

Mothers' Lived Experiences in Caring for Adolescents with Leukemia in the Northeast of Thailand

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ABSTRACT

Aim: This research was to explore the lived experiences of the mothers caring for adolescents with leukemia, using a qualitative research method based on the concept of interpretative phenomenology/ hermeneutic phenomenology.

Methods: Data were collected by in-depth interviews with 15 mothers of the adolescents with leukemia who had been treated or followed up for treatment in the pediatric cancer ward and the pediatric outpatient department in a tertiary hospital in the northeastern region of Thailand. The qualitative data were analyzed based on the technique of Diekmann and Allen.

Results: The study results revealed the meanings of mothers caring for adolescents with leukemia and experience of leukemia, which can be summarized into the following key points. 1) The meaning of life as mothers of adolescents with leukemia was defined as a suffer life. 2) The lived experiences of mothers of adolescents with leukemia consisted of 3 sub-themes: (1) caring with patience (providing care based on the symptoms, strengthening the mind, need to be the ones who suffer instead of seeing their children suffer), (2) a life of struggle (financial struggles, psychological struggles, supporting -received) and (3) beliefs and care (beliefs -based care and beliefs -based parenting).

Conclusion: The results of this research led to a clearer understanding about the experiences of mothers of adolescents with leukemia. The data from the study can be used to support practice and management of nursing education and research in the future.

Keywords: Mothers' Lived Experiences, Caring, Adolescents with Leukemia, Phenomenology

INTRODUCTION

Cancer is the leading cause of death in children and adolescents. At present, 15,270 children and adolescents worldwide are diagnosed with cancer [1]. In Thailand, according to the statistics, in 2015, 37.93% of children and adolescents had cancer while that of 2016 was 58.06% and it was 62.50% in 2017 [2]. It is more likely to be found among adolescents between the ages of 10-19 years. This is consistent with the statistics of cancer patients at Srinagarind Hospital, Khon Kaen University, a super tertiary hospital and center for pediatric cancer treatment in northeastern region of Thailand, which found that in 2017, 44.30% of children and adolescents aged between 10 and 19 were diagnosed with cancer. [3] The most common cancer among children aged 0-14 years was leukemia [4]. It is an important problem in the health system. Although the current treatment approaches have been developed by the Thai Society of Hematology to make chemotherapy more effective in children and reduce complications [5]. Leukemia is a matter that greatly affects adolescents. It also affects parents as they need to adjust their roles as important caregivers for their children suffering from severe and this life-threatening illness. Although fathers play a key role in financial responsibility [6], mothers are expected to be caregivers than fathers [7]. Apart from caring for sick children, mothers also have to take care of other family members.

The studies on the experiences of caregivers of children with cancer were mostly conducted among school-age children. The studies on the experiences of mothers caring for adolescents with leukemia are rarely found. Children with different ages have different care needs. Moreover, the experiences of parents and caregivers in different cultural contexts have different needs and care approaches [8]. Therefore, this study aimed to examine the lived experiences of mothers caring for adolescents with leukemia in the northeastern region of Thailand.

MATERIAL AND METHODS

This was qualitative research based on the Heidegger's interpretative phenomenology with the aim to understand the mothers' lived experiences in caring for adolescents with leukemia. Lived experiences are subjective and complex phenomena. Data were collected by in-depth interviews. A semi-structured interview was used as a guide for the interviews. It took approximately 45-60 minutes for each interview.

Purposive sampling was used, the inclusion criteria were as follows: 1) mothers of adolescent patients with leukemia aged 12-18 years; 2) primary caregivers of adolescents with leukemia, 3) adolescents that were not in the early stages of diagnosis, 4) not having cognitive and communication impairments, and 5) being ready and willing to provide information. The researcher coordinated with the ward nurse to contact the qualified mothers to inquire about their willingness to participate in the study. The researcher collected the data until the data with duplicate patterns were obtained. Saturated data after fifteen mothers were the key informants.

The research instrument was the researcher. The data collection instruments were a semi-structured interview form about the mothers' lived experiences in caring for adolescents with cancer, which was constructed based on the literature review and verified by three experts, a field record form and a voice recorder.

After the nurse at the pediatric cancer ward coordinated and contacted with the qualified informants, the informants were asked about their willingness to participate in the study. Once they agreed to participate in the study, the researcher contacted them in order to clarify the details of the study and ask about the willingness to participate in the study again. After the consent from the informants was obtained, the researcher began to study about the information about the health and treatment of the informants.

The qualitative data were analyzed based on the technique of Diekmann and Allen which can be divided into seven stages. 1) The interviews were transcribed the interviews and the transcriptions were read. 2) A summary of each interview was summarized and categorized in the record form. 3) The data obtained from the interviews were analyzed and the similarities and differences of the data were compared to verify a variety of data. 4) The relationship model was considered. The obtained data linked together. The correctness of the interpretation was checked. Data triangulation was conducted to check the data's correctness with the informants and existing theories or literature as well as the experts with experiences in caring for pediatric cancer patients. 5) The similarities and differences of the content were compared. 6) The relationships between the important issues were investigated. The relationships from the index lists or categories of the obtained information were considered in order to draw conclusions from the study. 7) The outlines of the key points were listed in order to combine them into a final outline. The researcher verified and analyzed the obtained information with supervisor in order to

reduce any potential bias. Moreover, the researcher checked the information using triangulation and verifying it with the key informant.

