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The needs of adolescents with leukemia in northeastern Thailand: Qualitative study.

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Abstract

Objective: The objective of this study was to examine the needs of adolescents with leukemia who received the treatment and follow-up treatment at a large tertiary care hospital in the northeastern Thailand.

Methods: This was qualitative research obtaining the information using in-depth interviews and observation techniques. Content analysis was employed to analyze qualitative information obtained from the study. The researcher purposively selected the key informants with specific qualification. The total number 15 adolescents with leukemia were recruited to participate in the study. The qualitative information was obtained from the key informants until the data saturation has been reached.

Results: The findings showed 2 key important issues were found including 1) The meaning of adolescents with leukemia; and 2) The needs of adolescents with leukemia. The needs were classified into five sub-categories: (1) The need to obtain information related to the disease and its treatment; (2) The need for care to relieve the symptoms; (3) The need for continuing education; (4) The need for having a career; and (5) The need to live a normal teenage life.

Conclusion: The findings of this study are very important for improving care for adolescents with leukemia; therefore, the needs of adolescents adhering to the principles of family center care should be taken into account. The recommendations obtained from the study should be discussed among nurses, primary caregivers, schools and local administrative organizations in order to design and provide mutual care for adolescents with leukemia and to improve quality of life through holistic approaches.

Keywords: Adolescents needs, Leukemia, Qualitative research.

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Introduction

Adolescence is a very vital period which determines how young people view and interact with the world as adult; and this period is a critical link between childhood and adulthood. It is a crucial phase of rapid transitioning in both physical and mental development of young persons. Sometimes adolescents cannot keep up with the sudden change which it creates confusion in decision makings, mood disruptions and risk behaviors which we called this period of heightened “storm and stress” [1]. It can be seen that with a single natural change in age can be complicated for adolescents; however, the current health situations can lead to health risks which affect their growth and potential development with age [2]. When serious illness occurs, the health situation among adolescents is even more complicated, especially with severe chronic illness such as cancer.

Cancer is one of the leading causes of death in children and adolescents. Currently, there are 15,270 children and adolescents diagnosed with cancer, and the trend is more likely to be found among adolescents between the ages of 10 to 19 [3]. There are children and adolescents with cancer in Thailand, and the statistics showed that in 2015 found (37.93%), 2016 (58.58%), 2017 (62.50%) [4]. This is consistent with the cancer patient’s statistics of Srinakarin Hospital, Khon Kaen University, which it is a supper tertiary hospital and a center for pediatric cancer treatment in Northeastern Thailand. It was found; that in 2017, there were children and adolescents between ages of 10 to 19 (44.30%) diagnosed with cancer [5]. The incidence of leukemia is higher among school-age children and early adolescence. However, when children are diagnosed with leukemia; and then they need continued hospitalization for a long duration of treatment; as a result, some school-age children with leukemia grow into their teens with cancer. Thus, adolescents with leukemia can be found at all stages of treatment and in both new and existing patients.

Leukemia among adolescents is one of important health problems in health system. This is because adolescence is the age for preparing and learning to become a quality adult; and adolescents are an important force of human resource for the country’s future development. Adolescents with leukemia take few years or more to go through the process of treatment [6]. Although pediatric leukemia treatment can increase survival among young patients, it has been found that there are health adverse effects in the process of treatment and post-treatment stages such as neurological impairments, slow growth and potential development, and a risk of developing secondary cancer [7]. The treatment process for leukemia takes a long time, so that both adolescents and family members will have to experience a wide range of stress and health effects.

From the literature review, it was found that several studies focused about the needs of the parents of adolescents diagnosed with the early stage of cancer. A study among school age children towards the care, the needs and self-care readiness in adolescents with cancer who need hospitalization for chemotherapy is only specific on the problems and needs of illness and treatment stage. However, there was no study which focused on the overall problems and needs among adolescents diagnosed with leukemia. Accessing the needs of adolescents with leukemia is an important initial step in nursing process in order to provide appropriate care for each patient in accordance with their needs. Therefore, this qualitative study aimed to examine the needs of adolescents with leukemia at all stages of treatment in order to reflect the problems and needs along the course of leukemia treatment at a large tertiary care hospital in the northeastern Thailand.

