

Caring for Pediatric Patients with Acute Lymphoblastic Leukemia of Caregivers: Qualitative Study

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ABSTRACT

Objective: The objective of this research was to study the care of the pediatric patients with acute lymphoblastic leukemia (ALL) using a descriptive qualitative research method.

Methods: Data were collected by in-depth interviews with 14 of the pediatric patients with ALL who were admitted to the pediatric ward at a tertiary hospital in the eastern region of Thailand. Data were analyzed by content analysis.

Results: The care of the pediatric patients with ALL of the caregivers can be summarized into 5 important aspects as follows: 1) caring based on expectation, consisting of 2 sub-aspects: (1) decision-making on the choice of treatment and (2) inquiry sources of knowledge about care; 2) supportive care while receiving treatment, consisting of 4 sub-aspects: (1) managing complications, (2) preventing infection, (3) staying healthy and (4) receiving continuing treatment; 3) prevention the same situation care, consisting of 3 sub-aspects: (1) providing close care, (2) noticing abnormalities, and (3) changing the way of life at home; 4) fulfill the missing parts, consisting of 2 sub-aspects: (1) learning according to age and (2) brightness of age and 5) caring based on hopeless, consisting of 2 sub-aspects: (1) relieving discomfort and (2) not abandoning.

Conclusion: These findings have led to a clearer understanding about the care for the pediatric with ALL of the caregivers. In addition, the data can be used to support the nursing practice in the care for the pediatric with ALL in accordance with the needs of the caregivers, the management of nursing education and further research.

Keywords: Caring, Pediatric Patients, Acute Lymphoblastic Leukemia, Caregivers

INTRODUCTION

Childhood cancer is chronic and life-threatening. According to the World Health Organization report, the most common childhood cancer is leukemia, accounting for 26%. [1] In Thailand, the top three cancers among children under 15 years of age are leukemia, lymphoma and brain cancer. The incidences are 38.1 people, 6.4 people, and 6.3 people per million people, respectively. Among children with leukemia, ALL is more common than other types of leukemia. [2] According to the statistics of the pediatric patients with leukemia at a tertiary hospital in the eastern region of Thailand, it was found that the number of the pediatric patients with leukemia was the highest among all patients with childhood cancer. In 2018, 2019 and 2020, there were 68.97%, 65.31%, and 69.23% of the pediatric patients with leukemia per year respectively. [3]

The pediatric patients with ALL are mainly treated with chemotherapy because they respond well to this type of treatment. [4]. The treatment will take a period of 2-3 years, and the follow-up after the treatment is complete within 5 years is needed. [5] Two-thirds or more of the pediatric patients with ALL can be cured. There is also a higher recurrence free survival rate. [6] As a result of improvements in the treatment protocol for the pediatric patients with ALL which is more appropriate for the disease process. The diagnosis is more accurate and faster. [7]. Therefore, the care for the pediatric patients with ALL should be changed according to the current situation.

The participation of family members in the care of hospitalized children is a key principle in family-centered care [8]. The pediatric patients with cancer usually have illnesses and receive complex treatment, so they need to be cared for by family caregivers. The literature review are also studies on innovation development and nursing activities focusing on the care of pediatric patients to receive continuous treatment or reduce complications that occur during treatment, [9-11] However, from previous studies, the study on the care of the pediatric patients with ALL was based on the traditional treatment approach.

In this study, the researcher was interested in studying the experience of caregiver (CG) in caring for the pediatric patients with ALL in the context of the tertiary hospital in the eastern region of Thailand according to belief and values of family. For these reasons, the purpose of this study is to determine the care of the pediatric patients with ALL of CG in the context of the eastern region of Thailand.

MATERIAL AND METHODS

This qualitative study aimed to understand the care of the CG of the pediatric patients with ALL who were admitted to a tertiary hospital in the eastern region of Thailand. Data were collected by in-depth interviews. A semi-structured questionnaire was used as the guideline for the interviews.

