hand, gradually cause exhaustion. It seems that health care providers and nurses should pay much more attention to the health status of this group of mothers.

Keywords: Mothers of children with leukemia - care - life processes - health status - grounded theory

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Introduction

Cancer is one of the most important diseases in childhood, which is still considered to be one of the most influential childhood chronic diseases, in spite of significant advances in its treatment (McGrath, 2002; Woodgate and Yanofsky, 2010). Leukemia is the most common form of childhood cancer the treatment of which has considerably advanced more than the past (Silverman et al., 2001; Mousavi et al., 2009). However, this success is impossible, unless through implementing long-term, invasive and very difficult treatment methods. Many treatment tables last for 2-3 years by which the child should be hospitalized for a long time or should be continuously controlled and monitored at home (Hansson et al., 2012). The acute onset as well as the long-term and chronic process of the disease and its constant risk of recurrence has given significance to it (Earle et al., 2007). The involvement of children with cancer greatly affects their family members, especially parents, such that researchers believe that cancer should be considered a family disease (Sloper, 2000; McGrath, 2001; Woodgate, 2006). Many parents consider this time as a starting point from which the reversal of the normal and expected family life stream begins. This is followed by a change in family views on life and death, their goals, expectations, dreams and hopes. (Woodgate and Degner, 2002; McCaffrey 2006; Earle et al., 2007)

Previous studies have reflected the lasting and significant effects of childhood cancers on the functionality of family members, parenting styles (Young et al., 2002; Long et al., 2013) and emotional interactions between

parents (McGrath, 2001; Da Silva et al., 2010). They not only should constantly reconstruct their roles, functions, and interactive and communicative patterns inside and outside of the family, but also are in charge of many caring responsibilities as a result of being the most substantial member of the treatment team (McGrath, 2002). It can be asserted that successful treatment largely depends on the cooperation and performance of parents (Flury et al., 2011). Clearly, parents should tolerate emotional and mental pressures, while they should also accomplish their medical tasks, parental supervision and all their roles and responsibilities (McGrath, 2001; Young et al., 2002; Woodgate, 2006).

Some specific characteristics of childhood often make a parent responsible for direct childcare and active accomplishment of other tasks. In most societies, mothers are mainly responsible for child and family care and support (Moreira and Angelo, 2008; et al., 2012; Khoury et al., 2013). As the core of families, they control education and promotion of children and are responsible for housework and health care of family members. In other words, the caring role is the role expected from mothers who make use of a variety of strategies to play it. For example, they adjust their working hours or even resign inevitably from their jobs to do routine housework and to meet the needs of their children (Young et al., 2002; Moreira and Angelo, 2008). The results of studies indicate that mothers often play the role of the main caregiver and fathers undertake the responsibility of paying family expenses and health care costs (Wills, 1999; Taleghani et

Having a child with cancer and providing them with

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24-hour care expose mothers to numerous physical, mental and emotional pressures. Previous studies show that mothers experience a higher level of stress and discomfort than fathers (Sloper, 2000; Rodrigues and Patterson, 2007). They should review and reestablish their roles as parents and caregivers, change their social and marital roles, and handle housework and their other children (Young et al., 2002; Khoury et al., 2013). In addition to their concern for the child's physical and mental health, mothers are worried about their health and that of their wives, other children and all other family members as well. Many physical (Meltzer and Mindell, 2006; Klassen et al., 2008) (headache, backache, anorexia, digestion disorders, palpitation) and emotional (von Essen et al., 2004; Grinyer, 2006) (senses of weariness, despair, anger, stress, anxiety and depression) problems have been reported by such mothers. Studies even have indicated the existence of the symptoms of the posttraumatic stress syndrome in mothers following treatment (Stuber et al., 1996; Kazak et al., 1997).