Material and Methods

Study design

This study was a qualitative research which seek knowledge toward the needs of adolescents with leukemia; in which, the needs of individuals are subjective and complex. The researcher obtained data using a semi-structured interview to guide the in-depth interview along with field observations and field recording.

Setting

The researcher selected the study area which was a Srinakarin Hospital to access the adolescence key informants with leukemia. The hospital is a large hospital that provides healthcare services to people in Khon Kaen and nearby provinces. The hospital is an important center for pediatric cancer treatment in the northeastern region. Although the current pediatric cancer treatment has been distributed to provincial hospitals and cancer treatment centers throughout the northeast region, specialized physician and interdisciplinary collaboration among health personnel are still needed. As a result, many leukemia pediatric patients are sent to receive continuous treatment at Srinakarin Hospital. When children and adolescent patients are sent for definitive diagnosis and ongoing treatment, they will be admitted to the Pediatric Outpatient Department. After that, the pediatric patient will be referred for wasp treatment for further procedures such as receiving chemotherapy and health treatment for complications at the oncology pediatric ward. The ward is designed to provide care for pediatric cancer patients of all systems. There is a meeting room in the ward with privacy area. So the researcher invited key informants to be interviewed in this room. In addition, Srinakarin Hospital also has a quality development center for chronically illness children. The atmosphere in the center is relaxed and very quiet which is suitable for performing the interviews. After the patient received complete chemotherapy treatment or the treatment for health complications, they would be sent back home. All patients are domiciled in the northeastern region provinces including Khon Kaen, Udon Thani, Maha Sarakham, Kalasin, Roi Et, Bueng Kan, Sakon Nakhon, Buriram, Surin and Nakhon Phanom.

Research instrument and reliability verification

The researcher learned the concepts, theories and practice regarding qualitative research skills including research methodology, data collection tools, research analysis, ethics and related topics using semi structure interview to collect relevant information such as observations and in-depth interviews techniques.

The tool used to collect data was a semi-structured interview question guideline regarding the problems and needs of adolescents with leukemia; in which the researcher has created based on the literature review and examination by 3 experts. Field recording technique and equipment for recording were used in the process of the interview.

Participants

The key informants were adolescents with leukemia; and the criteria to recruit the key informants to participate in this study were as follows: 1) Adolescent with leukemia age between 12-18 years old, currently studying in school grade 7-12; 2) Received treatment for leukemia and follow-up treatment in a tertiary hospital in the northeastern region; 3) Legal parents allowed to selected adolescents to participate in the study, 4) No intellectual and communication impairments, 5) Not a patient in the early stage diagnosed with leukemia. The researcher requested cooperation from a nurse who are specialized in pediatric cancer care at the patient ward to contact qualified adolescence patients. Nurses asked the key informants if they were willing to participate and to provide information in the study.

When adolescents voluntarily agreed to participate in the study, the researcher therefore began to build good relationships and collected data from the informants. The researcher collected the information until data saturation has been reached with no new issues arise. Then the researcher discontinued the data collection from the informants. The total number of key informants, 15 adolescents with leukemia were recruited to participate in the qualitative study.

Ethical Considerations

This research received research ethnic approval from the Human Research Ethnics Committee Khon Kaen University, HE 621040; and received a permission to enter the area to collect information from the director of Srinakarin Hospital and the head of the ward. The researcher has strictly followed the research ethnics and principle of fairness; and made sure that all the key informants would obtain the benefits from the study. The researcher respected the right and privacy of the key informants, clarified the purpose of the study, the research process starting from the key informants voluntarily provided information and signed the consent form to participate in the study. The informants have the right to stop providing information and leave the study at any time without affecting the treatment or follow-up care they should receive. The presentation and dissemination of the obtained knowledge and results of the study would be presented in an overview; and it could not be traced to the informant. The researcher prepared herself to deal with sensitive, uncomfortable issues that could occur during the interview such as stress and overemotional. If such situations occurred during the interview process, the researcher would immediately stop the interview and offer emotional support. When the key informants felt better and ready to continue with the session, the researcher would continue the interview again. When the key informant was not available to provide information, the researcher would close the interview and request a new appointment at their convenient time to continue the interview again.