Ethics: This research was approved by the Khon Kaen University Ethics Committee for Human Research, No. HE 621040. The researcher strictly followed the basic ethical principles: respect for persons, beneficence and justice. The informants were informed about the purposes of participating in the study and the study process once they agreed to provide information and signed the consent form to participate in the study. The informants had the right to stop providing information and leave the study at any time without affecting the care to be received. The overview of findings would be presented which cannot be traced to the informants. The researcher prepared to deal with the sensitive and uncomfortable events that might occurred during the interview. For example, when the informants cried, the researcher would immediately stop the interview and offer assistance using emotional support. When the informants felt better and were ready to provide the information, the researcher would continue the interviews. If not, the researcher would close the interview and make a new appointment when the informants were available and convenient to provide information.

RESULTS

The researcher collected the data along with conducting the data analysis. When the data became saturated, the researcher stopped collecting data. A total of 15 mothers were enrolled in the study. The mothers' personal information was as follows. The average age was 43 years. Six people cared for children with leukemia in the treatment stage. Seven of them cared for children with leukemia in the follow-up stage. Two of them cared for children with leukemia in the medication discontinuation stage. All of the informants were domiciled in the Northeast of Thailand. The average family income was 16,466.66 baht. Eight people finished primary education. Two of them finished junior high school. Three people finished high school. One person earned a bachelor's degree. Five of them ran small grocery stores in the village. Four people were farmers. Two of them were daily workers. Two people were factory workers. The rest of the mothers were housewives, and one served in the military. In terms of the marital status, eleven of them lived with husbands while four of them were single mothers (two got divorced and two were widowed due to the death of their husbands with cancer).

The meaning of life as mothers of adolescents with leukemia defined as a suffer life can be described as follows. When they were informed about their children' diagnosis of leukemia which was needed to be hospitalized for chemotherapy, they had to go back and forth from home to the hospital. They faced with challenging situations all the time. It was a repetitive way of life. The mothers, therefore, defined the life of caring for adolescents with leukemia as a "suffer life", referring to physical and financial suffer, and causing suffer for others.

"We have lived together like this. We have been frequently in and out of the hospital. In a month, we are at home only 4 days. It is suffer to travel. It is suffer to stay in the hospital."

(Key Informant: Mother 02)

"I do not have money. The savings were spent on caring for my husband who had cancer and died last year. It is quite suffer. I can take my child to the hospital only when I have money. If I borrow money from relatives, it will cause trouble for them."

(Key Informant: Mother 06)

Although leukemia occurs in adolescents who are expected to be able to take care of themselves. But in this study found that the mothers played a key role in caring, which consisted of three sub-themes as follows.

1 Caring with patience: The mothers were the ones who provided usual care for their children. When the early symptoms of leukemia appeared, the mothers provided care based on the symptoms. Until their children were diagnosed with leukemia, the

mothers provided physical and mental care to their children, as well as support and encouragement.

(1) Providing care based on the symptoms

"My child had a fever, and was pale and tired. Soon after his condition improved, he had a fever again. I kept wiping his body to bring down the temperature. I suspected that it must be wrong. Another one in village also had this symptom, and he had cancer. The symptoms of my child became more and more severe. So, he was sent to the hospital. The doctor said he had cancer. He has had fever, infection and mouth ulcers. I have to be patient. Sometimes, I have to take care of him so that I cannot sleep."

(Key Informant: Mother 01)

(2) Strengthening the mind

"I feel pity for my child. He always has vomiting blood. I am afraid that he will not survive, but I have to be patient and strong because I have to take care of him."

(Key Informant: Mother 07)

(3) Need to be the ones who suffer instead of seeing their children suffer

"It is very suffer for my son to have saline injection or blood drawing. His veins have been completely damaged from chemotherapy. Sometimes, even half a day, it cannot be done. My son cries every time the nurse injects him with a needle. Whenever he comes to the hospital, it is always like this. He is afraid of getting hurt. I always tell him to be patient. Looking at him makes me cry. If I could get hurt instead of him, I would be willing to do that."

(Key Informant: Mother 12)

2 A life of struggle: Continuously receiving treatment for leukemia in the hospital also affected the family. The mothers had to struggle, especially the single mothers and the low-income mothers. However, in their struggles, the mothers were supported by others.

(1) Financial struggles

"I have nothing left. The rice fields were mortgaged because I needed money for curing my husband (her husband had lymphoma and died last year). Finally, the rice fields were sequestrated. I have to be a daily worker in the village to earn money to buy food for my child. If I have money, I will take her to the hospital according to the appointment. If not, I will not take her to the hospital because traveling there costs a lot of expenses. I do not want to borrow money from others. I do not want to cause burden for them."