Since 1970, many investigations have been carried out on different aspects of childhood cancer, which mostly have focused on the parent-child adaptability process (Khoury, 2013), psychological impacts of diseases on children and families (Long and Marsland, 2011), and the effects of diseases on the family system (Patterson et al., 2004; Woodgate, 2006; Tedford and Price, 2011). In the majority of these studies, psychological aspects of the disease and family-child adaptability (Khoury, 2013) have been examined but less attention has been paid to the effect of daily care of children with cancer on mothers' health. How the health of mothers with sick children is endangered in their everyday life process is an issue that needs contemplation. The reason is that effective and practical solutions to the improvement of patient's health can be proposed only through a deep understanding of the lifestyle of mothers dealing with sick children. Undoubtedly, no effective relationship will be established with such mothers, no care plan can be designed based on value put on mother caregivers, and no appropriate preventive solution can be suggested to support and maintain the health of mothers of children suffering from cancer, unless by understanding the everyday life process, feelings and beliefs of these mothers as well as the ups and downs of the process of providing care to such children.

Materials and Methods

The present study aims to determine the everyday life process of the mothers whose children suffer from leukemia, and investigate how mothers Everyday Life process after child illness effect on their health status.

Design:As part of a wider study of everyday life process of mother's living with a child with cancer, semi-structured interviews were scheduled and carried out with sixteen mothers whose children were diagnosed with leukemia. The mother's everyday life was the focus of the interview. A qualitative design that employed grounded theory was used in order to provide us with the description of the phenomenon (Strauss and Corbin, 1997; Polit, 2008). This method involves systematically generating

theory or concepts and their inter-relationships, which can be accounted for, and explicating and interpreting variations in behavior (Streubert and Carpenter, 2003; Glaser and Strauss, 2009). Glaser and Straus (2009) claims Grounded Theory can be used in many fields. According to Holloway (2009) grounded theory is rooted in symbolic interaction which is the underlying theoretical perspective in which people give meaning to their situations while interacting with others. The starting point for data collection and analysis was the constant comparative method of Grounded Theory (Strauss and Corbin, 1997; Glaser and Strauss, 2009)

Participants

The study population included 18 participants. The main participants of the study were the mothers of the 2 -14-year-old children with leukemia, who lived with their husbands and their children had been suffering from the disease for at least 6 months (the time required for a mother to cope with the disease and pass the initial critical situation). In the present study, there were 14 mothers aged 23-50 (32.7±8.7), among whom 7 (48.3%) had a college diploma, 4 (25%) had primary education, 4 (25%) had a BA degree, and 1 (4%) had an MA degree. From among the participants, 12 (75%) were housewives, 2 (12.5%) were employed, and 2 (12.5%) were university students. There were 4 (25%) with one child, and the rest had more than one. The children (9 boys and 7 girls) were 2-14 years old (8.25±4.4) and under different phases of treatment.

Data collection

Initial selection focused on maximum variation on factors related to illness (phase of treatment, prognosis) and family demographics (child age, family size, mothers education). Purposeful sampling was used in order to choose respondents who were of importance with respect to the emerging theory which is about the everyday life of a mother whose child is diagnosed with leukemia.

To have a more complete and better understanding of this phenomenon, a semi-structured interview and field notes techniques were used in this study. The initial questions were designed through consulting with a research team, and the obtained information was reviewed after each interview and analysis.

The nursing staff of the Tehran University Hospital asked the mothers for permission so that the researcher can keep in touch with them. In-depth semi-structured interviews were carried out in order to collect data. Interviews were conducted from January 2011 to February 2012 in two paediatric teaching hospitals in Tehran. Each interview session lasted 45-108 minutes. All interviews were audio taped in the format of MP3 for future analysis. All the interviews were transcribed by the interviewer (first author) and were analysed meticulously. Having a discussion with the project's team, the researcher came up with interview prompt list which was used for the first 2-3 interviews. During the first interview with parents, participants' perception of their child's illness and caregiving experiences were approached broadly by asking general questions, for example, how do you feel about caring for the sick child? Some of the interview

questions are the followings: What do you usually do in your everyday life after your child illness? What are the influences of this event (child illness) on your life? What are the influences of this event (child illness) on your health? After some interviews were done, some new areas such as beliefs about the illness, beliefs about the process of treatment, and mother's perception of their roles were aroused.

Ethical issues and approval

Ethical approval was obtained from the Ethics Committee of the Research Deputy in Tehran University of Medical Sciences (TUMS). Participants were clearly informed about the study purpose prior to the data collection procedure. Pseudo-names were chosen and used for participants in their report files so that the reports could be kept anonymous. A written informed consent form was signed by each participant before the interviews.