Data Collection and Data Analysis

When adolescents with leukemia would be willingly to provide information, the researcher therefore started an appointment for an interview. The researcher made an appointment where the adolescents were convenient to meet, such as a meeting room in a ward or the center for improving a quality of life for chronically illness children in the hospital in case of that adolescents were hospitalized at that day. In addition, some adolescents were interviewed at home using the area under the tree or living room of their house.

The researchers spent approximately 45 minutes for each interview of adolescence informant. The researcher used language that is easy for adolescents to understand, and sometimes used slang terms. The researcher learned the connotation of adolescent terminology that is commonly used nowadays through various online media, studied the academic articles on the language used among adolescents, and discussed with her children who are in their teens in order to understand better toward adolescents' perspectives. These techniques allowed the researcher to understand the meaning of adolescents and their perspectives more in depth. The researcher divided the interview into two sessions. The first part of the interview was performed with the primary caregiver which lasted about 30 minutes, asking about general information and the illness of adolescents. Then the researcher requested for cooperation from the primary caregiver to interview adolescent alone, so the primary caregiver distanced herself during the interview. The primary caregivers and adolescents who provided information during the interview understood and cooperated very well with the researcher in the interview session.

The researcher defined the interview process into 3 steps as follows: initial interview, in-depth interview, and closing interview. For the initial interview, the researcher started the conversation about general matters in an environmentally friendly atmosphere. The researcher explained to the key informants about the duration of the interview, interview process, and the right and privacy of the information providers. For in-depth interview, the researcher asked a main question leading to the study issue, followed by a secondary question that encouraged key informants to provide more details and reflection of his/her story. The questionnaire was designed to be flexible and unpredictable which allowed the key informants to be able to convey his/her story freely. The researcher asked additional questions based on the received information using the techniques of reviewing, summarizing, reflection and storytelling. At the closing interview, the researcher interviewed the key informants until an appropriate time to stop; then the researcher diverted formal information into general conversation to ease the mood and feeling of the interviewee. The key informant was asked to speak more if there was anything he/she would like to provide information more to the researcher. In summary, the researcher summarized the issue that raised from the interview; and the interviewee were emphasized that the information obtained from the interview session would be kept confidential. The researcher said thank you for having met the key informants and engaging in the interview; and gave words of encouragement to the informants depending on the person; and asked permission to make an additional appointment for the next time if it needed; then closed the interview and left the area.

The researchers collected information among 15 adolescents using interview guidelines and recorder during the interview. The researcher performed the interview 1 time with 10 people, with the total of 2 times of the interview, and interviewed 5 additional key informants because there was additional information that needed to be obtained. The interview focus was about the needs of adolescents with leukemia which was a sensitive issue. However, the researcher was aware of the incident that may occur during the interview; therefore, the researcher prepared to face with the sensitive events. The researchers prepared facial tissues to wipe away tears when the informant cried; prepared refreshing candies to help informants feel more relaxed, refreshed; and prepared communication techniques including using silence, touching, and comforting to use in the conversation to support the key informant. The researchers recorded their feelings each time a sensitive event occurred in order to reduce bias in data collection and subsequent analysis. When entering the conducting an interview area, it appeared that there were 6 key informants who showed signs of crying with tears in their eyes, but not fluffing or whining; therefore, the researcher followed the methods that were prepared, so that the situation had eased, and the informants could continue to provide information.

The researcher recorded the relevant data obtained from the observations, atmosphere, interviews, behaviors, facial expressions, gestures, voice tone, and the interactions expressed by the adolescents. Various interactions that occurred in the duration of the interview were recorded, analyzed, and brought together the ideas for planning, summarizing the information periodically.

The researcher took notes in the form of mind mapping together with a short lecture in order to document the key points, and used them to create questions that encourage further storytelling questions of informative adolescents. As well as, the researcher recorded her feelings and opinions towards the stories told by the key informants. This way was to prevent potential bias in asking questions and bracketing, and to avoid the stressful atmosphere of the interview from focusing too much on note-taking.