Participants: The inclusion criteria were as follows: 1) parents or CG of male and female pediatric patients with ALL; 2) primary CG in the family providing care for pediatric patients with ALL; 3) not having cognitive and communication impairments; and 4) being ready and willing to provide information. The researcher coordinated with the ward nurse in order to contact parents whose qualifications met the inclusion criteria to inquire about their willingness to participate in the study. Data were collected until saturation, there were 14 informants in total.

Research instruments: The data collection instruments included a semi-structured interview form on the parent's care for the pediatric patients with ALL developed by the researcher based on the literature review and expert opinion. A field note and audio recording was used to record during interview.

Ethics: This research was certified by the Khon Kaen University Ethics Committee for Human Research code HE 622019. The researcher strictly followed the ethical principles

Analysis: The researcher analyzed and collected the data simultaneously using the content analysis. [12] The researcher reviewed all the obtained information. Then it was organized and classified into categories

RESULTS

The informants in this research were 14 primary CG providing care for the pediatric patients with ALL. Most of them are mothers (11 people), followed by aunt-uncle (2 people) and grandmother (1 person), aged between 30-40 years old (9 people), 41-50 years old (4 people) and 51 years old (1 person). Most of their educational levels are primary and secondary education but one of them is uneducated. In terms of occupations, most of them are general employees (8 people), working in fisheries (2 people), working in companies (2 people) and housewives (2 people).

Caring for the pediatric patients with ALL in the context of a tertiary hospital in the eastern region of Thailand can be divided into 5 main aspects

Caring based on expectation: When the CG of the pediatric patients with ALL are aware of the underlying medical conditions of

the pediatric patient and informed about the prognosis and treatment guidelines from the health team personnel which can give the pediatric patients the opportunity to recover from the illness, they have hope in the treatment. This type of care consists of 2 sub-aspects as follows:

1 Decision-making on the choice of treatment: The CG of the pediatric patients ALL have used two methods of treatment. First, it is chemotherapy because it can give the patients a chance to be cured although it may cause side effects while being treated. Second, they have used superstition-based treatment combined with chemotherapy. The CG consider that their children are sick because they have insulted sacred things or done bad things. When performing the curing ceremony, the pediatric patients have to ask for forgiveness and drink holy water which is believed to solve such bad things.

"When I know that my child has this illness, I have to accept it and take care of him as best as possible. The doctor said that there is an 80% chance of recovering if being treated by chemotherapy. During chemotherapy, there may be complications. However, my child must be cured. I can only hope that he will be healed."

(Key Informant 4)

"I thought that my child might insult any sacred things or do something bad, so I took him to Mortham (a wisdom scholar treating sick people based on superstition). My child had to ask for forgiveness from the sacred things and drink holy water and give lots of rest. I have also brought my child to the hospital for chemotherapy. I have relied on two ways of treatment. I hope he will recovery."

(Key Informant 2: Mother)

Inquiry sources of knowledge about care: It is the pursuit of knowledge from various sources that the CG have used as the guideline for caring for children with ALL.

"Most of the doctors and nurses told me how to take care of my child. But sometimes I did not know what kind of food my child can eat. So, I searched from the Internet and asked from the mother whose child had the same disease and received chemotherapy like my child. I have gained knowledge from doing this.

(Key Informant 10: Mother)

Supportive care while receiving treatment: It is to ensure that the pediatric patients with ALL are treated according to the chemotherapy protocol without complications during treatment and receiving continuing treatment.

1) Managing complications: It is the care when the pediatric patients have complications after receiving chemotherapy. The CG have dealt with the symptoms based on their belief.

"When my child gets chemo, his mouth usually becomes bitter, and he cannot eat. I have to get him something to eat before he gets chemo, such as milk. I also give him at least 3-4 egg whites every day."