Data analysis

Data were progressively analyzed throughout the procedure of data collection. As the data were received and transcribed, a constant comparative method (Strauss and Corbin, 1997) was used for data analysis. Open coding without preconceived codes was used initially. Then codes were constantly compared with each other, later codes with category, and category with category (Strauss and Corbin, 1997; Hutchinson, 2001). The first researcher coded the interviews. The team members individually read the transcripts and the coding results. Several meetings were arranged and all the team members worked together in order to reach to an agreement concerning the interpretation of interviews. The first researcher analyzed all the interpretations by comparing them with the existing data. For instance, questions about (dis)similarities in caring intentions and activities were posed and explored in subsequent data collection. By using memos and explicating provisional conclusions and interpretations, the transparency of the analytical process and verifiability of the research were enhanced.

Trustworthiness

Criteria outlined by Lincoln and Guba (1985) were followed to address trustworthiness of the data. Prolonged engagement with data and peer debriefing were used. The emerging analysis was discussed periodically with faculty members. Maximum variation of sampling also enhanced the confirmability and credibility of data. This sampling strategy enabled us to carefully capture a vast wide range of views and experiences. We saved all evidences and documents securely to maintain auditability (Polit, 2008).

Results

Living in uncertainty and worriedness

The main category (core) in this study was "living in uncertainty and worriedness "which includes and links the three main categories of self-neglect", "being imprisoned in taking-care-of-the-child position" and "seeking stability and balance" At different stages of life process of mothers life process of children with leukemia (Table 1). This concept was the most obvious concept revealed in the data and the most abstract category encompassing all other categories and connecting them together. During their remarks, all participants repeatedly talked about the uncertainty of their future and that of their child, spouse and other children as well as their anxiety and its impact on their lives and behavior. During a stage of disease, they hanged on hoping that hard conditions will end and entering the next stage, they encountered a range of new concerns, while their previous concerns have still persisted.

The life process of this group of mothers made a sudden massive change immediately after the diagnosis of the child's disease. Without any preparation, they entered a new stage of their lives and went through an unreturnable process. They sacrificed themselves to pass this difficult road.

After the child's diseases, these mothers put their health at risk by permanent self-neglect, being imprisoned in taking-care-of-the-child position and uninterrupted effort to seeking balance and stability in life. In the early stages, they considered this path temporary and thought that they will return to the previous life process with child's rapid improvement, but as time passed, they began to realize that they have started a long vague journey and the changes are so vast and profound that make it impossible to return to the condition before the child's illness and this situation jeopardizes their health.

1 Self-neglect

From the onset of illness, this group of mothers tolerated any pressure and ignored their health, taking responsibility of the patient's care as the main task regardless of their physical needs. After the illness, child becomes the first priority in the lives of these mothers and they turned all their attention towards the child's recovery. This group of mothers was fully immersed in the treatment process and child care and ignored themselves in all aspects. At first, it seemed that this ignorance or self-neglect is the result of child's disease hard condition in the early diagnosis. However, results showed that mothers continued to ignore themselves even after the

Table 1. Categories Based on Mothers Description of their Everyday Life

| Core category | Categories | Subcategories |
|---------------------------------------|--|---|
| Living in uncertainty and worriedness | 1. Self- neglect | a. Sacrificing physical needs during the caring process b. Sacrificing their health |
| | 2. Being imprisoned in taking-care-of-the- child position | a. Sacrificing psycho-social needs b. Scarifying wishes and desires |
| | 3.Seeking Balance and stability | a. Being normal b. Searching for stability |

end of difficult process of child's illness. That is because passing every stage of the treatment and entering the next stage, conditions remained unclear and they encountered with new issues regarding the illness process, their family and their situations. It can be said that self- neglect in these mothers was intensified and weakened at the peak and trough of the disease, but it never stopped. Although the mother's attention to herself increased after the child's treatment stoppage, it never reached to the level before the child's illness.

a: Sacrificing physical needs during the caring process: From the onset of illness, this group of mothers was under so much physical pressure taking responsibility of the patient's care as the daily main task. Not only were they responsible for full-time child care, but they also tried to do their other tasks as well. They did not care about their own physical capacity and claimed that although they are suffering from fatigue in many cases, they cannot do anything for themselves, because they cannot entrust care responsibilities and their tasks and responsibilities to anyone else and they should go on. They would indulge in the process as much as possible. Transportation of child, frequent nightly awakening to visit the child in case of child's sickness and increased need for care on the one hand, and performing other tasks and responsibilities during the child's rest and neglect of their own nutrition and sleep were issues that mentioned by these mothers. Neglect of the basic physical needs continued over the years after the child's illness and was intensified and weakened depending on the child's condition, but it never stopped.