The researcher used a digital audio recorder to record the interviews. It's small, inconspicuous, easy to charge, and can transfer data for easy tape removal and to prevent mistakes in the voice recorder during the interview. The researchers also used a smartphone-like cell phone to record audio and had it turned off the signal before using for recording.

The researcher analyzed the qualitative data using the content analysis method on the needs of adolescents with leukemia which applied the process step-by-step analysis of qualitative research data analysis according to the method of Benja-Attix and Kanchana Tangcholathip. The procedures started from listening to the recorded conversations, transliterating conversations into letter word for word, and reading carefully the transcripts of the dialogue to gain insight and understanding of the main points. The researcher took the key points and created a list and code of information individually; then general information was analyzed and categorized. The researcher compared the similarities and differences of the obtained information; then considered relationships in order to group or categorize data. After that, the researcher started looking for the relationships of each category until creating a conclusion by considering relationships from different categories and write them as the main subject matter to answer the study [8]. The researcher went back to meet with 2 key informants in order to summarize the research results which matched the opinions of the other informants and had no further issues.

Results

Personal data

The researcher collected the data along with the data analysis at the same time. When data saturation has been researched, the researcher discontinued the data collection process.

There were 15 adolescents with leukemia who participated in the study including 7 male adolescents, 8 female adolescents; the minimum age was 12 and the maximum age was 18; the mean age was 14.13.

In terms of treatment status, it was found that 6 adolescents were ongoing treatment; 7 adolescents were in a follow-up stage, and 2 adolescents had stopped the treatment.

All informants were domiciled in the Northeastern region. Regarding educational status, 10 informants continued to study in the education system; 2 of them were suspended, and 3 of them had stopped studying because of their satisfactory qualifications. Personal data of key informants as shown in Table 1.

Key Informant	Age (Year)	Gender	Education status	Treatment status	Treatment duration(Year)
1	14	Female	Informal education system	Treatment phase	2
2	15	Male	Vocational college	Follow up phase	5
3	18	Male	Finished primary 6	Follow up phase	5
4	18	Male	Informal education system	Follow up phase	4
5	12	Female	Secondary 2	Follow up phase	4
6	16	Female	Suspended	Treatment phase	1
7	16	Female	Informal education system	Stopped treatment	2
8	17	Male	Finished secondary 3	Stopped treatment	10
9	18	Female	Finished secondary 6	Follow up phase	6
10	16	Female	Secondary 3	Treatment phase	2
11	13	Male	Secondary 1	Treatment phase	8 (month)
12	14	Female	Secondary 2	Follow up phase	12
13	13	Female	Suspended	Treatment phase	1
14	16	Male	Vocational college	Follow up phase	5
15	12	Male	Secondary 1	Treatment phase	3

Table 1. Personal data of key informants.

This study revealed qualitative information relevant to the meaning of life and the needs of adolescents with leukemia as shown in Figure 1.

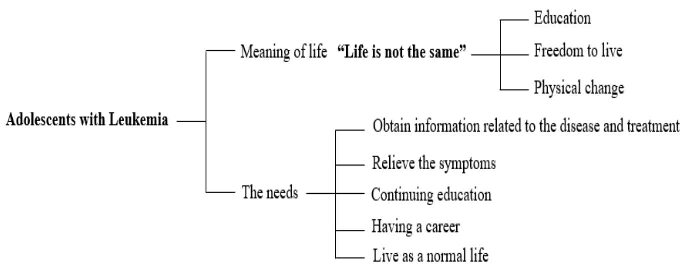

Figure 1. Typology of the meaning of life and the needs of adolescents with leukemia.

The meaning of leukemia as perceived by adolescents

Most key informants defined leukemia based on their perceptions and experience of illness with leukemia as "Life is not the same". Their lives had changed from the beginning in term of education, freedom to live life, changes in physical conditions due to health complications from the disease and treatment, and the changes in family situation. Details information are shown as follows: Adolescents once could go to school and performed well in school. However, when they were sick, they could not go to school anymore and could not catch up with the study and their friends; for instance,

"Now, I do not go to school anymore. I haven't studied since primary school grade 5 (studied in school until grade 5). Before I used to study very well, but now I cannot do some math problems and I think slower. In the past I went to school and I had an infectious fever, I had to stay in the hospital for almost a month. My mother did not let me go to school again" (Informant 1, female, 14 years old).