(Key Informant 8: Mother)

"After chemotherapy, my grandchild's mouth is sore. When he has a sore mouth, he asks for mouthwash often and wipes the mouth with cotton pad and eats soft, not spicy food."

(Key Informant 6: Grandmother)

Preventing infection: The pediatric patients and their CG have used several methods of care to prevent infection.

"I am very carefully not to let my child get infected. I really concern about cleanliness. I clean everything. I change the bedsheet very often, around every three to four days to avoid having dust in the room. I wash hands often, especially when touching or doing anything with my child."

(Key Informant 9: Mother)

Staying healthy: The CG always get the pediatric patients to eat nutritious food so that the pediatric patients are healthy. Smokers are not allowed to get close to the pediatric patients.

"If children are strong, the germs cannot get inside their body. Children need to eat nutritious food. They must not eat snacks. I always protect my niece, such as not letting her to get

close to smokers or go to a place where there is smoke from the car."

(Key Informant 11: Aunt)

"When my child cannot eat, I buy Ensure (brand name of a milk) for him instead because it is full of nutrients and easy to drink. Even if my child can eat it a little, it is still good. His body will be strong."

(Key Informant 5: Mother)

Receiving continuing treatment: This includes receiving treatment as appointed, following up of symptoms and receiving treatment for a specified period which provides effective treatment.

"I have to take my child to get chemotherapy as prescribed by the doctor every time. The doctor usually makes an appointment for the medication on Thursday. I never postpone appointments. If there is anything I have to do, I will finish it first in order to bring my child to the hospital for treatment"

(Key Informant: Mother 4)

Prevention the same situation care, it refers to the care given for the pediatric patients with ALL who develop diseases or complications during treatment that cause the need to temporarily stop the treatment, such as having an infection in the body. Therefore, the care is given for the pediatric patients with ALL so that they can return to receive the treatment according to the original treatment guidelines and prevent further diseases or complications during treatment.

1) Providing close care: It is the care focusing on preventing diseases or complications that cause the pediatric patients to stop receiving chemotherapy in order to prevent them from developing diseases or complications.

"When my child gets infected, I have to calm my mind down and pray that the infection would not enter the bloodstream because if it enters the bloodstream, it is difficult to cure, and few can be healed. So, I have to take care of my child as closely as possible. My child has to get complete disinfectant, so that she can continue receiving chemotherapy."

(Key Informant 13: Mother)

2) Noticing abnormalities: It is the observation of abnormal symptoms related to diseases or complications that may cause temporary discontinuation of treatment, such as the symptoms caused by chemotherapy.

"I have to keep an eye on my child's symptoms at all times. When he has abnormal symptoms, I have to rush to the hospital and go to the emergency room."

(Key Informant: Mother 11)

Changing the way of life at home: It is to provide continuing care for the pediatric patients with leukemia from the hospital to the home. The CG think that it is to take good care of the pediatric patients like being in a hospital.

"When my child goes back home, I try to treat him like when he was in the hospital. I have adjusted the house to be like a hospital. That is, I let my child stay at home in an air-conditioned room with an air purifier, which is like being in a sterilization room in a hospital. I clean the room every day because my child has a low immune system which is easy to be infected."

(Key Informant 12: Mother)

Fulfil the missing parts: It is to provide care for the pediatric patients with ALL so that they can learn according to their age and development and to have fun and travel like normal children.

1) Learning according to age

"When receiving chemotherapy, my niece has to stay in the hospital for several days. As she does not go to school, she is worried about her homework. I also have her elder brother to take the homework from the teachers so that my niece can do it at the hospital. When the homework is done, her elder brother will submit it to the teachers and take her new homework."

(Key Informant 11: Aunt)

2) Brightness of age

"Sometimes, my child wants to play with toys and friends. I usually give her a phone, some dolls, or allow her to play the child who is on the bed next to her. But when going back home, she

mostly plays in the house. I usually watch her from a distance and do not let other children play harshly with her."