The first participant discussed that: I do not have a good sleep at home. My son still sleeps at his bedroom and we sleep at our bedroom. However, I should sleep too light to hear him as soon as he calls me to see what he wants and do it for him. That is why I stopped sleeping well for so long.

Accordingly, the sixteenth participant said that: My daughter was always in my dream, I always saw nightmares and I was worried constantly. You know? This unorganized condition continued until her treatment stopped and it got better and worse with her illness intensity. I was better when she was better and it was ruined my day when she was bad. However one obtains bit of information regarding the disease, this information does not assure one to go on to live comfortably.

The thirteenth participant said that: In the next morning when I get up, I wash dishes and cook meals and care for my son. Imagine what would you do at home, I go home worn-out. At home, all I do is wash and dry. He has had diarrhea for 3 months and I wash blankets all the time. I should wash and dryer at night and I should get back to hospital tomorrow with the same schedule.

The eighth participant said that: I was a type of person who used to wake up in the morning when I put my head on the pillow at nights, but now, I wake up every one hour, put my hand on my daughter's forehead to see if she has fever or if she is uncovered. I am worried about her. I sleep very little. For example, when she sleeps at noon, I sleep to get some rest beside her, but I think I'd better not sleep

and go to do my other works.

The fifth participant said that: We are mostly here and when I'm home, I am often worried that she would beat her head somewhere. Her anus becomes tough with severe pain due to the drugs taken. She is constantly either in bath tub or I am getting her out of bath tub. I am with her in the bathroom, get her food ready or bring her to the clinic.

b: Sacrificing their health. After child's illness, this group of mothers ignored their health issue in two aspects of treatment and prevention. Despite knowing their physical and mental conditions, they did not visit the doctor and only took analgesic. They abandoned their previous treatments and stopped health activities such as exercise, yoga etc. They allocated minimum time for attention to themselves and most of them were oblivious to their appearance. This self-neglect continued over the years after the child's illness condition and it was intensified or weakened depending on the child's condition, but it never stopped. All participants had varying degrees of physical problems and most of them felt depressed. But none of them put serious and sustained effort to resolve their problem and they were not even willing to go to see a doctor. They allocated minimum time for their health, and refused to do any work requiring planning for them, such as seeing a doctor or regular visits to psychologist.

The first participant said that: I went to yoga for neck pain. However I don't go now, because I cannot continue it regularly. I cannot follow any regular course and I don't do irregular recreations like swimming and the like, because I'm bored and it is quite impossible. I had false nails which I cut out, I removed my artificial eyelashes. I even cannot have a haircut. I cannot go to Massage anymore, because basically I cannot have and follow a targeted program. I talk too much about recreation, but I am not in the mood even when there is an opportunity. We have a pool at home and there has been opportunity to go and do a little swimming, but I am not in the mood despite the easy access, while I used to go every day.

The eighth participant said that: I get sick more than before, maybe I do not care about myself too much. I do not have time for that. Maybe these things have taken all my time, so I do not care that much about myself. If I feel pain, I take pain killers. I have a toothache which I have tranquilized for a week.

The seventh participant said that: Before my daughter's illness, I took angiography and I was told that my heart vessels are blocked. I go to doctor too much. I went to a doctor as soon as something went wrong. However, after her illness, I did not go to doctor at all. Sometimes, I have a headache or dizziness, so that I take my head in my hands for hours. There has been a few times when I felt so bad that my children were frightened and called neighbors who helped me, but I did not go to a doctor. I'm not important when my child feels so much pain and is not doing well.

Regarding the attention to her appearance, she said that: I became a slut from the time when she got sick. I used to attend to my appearance, got myself a little makeup,

and I was always tidy. I always dyed my hair and I used to go to the barber regularly. Now, I do not go to barber at all. I rarely dye my hair. Now you can see that all my hair has turned grey. My hair was not that grey before, but I got so old that my husband seems to by my son.