An adolescent was able to choose and perform any activities he wanted before. Now, he has no freedom because of the illness having prevented him from doing want he wanted. He was strictly supervised and cared by a primary caregiver; for instance, "Since having the treatment, what I want to do and what I want to eat, my mother would be the one who tells me that I can or cannot. I have to follow what she requests a bit" (Informant 12, male, 12 years old). Physical changes are caused by the complications from the treatment. Previously, an adolescent used to move his body, stand and walk normally, but after the treatment, he received health complications; for instance,

"My ankle twisted inward when I was given chemotherapy to a vein in my ankle. The doctor said that the drug had leaked out of the vein; and the muscles in the ankle were burned, became necrotic and turned black. The doctor gave me an operation and then put a piece of leather in front of my leg so that my ankles turned twisted like this. I cannot stand and walk for a long period of time" (Informant 2, male, 15 years old).

Family situation has changed and it is not the same. This is because the treatment of leukemia takes about 2-3 years. Each time when the child is hospitalized, it takes long time to stay in a hospital. Especially, when a child experienced complications and prolonged hospital stay, this affects family relationships causing some families to split up because of father mother separation.

"As I was in the hospital for a long time, my dad didn't come to visit me. If he came, he would stay just for a short time. My mom soon found out that my dad had gone out with another woman. During my mother's visit to the hospital, my father moved to live with another woman in a different district. My dad was no father living in the house as usual. I felt angry, regret, and pity for my mother, and sometimes I missed my father (Informant 9, male, 18 years old).

The needs of adolescents with leukemia

The needs were classified into five sub-categories: (1) The need to obtain information related to the disease and its treatment; (2) The need for care to alleviate the symptoms; (3) The need for continuing education; (4) The need for having a career; and (5) The need to live a normal teenage life.

The need to obtain information related to the disease and its treatment: At first when the adolescents were informed of the diagnosis of leukemia, they tried to learn and understand the disease what they were experiencing. Nowadays, there are many online media channels that provide information related to cancer which is easily accessible. However, the findings showed that it was found that adolescents with leukemia had first-hand experience of losing a father to cancer. Together with self-seeking information on the internet, they found a lot of information mentioning about death related to the treatment causing them to fear about their illness situation. Therefore, adolescents have desire to receive information clearly, correctly and easy to understand and access, so that they can obtain more knowledge and understanding towards the disease.

"I searched for the information from the internet. I found out that the disease is curable. But if it cannot be cured, you will be dead. So I think that if I have cancer, I will surely die. I was afraid that I would die like my father (my dad died from liver cancer a year ago). But soon after the treatment, it was not like what the internet said. If the hospital had told you from the beginning, it would be nice to get the information from the hospital"(Informant 7, female, 16 years old).

"I thought cancer was incurable and it wouldn't go away. I was very scared. At first I went to search from the internet. It said that cancer is an incurable disease. Now I read many articles of them. Some of what I read said that the disease couldn't go away, so I was confused with the flooded information from the internet" (Informant 9, male, 18 years old).

The need for care to relieve the symptoms: After the adolescents having a leukemia treatment, they had experience toward undesirable symptoms resulting from the chemotherapy and radiation therapy. The finding of the study showed that adolescents need for care to relieve the symptoms from health personnel and primary caregivers. The adolescents who provided the information rank the side effects from the most prevalent chemotherapy to the least common symptoms including nausea, vomiting, sore mouth, inability to eat, foul smell, hair loss, tiredness, suffering, burning sensation, constipation and headache. Adolescents would like to receive care to alleviate the symptoms side effects from chemotherapy and radiation therapy as follows: 1) Nausea and vomiting: the informants were provided with sour fruits when vomiting; 2) Sore mouth: the informants were provided with soft food; 3) Foul smell: the informants wanted to smell inhaler or cover their face with cloth; 4) Hair loss: the informants wanted to use a bandage or wear a wig; 5) Feel tired and exhausted: the informants needed to lie down or smell an inhaler; 6) The feeling of suffering: the informants needed emotional support from their mother; and 7) The informants had pain where the chemotherapy was injected into the muscle. They preferred a sleeping position that avoid lying on the painful area.