(Key Informant 14: Mother)

"Since my nephew is sick, I have never taken him out on a long trip like before. Mostly, we ride a motorcycle and go to see the sea because he likes the sea."

(Key Informant 3: Uncle)

Caring based on hopeless: When the CG know that they have a recurrence of the disease and do not respond to the treatment making it impossible to continue receiving treatment, they will feel hopeless.

Relieving discomfort:

"My child has been treated for a very long time. Recently, he has had seizures, the doctor took a spinal tap. They said the result shown recurrent of the disease, I am very desperate. When he has a headache, I am afraid that seizures start again. I will do whatever I can to keep my child out of pain and make him feel as comfortable as possible."

(Key Informant 7: Mother)

Not abandoning

"I am always with my child. I never leave him alone. When he has a headache, he may have seizures, so I have to keep an eye on him. Sometimes, he is in pain all night and cannot sleep. I feel really pity for him. He does not have any friends."

(Key Informant 7: Mother)

DISCUSSION

When the pediatric patients are diagnosed with ALL, the CG will provide care based on expectations. CG have high expectations in curing the pediatric patients. They have decided to treat the pediatric and also searched for knowledge in patient care from various sources. When the pediatric patients are diagnosed with life-threatening diseases, their families would like to know about the progression of the disease and hope that their children can be cured. They also want to know about both physical and mental changes that will occur to the patients and the side effects from regular treatment. [13] They also want the information that is true and not concealed regularly or when symptoms change from the doctor directly. [14] If the pediatric patients with ALL are treated with chemotherapy which provides many side effects do not receive good care and surveillance, they may not be able to get the full course of chemotherapy, and there will be an exacerbation of the disease. Preventing potential complications and dealing with the complications will allow the pediatric patients to continue receiving treatment. [15] When the pediatric patients develop diseases or complications during treatment that causes the need to temporarily stop receiving treatment, the CG usually provide prevention care. It also helps prevent other diseases or complications that may occur during treatment. When an infection occurs, the pediatric patients have to temporarily refrain from chemotherapy. As a result, the effectiveness of treatment is reduced, and the duration of treatment is increased. Moreover, there is a chance of recurrence of the disease, and more severe infections can lead to death in the pediatric patients. [16] The pediatric patients with cancer need to be cared for by their CG. Moreover, proper anti-infective behaviors are part of helping to prevent or reduce the risk of infection in pediatric patients. [17] In addition, during illness and treatment, there are side effects that affect the development of children. Children must be supervised to promote continuous learning. [18] When the pediatric patients' symptoms spread to other systems of the body and the body do not respond to treatment, the CG will provide care based on despair. From the study, when the CG have perceived that their children have a recurrence of the disease and cannot receive further treatment, they usually feel hopeless.

The CG would provide full care to the pediatric patients so that the pediatric patients feel comfortable and relieve from symptoms that cause both physically and mentally distress or pain. Most of the CG in this study are mothers. Therefore, they provide care to their children based on their roles as parents. Parents want

their children to be cared for as safely as possible. They try to participate in the consideration of the pros and cons of various treatments. They also collaborate with the doctor to set treatment goals to provide the pediatric patients with the best quality of life. [19] In addition, the pediatric patients need psychosocial care. They want to do things according to their own needs and contact or be with loved ones and friends or talk to their brothers or sisters. [14]

CONCLUSION

The study reflects the care of CG of the pediatric with ALL in the family. The pediatric patients with ALL received different treatments for each stage. For these reasons, caring for the pediatric patients with ALL throughout the duration of the illness and treatment is extremely important to ensure that they will not have complications during treatment and receive continuing effective treatment. Although receiving the treatment according to the protocol is necessary in curing pediatric patients, family care is still of paramount importance. Therefore, the principle of patient and family centered care should be adhered to in order to be able to provide comprehensive and holistic care for the pediatric patients with ALL.

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