The third participant said that: after my son's illness, the only doctor I regularly went was neurologist that my husband forced me to. Now, I have stopped the drugs. I do not think about my pain at all. I have been feeling abdominal pain, but I only take analgesic and do not care too much. I do not enjoy eating, and after his disease, I lost weight by 8-10 Kilos. Regarding the attention to her appearance, she said that: I used to wear too much make up, so that my mother in law kept criticizing me, but now... I do not wear makeup at all, I care about my appearance so little that a few nights ago when I used make up, my husband said what a surprise you care about your appearance! I am not in the mood of going to barbers'; while; I used to go too much. I wait for my sister, or someone else comes and prunes my eyebrows.

2 Being imprisoned in taking-care-of-the-child position

After child's illness, these mothers ignored their own psycho-social needs and sacrificed their own desires and wishes. It seems as though there is a fence of illness and care around their life and they lived in the area within the fence, and whatever is provided for them within this fence.

a: Sacrificing psycho-social needs. After their child's illness, these mothers abandoned or minimized all their social activities. They abandoned shopping, leisure and travel and spent most of their time at home. Adherence to the treatment and the child's adverse physical and apparent condition exacerbated this living style. Having been supported, they still more felt more comfortable with this living style and were willing to continue these conditions through applying some strategies. Over time when the child's condition is changed, this condition will be intensified or weakened. However, it never reached the level before the child's illness.

Regarding shopping and recreation, the second participant said that: I used to go shopping, but now I don't go out shopping too much. We are mostly at home. Neither anyone comes to my home staying for one hour nor do I go somewhere. We are at home day and night. My days are all the same, but I should tolerate it. I have no other options. I am a mother, what else I can I do.

Regarding recreation, the third participant said that: I have not gone anywhere since my son's illness. I have not gone to my sister's for 1 year did not, because I am not in the mood.

In this case, the first participant said that: I cannot do anything planned. I cannot spend time having fun, taking courses, going to a doctor or anything else, for example, "once a week, every Saturday....

Regarding recreation, the tenth participant said that: I used to go out with my friend. It means that I left her at my mother's home and I went to class and I did not stay at home. However, they all stopped since her illness.

Accordingly, the fifth participant said that: *I did not go to club, but I went to charity. I went to the local mosque*

on Wednesdays, but I was not a person of recreation. I went there with her for prayers. These all stopped since her illness.

b: Scarifying wishes and desires After child's illness, these mothers ignored all their desires and wishes. They not only left their previous habits, but also minimized the things that they used to enjoy doing. Staying in the fence of illness, care and focus on the issues and their related concerns, they deprive themselves from progress as if their identity is linked to child care and his survival.

Instability in life condition and prioritization to other issues, keep them away from their wishes so that most of them claimed their desires and dreams were forgotten since the child's illness. Accordingly, one of the mothers said that now that my daughter has stopped treatment for several years, I look at myself and see myself with no identity. I did not achieve any of my wishes and desires. Now, it is impossible to achieve many of those wishes anymore (the sixteenth participant).

In this regard, the fourth participant said that: I lost many of my dreams. I loved to continue education and get my diploma. My husband also somewhat agreed. However, it was totally forgotten with my son's illness. I loved to learn hairdressing and I have talent. I though this skill can be helpful in the future. However, my son's condition did not allow me to do this. Neither we could not afford the class nor could I go to the classes regularly. I was not in the mood and if I something happened, my husband would say that the child got bad because you had gone to the class. I even could not get a driver's license.

The eighth participant said that: I do not plan anything, because everything depends on my daughter's condition which is unknown. Now, my neighbor has advanced Grimm. She tells me to start a barber, but I cannot accept, because my condition is unknown. I said that if she stops her treatment and if I make sure that she has recovered completely, I can join her. I do not plan anything, because the situation is unclear.