“When I received the red chemotherapy drug, I felt very tired. When the drug entered through the veins, the smell of medicine got in my nose. If I was going to get injected the drug into my vein, I needed to prepare something sour to eat so that I could feel better. So I asked my mom to buy something sour for me. The nurse gave me an anti-vomiting injection. But I didn't think it helps much”(Informant 11, female, 16 years old) .

“When talking about chemotherapy drugs, I get goose bumps. I'm scared. Because the chemotherapy drug looks white and has a foul smell. When chemotherapy was injected into a vein; then I would vomit. The pungent smell of the drug ran through my nose. I would find a cloth to cover my nose. The chemotherapy drug orange color sting and tortured my arm. My mother assisted me by patting softly on my arm” (Informant 8, female, 16 years old).

Adolescents received chemotherapy which was injected into the hip muscle. After the injection, there were side effects from receiving the drug, namely fever and the injection site would be very painful and swollen. She had to lie down on her side without overlapping the injection area which help lessen the pain.

“I dislike L-Asp that was injected into my hip, I felt pain, and I had an allergic reaction. After the injection, I had a fever and the injected site was swollen. If I moved, it hurted a lot. I needed my mother to help me arrange to sleep on the side that did not cover the hip. The injection side would be better in 3-4 days” (Informant 11, female, 16 years old)

“I used to complain that I wanted to die. (Informants cry..). Mother heard it and cried. I said that I was in pain. Why didn't I die, why live, why me? My mom told me if she thought it didn't hurt, it didn't hurt. It's in my heart, I tried to pretend that it didn't hurt and it helped”(Informant 10, female, 18 years old).

Besides having a treatment and follow-up treatment, throughout the course of treatment informants faced painful procedures. Informants need care to alleviate the pain and they experienced fear of the procedure. Seven key informants reported that the most painful procedure was a bone marrow puncture. It hurt so much that they were scared. They needed intravenous infusion of sleeping and sleeping pills, and wanting anesthesia to help reduce the pain during the procedure.

The study found that the most frequently performed procedures were venipuncture to provide fluids. Although the informant felt very hurt, but they had to accept it. There was no other nursing activities or medications used to help alleviate the pain during blood drawing and bone marrow puncture. Adolescents found ways to deal with the pain such as being patient, feeling empathy and stay numbness.

“I was terrified of having a bone marrow puncture because it hurt so much. Before piercing the needle, the doctor asked me to choose whether to take an anesthetic or sleeping pill. I preferred to take anesthetics more than sleeping pills because when I woke up I got dizzy (Informant 3, male, 18 years old).

“When the bone marrow was pierced, I took sleeping pills. Let it go to sleep, it wouldn’t hurt, but I still felt pain” (Informant 2, male, 15 years old).

The need for education: The findings showed that adolescents needed to continue their education whether having a treatment in the hospital, convalescent at home, or already completed the treatment.

Moreover, families have been organized and coordinated with school so that adolescents can maintain their studies and perform in school assignment. The findings revealed that the informants had 3 learning statuses including: 10 informants were still studying classified as 5 informants were classified as studying in the normal school system; 3 informants were studying in an informal school system; 3 informants were studying in vocational school; and 2 informants were taking a break from studying during treatment; 3 informants graduated at the school level they satisfied

It was found that most of adolescents’ parents did not allow their children with leukemia to go to school because they concerned about the dangers of health complications. However, adolescents still wanted to go to school; for instance, “I want to go to school and I feel like studying. Once I get better, I will continue my study. Normally, I study at Ban Nong Yai sub-district School. Now, I had to say goodbye to my teacher for health treatment first. As soon as the semester starts, I will go back to my Mathayom 3rd grade” (Informant 7, female, 16 years old).

Studying in school is a normal functioning of adolescents’ lives. Although some informants are unable to attend school as usual, their efforts have been made to maintain student roles by following up work from school, taking school work to do at home, and having family members coordinated with the teacher for assignments. These adolescents can be passed to the next grade even though they are on the course of treatment.