(Key Informant: Mother 06)

(2) Psychological struggles

"It was not easy when the doctor told me that the cancer recurred. I was exhausted and afraid that the events would repeat the same. I prayed for holy things to ask them to help my child to recover."

(Key Informant: Mother 08)

"I used to ask my child to commit suicide together. If we died, we would get out of this suffering (cried)...but I felt pity for my child. So, I had to think of a way to survive and live with it."

(Key Informant: Mother 06)

(3) Supporting received

"My relatives also lent me money. A nurse at the hospital called and told me to borrow other people's money for taking my child to the hospital and when I was at the hospital the nurse and the doctor would give money to me."

(Key Informant: Mother 06)

"The Subdistrict Administrative Organization registered my child as a chronic patient. Each month, we are paid with allowance. The Subdistrict Administrative Organization also provides a car to deliver us to the city. Then we have to take another bus to the hospital. This can alleviate the burden of travel expenses."

(Key Informant: Mother 04)

3 Beliefs and Care: This study found that there were two aspects of mothers' beliefs in caring as follows. First, it was the use of herbal remedies. The adolescents would seek alternatives based on their beliefs in treatment with their mothers. Most of the

time, the adolescents searched online engines, and the mothers decided on alternative herbs for treatment. Second, it was the beliefs in raising their children. The mothers and their families believed in parenting their children while recuperating at home.

(1) Beliefs-based care

"My son told me that he did not want to go to the hospital for treatment anymore. He was tired, so I found a very famous herb on the internet called "Angkab Noo" (porcupine flower). I boil it and my son drinks it instead of water. It tastes a bit bitter. But my son gets better than going to chemotherapy."

(Key Informant: Mother 07)

"My boss gave me an herb. I have my child take it 2 capsules a day. I think it makes my child's symptoms better. He can walk after taking it continuously."

(Key Informant: Mother 08)

2) Beliefs-based parenting

"My son is self-willed. He likes hanging out with friends and does not obey me. This is because chemotherapy kill all the cancer cells and his normal cell. Now, the new cells are growth in his body. So, his habits are like children. I have to gradually teach him."

(Key Informant: Mother 03)

"I think the cancer that my son has is caused by eating slang food such as meat and pickles. Now, he is forbidden to eat them. I have to keep an eye on what he eats and does. He sometimes listens to me, but sometimes he does not."

(Key Informant: Mother 11)

DISCUSSION

The mothers defined the life with adolescents with leukemia as a life full of hardships because it took a long time to cure leukemia. They had to go in and out of the hospital for a period of 2-3 years. So, the mother became tired [10], especially those lacking sources of support [8]. They had to seek help from close people.

The mothers took care of their children with patience. The mothers provided care to alleviate symptoms associated with the disease and played a key role in caring for their children while they were treated and had complications [7]. When their children exposed to adverse situations, the mothers experienced with their children by watching the situations and participating in providing care. They were also stressed and anxious [10]. It was found that the mothers used coping strategies by strengthening their own mind in order to be able to take care of their children [8]. When the children expressed the suffering caused by painful procedures, the mothers were part of the phenomenon and realized the suffering. The mothers also desired to alleviate and take the pain and suffering with them instead. This demonstrates the duty of mothers who are able to take care of their own children without question.

It was also found that the mothers who lacked social support had a life of struggle. The single mothers were in difficult situations. In particular, the financial problems caused stress [11] as they did not have fathers who played a role in earning income for the family [12]. In addition, it was found that the mothers experienced despair both from adversity and disease progression. They needed spiritual anchor. They had their children as anchors and relied on the supernatural things. The mothers and children were assisted by their relatives and medical personnel so that they can get through critical situations in each moment. It was also found that the community government agencies supported the mothers and children by providing welfare and facilitating access to health services for the children.

In addition to taking care in the dimension of the medical model, the mothers also used herbs to take care of their children

by seeking information from social media and from the advice of close people. It was also found that the mothers also had beliefs in raising their children due to the illness, so they spoiled and overprotected their children, making the children felt pressured [13].

Therefore, in caring for adolescents with cancer, health care workers should provide psychosocial care to the mothers or primary caregivers. The need for assistance should also be assessed among the mothers with difficult conditions. The cooperation network in providing continuous care for patients from the hospital to the community should also be developed. Moreover, health teams should design the care model that promotes mothers' life skills in using online information critically or recommend appropriate sources of benefit in decision-making to use beliefs in care and help mothers to promote the adolescents' potential in taking care of themselves independently.

CONCLUSION

This study has reflected the lived experiences of the mothers caring for their children who are in sophisticated adolescence. Patient-centered approach for leukemia treatment is inadequate. Therefore, family center care should be used in conjunction with understanding the development of adolescents so that comprehensive and holistic care can be provided to the adolescents with leukemia.

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