3-Making Balance and Stability

They spent lots of time making balance in their own life and that of the child and the other family members and maintaining family structure and processes. This effort was initiated after passing the primary critical period and after the first few days these mothers tried to recover their composure as soon as possible. They put efforts to settle the family during the child's illness and even after his/her treatment stops, unless under the conditions such as the child's sever sickness or losing hope of his/her treatment by the doctor when they face crisis again. Constant efforts to make balance in the family and failure to establish previous routines sometimes caused inadequacy and guilt in them and exhaust them physically and mentally.

a: Being normal. They tried to present everything apparently normal and the same as the past. Hiding their pain and sorrow, crying alone, avoid saying the name of the disease even in the absence of child, hiding bad news from family members and constant efforts to present everything normal and good to the child, family, relatives

and acquaintances and even hiding the child's disease from others as much as possible would constitute an important part of their everyday life process.

The fourth participant said that: I went home from here with a sick child. It was so hard for me and I suffered so much. His father called and asked "did you get home comfortably" and I said "yes, get home comfortably. It was not hard". However, it was not true.

The third participant said that: I do not like people to think I am surrendered or that our life is ruined due to this disease. Thus, somehow I try to keep up appearances.

The first participant said that: I pretend to be ok to my husband when I'm sick, because I don't want to make him upset. I cannot talk to my parents about my sorrows. I pretend to be ok to all my children, especially my sick child. Meanwhile I am constantly trying to look good.

b: Searching for stability. Regardless of their capability, they put so much effort to preserve the family structure and processes. The fear of ruining family and losing her husband would exacerbate the situation. Mothers somehow tried to establish stability in the family to create a peaceful, desirable and stress-free environment for the sick child on the one hand, and to avoid experiencing extra stressors on the other hand. In this regard, they had to ignore themselves constantly and perform activities regardless of their capability, and constantly pretend. Under the conditions when they required support, this issue imposed great deal of physical and psychological pressures on them.

The third participant said that: At the beginning, I tried to normalize family process like before the illness, but to no avail. On Nowrooz celebration, I spent 2 hours setting haft-sin, but no one sat around it. First, I tried to be present life normal but not all of it was possible.

The sixth participant said that: At the beginning, I thought to myself how our happy family was ripped apart. But then I said to myself, I am responsible for this family. I keep saying to myself this is my task and I have to do it. I know my duty. I keep saying to my husband that we should live our lives. I do not want our life to be ripped apart. If I feel inattention by my husband, I talk to him claiming that not everything can be satisfied for our child being sick. There are lots of people like. Some are even sick themselves, but they are living their lives. Elsewhere, she said that I would not neglect my husband and my children even if I neglect myself.

The eighth participant said that: All my fatigue is mine. With all fatigue, my husband's food should be ready house works should be done properly. I don't want anything to change or make fights.

Regarding her mother's efforts to stabilize home condition, the sister of one of the patients (Interview No. 15) said that they used to quarrel and have disputes. After my sister's illness, my mom recedes and trying to make home calm for my sister and they let one another alone.

These efforts gradually began from the early days. Over time and after passing the critical condition, these mothers tried to recover their composure. They tried not only to make family routines process look normal and preserve its processes, but also to erase the impact and

symptoms of the disease completely, after the child's relative recovery.

Discussion

The everyday life process of the mothers with children suffering from leukemia is a complex and culture-oriented one, to the extent that most studies emphasize the effect of culture on decision-making and defining the roles in these families (Wills, 1999; Patistea et al., 2000; Huang et al., 2008; Moreira and Angelo, 2008; Khoury et al., 2013). The findings of the present study also showed that the Iranian women's belief in maternal role is very effective in their everyday life process after the child is being diagnosed with leukemia. All the participants somehow believed that mothers should sacrifice themselves for their children, and that they had no choice but to continue. In his study, Taleghani et al (2012) describes "the feeling trapped in the cancer" for this group of mothers.

In the present study, living with uncertainty and worriedness appeared as a central level in the life process of the mothers with children suffering from leukemia. What leads and forms the life process of these mothers are uncertainty and worriedness. Uncertainty and worriedness resulted from the child's disease and provoked reactions from mothers in the forms of sacrificing themselves, committing themselves to child care, and attempting to achieve balance and stability. The lives of these mothers underwent a dramatic change as the degree of uncertainty and concern fluctuated. At initial diagnosis and when relapses occurred, these mothers experienced the greatest changes in their everyday life process due to the severity of the disease and uncertainty of the patient's future. Therefore, they sacrificed themselves, committed themselves to child care, and attempted to achieve balance and stability as much as they could. Since mothers' concern over their children and the relevant issues reduced during the periods of remission, recovery, and patient's stable clinical condition, these changes reduced among these mothers as well. However, since they always lived in the shadow of the disease, their life process condition never became as good as it was before their children get the disease. Other studies with similar findings have also shown that uncertainty and concern are the main issues that shape mothers' lives and behaviors and guide their life process (Bjork et al., 2005; Moreira and Angelo, 2008; Khoury et al., 2013). In his theory entitled "A model of the family transition to living with childhood cancer", Clarke-Steffen (1997) mentions that living with uncertainty is a part of a new normal in family life process after a child's disease.