“Last year, all year I didn't go to school at all. But the school allowed me to take the exam home. After receiving chemotherapy, my mother took me to school to ask the teacher for the exam. But I couldn’t do the exam. I did not know how to do it. So the teacher asked me to do my homework at home first and then took the exam later. Because of that I could actually do the exam. While I was being treated in the hospital I did not do anything. I wanted to study only. I could do my homework. Even if I didn't go to school, it was okay" (Informant 15, male, 12 years old).

"I stopped studying when I was in Mathayom 1, term 2. After that, I came back to study in Mathayom 3. When I was in high school, I couldn't go to school all the time. I was worried about my study. I wanted to go to school but I couldn't. Mother requested my brother to take homework home for me. When finished, I asked my brother to take it back to the teacher" (Informant 11, female, 16 years old).

"I went to study in school as normal. When I couldn't go to school I asked my teacher to finish my work at home and turned it in. So I didn't have to repeat the class. I told the teacher myself that I still wanted to study. I studied privately; and when I got sick, I had to transfer my school to Ban Nong Saeng School" (Informant 10, female, 18 years old).

Informants with disabilities from complications of leukemia and treatment mentioned that after leaving the hospital, they recovered their health until they were able to go to school. Informants with physical limitations have specific needs for school; for instance, "My legs are like this (foot deformed, toes twisted inward). I can't walk very well. I can't stand for long period of time. For example, when studying mechanic, I had to stand for a long time. The teacher told me to take a break for a while. I think my legs were still bad and I wanted to rest my legs. In physical education class, I could not join, I only sat and watched my friends on the field" (Informant 2, male, 15 years old).

One of the informants was affected by both leg infections. Therefore, it was necessary to have the leg amputated to prevent the spread of infection resulting in having physical deformed condition. Her both legs are torn and still in the process of walking with a prosthetic legs. When going to school, she has to use a wheelchair instead.

"My father was the one who carried me up and down into the car when go to school. When I got to school, I sat alone in the hospital room. Because I couldn't go up the stairs to the 3rd floor. My teacher would bring homework down to me. I have been thinking that when I finish high school, I will study at Srisangwan School, Khon Kaen. It is a school for the disabled persons. I think I should be able to go to this school because there are slopes for wheelchairs (Informant 11, female, 16 years old).

The informant described complications arising from viral eye infections which affect his vision. "The doctor said that my eye was infected with the CMV virus. At first it was only on the right side, but it was still visible. I started not to see both of my eyes clearly when I was in Middle School. At the end of last semester, I could not see the text. Gradually, it became dimming. I had to have help from friends to read for me. I have undergone lens replacement surgery, and now I have to use glasses when reading. My friends also help me read the book sometimes" (Informant 14, male, 16 years old).

The need for having a career: Most of the adolescents who were admitted to the hospital and participated in the study were from poor families. Their families have to experience a burden costs when their children are hospitalized for a long time. However, these adolescents are aware of this financial problem. Majority of them have the need to get a job, to earn money for their own expenses and to help their family financially.

"When I came home from the hospital I sold second-hand clothes online on Facebook.

My friends went to pick up some of my clothes. Some of them were sold, but some couldn't. At least I could get enough for transportation to the hospital next time. I wanted to help lessen my mother's burden on expenses" (Informant 6, female, 16 years old).

"When I was fine and lived life as normal, I went to work at a karaoke shop. I went to work at 1 pm and left at 2 am. I was bald and had to wear a wig. I wanted to learn how to work first to know what kind of restaurant people have. I want to open my own restaurant" (Informant 9, female, 18 years old).

"I want to have money for my own expenses. I don't want to ask my mother. I used to work in a metal plating factory in Bangkok. I went with friends from the village. But the mother was afraid that the disease would return. I didn't do it for a long time so I came back to stay at home. Actually, I want to be in a military; but I'm afraid that I can't be because I have a congenital disease. And I cannot take the exam to become a military student because I didn't finish high school" (Informant 3, male, 18 years old).

The need to live as a normal life: The finding revealed that adolescents want to live a normal life. These adolescents with leukemia have had treatment for a long time and had adverse effects from the treatment. However, they have desire to life as normal life as adolescence. They are at age of experiencing new things, wanting to do many activities, and want to be attracted by the opposite sex.