By exerting the pressures of taking the role of a primary caregiver on themselves, and ignoring their physical health in the two dimensions of prevention and treatment, these mothers marginalized their health issues. The notion that everything will be compensated after the child recovers was so strong in them. Most of them believed that, under these conditions, they did not have a chance to think about themselves. This notion was intensified with unfavorable economic conditions. This finding has been confirmed in many studies, showing that the quality of life decreased

among these mothers after their children got the disease (Levi and Drotar, 1999; Eiser et al., 2005; Klassen et al., 2008). The finding also shows that this group of mothers suffers from some degree of physical problems (Grinyer, 2006).

After their children got the disease, this group of mothers dedicated themselves to the disease and child care, trying to concentrate on their caring role by restricting their habits and giving up recreational and social activities. This condition gradually took them away from their previous wishes and demands, and shaped new wishes and demands among them, mostly concentrated on child health and family preservation. Moreover, the feelings such as the sense of isolation have been described in various studies (Taleghani et al., 2012; Khoury et al., 2013). Young et al. (2002) describes this condition with the concept of biographical shift. What is certain is that staying in such a restrictive condition for a long time caused emotional and psycho-social problems for these mothers so that all the participants stated that they suffered from some degree of depression and fatigue. Other studies have also confirmed these findings and shown that these mothers endure severe emotional distress and experience a range of psycho-social problems (Stuber et al., 1996; Sloper, 2000).

These mothers' constant attempt to establish balance and stability was another issue threatening their health. The child's unstable condition, continuous change in family status after hospitalization, and the unsuitable condition of other children and husband made these mothers constantly fluctuate between balance and imbalance. This changing condition made them constantly live in the present, unable to plan for their own lives. They constantly attempted to establish balance and maintain a semblance in the family process, and had no chance to pay attention to themselves. Depending on the child's condition, these mothers sometimes had a feeling of success and sometimes failure. This made them prefer their children and other family members to themselves and constantly ignore their emotional and physical needs while they were desperately in need of receiving support. Other studies also indicate that these mothers put a lot of effort into establishing a balance in their family (McGrath, 2001; Young et al., 2002; Bjork et al., 2005; Woodgate, 2006; Moreira and Angelo, 2008; Taleghani et al., 2012).

According to the findings, taking care of these mothers is as important as, or even more important than, taking care of a child with leukemia. This importance is due to the fact that a successful childhood cancer treatment is depend to a great extent on family child care, and that mothers have nowadays turned into an active member in health care teams, largely responsible for child care. When nurses and health care providers encounter and communicate with these mothers, they should consider the factor of fatigue among them, and understand their behavioral responses. Since there is no compiled program regarding the health status of caregivers, and given that mental health counseling is mainly focused on the early days of hospitalization, or done sporadically based on family needs, it seems that health care providers should pay much more attention to the health status of this group of mothers. However, the results show that these mothers often do not understand that they need to receive support and care, and they would rather not ask for help except in emergency.

According to the results of the present study, nurses and health care providers should know that with prolonged course of disease, disease prognosis change into an unfavorable condition, and any occurrence that could undermine stability, these mothers would seem much more helpless and their willingness to communicate with others and treatment team would reduce. Therefore, these mothers would need extra health care and support.

In conclusion, The everyday life process in mothers would dramatically endanger their physical and psychoemotional health after their children get a disease. These mothers, though desperately in need of receiving support and care, usually marginalize themselves and ignore their own needs. Therefore, it seems necessary that nurses and health-care providers pay attention to the physical and mental health of these mothers by recognizing the everyday life process after their children get a disease. However, it is necessary to conduct further studies in different cultural contexts to get a deeper insight into the phenomenon.

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