"I think one thing that is not okay for me is not being able to go to school. I wanted to go to school but my mom did not let me go. Now that I've gone to school but I cannot catch up with my assignment. When I go to school, I get to hang out with my friends and go on a field trip" (Informant 15, male, 12 years old).

"I really wanted to see my friends at school. But I would not be able to go because my father would not let me go. Really. I want to go to school ....(crying) I want to go because my friends are there. I miss my friends I want to play with my friends (crying..). I have a close friend at school and I keep in touch *via* Line and Messenger" (Informant 13, female,13 years old).

"I used to be a beautiful person. After receiving chemotherapy, I became fat and bald. I didn't have a boyfriend back then. Later on, I had one. Most of the time, I found someone to talk to on IG. Some guys couldn't accept that I had a cancer. I didn't talk anymore. But this boyfriend knows that I have cancer. He calls me bald (Bald hair from chemotherapy) (Informant 9, female, 18 years old).

“I have a guy to talk to. I've been chatting with him for a long time. Later on, I opened up to him. My greatest fear was that if he knew I had cancer. But it is impossible to hide it right? If he can accept it, he can. If not he will leave”(Informant 12, female, 14 years old).

“I want to go dancing with the parade with my friends, it's so much fun. The parade only has it once a year such as a parade in Songkran and Bun Bang Fai festivals”(Informant 3, male, 18 years old).

Discussion

This qualitative study aimed to examine the needs of adolescents with leukemia in order to understand and provide care in accordance with the needs. It was found that adolescents had meaning their life with leukemia as “Life is not the same”. The needs of adolescents including physical, mental, and social development during treatment and follow-up treatment are shown as follows:

The meaning of leukemia as perceived by adolescents

Adolescence is a very vital period which it determines how young people view and interact with the world as adult. It is the stage of learning life experience and developing to an adulthood for the body, psychosocial, and spiritual. Adolescents who are diagnosed with leukemia have to adjust their life in different dimensions such family, school and social because their lives would not be the same after having diagnosed with cancer. Leukemia is a serious chronic illness which it requires long hospitalization; as a results, it affects a normal routine life of adolescents with leukemia. This creates a situation of inability to live a normal life as a teenage [9]; for instance, unable to go or to perform well in school, becoming dependent, lack of freedom, and being restricted to do things from family or caregivers. In general, adolescence is an independent age; however, the illness itself and long treatment have affected adolescents’ life and created frustration about what happening. Adolescents have described how they live their lives in the hospital after being diagnosed with cancer; for instance, must learn about the rules and regulations of the ward, and must learn new routines in the hospital which these are new life situations they have to experience as “life is not the same”. Adolescents feel loss of their own normal life and have negative feelings about oneself. They are more stressed and deprived of normal life, preventing them from meeting friends, restricting them from having freedom, lack of individuality because they cannot go to school or participate in certain activities.

The need of adolescent with leukemia

Leukemia is a complicate illness and it requires chemotherapy and radiation therapy which takes long period of time. The complications from the treatment arise from the treatment and patients need to continue hospitalization for 2-3 years and follow-up the treatment for another 2 years. Adolescents have to live with illness and continue having treatment in and out of the hospital at least for 5 years.

With the situation, adolescents with leukemia need more than just having physical therapy, they need to participate in activities in society and future normal life as a teenager.

The need to obtain information related to the disease and its treatment

Getting information about leukemia for adolescents is a new experience. Nowadays, it is easy to access to information using technology and many social media channels. Adolescence is the age that can easily access to computer and use social media a lot [10]. They can search for information about their illnesses and treatment. However, the vast amount of information is flooded on the internet and it has different credibility. Adolescents with cancer need reliable information for them to learn and understand what is happening to their physical body. There are many form of information channels. Adolescents are able to obtain information from a group of friends, social media, websites, or face to face conversation with health personnel. In addition, it was found that most adolescents with cancer search for information on social media or websites for relevant information. Adolescents read what others have posted on online media and watched video clips and share articles or links from social media [11]. The information that adolescents need the most are about illness and symptoms, treatment, risk, recurrence of the disease and a likelihood of developing secondary cancer. In addition, appropriate information about cancer and learning resources are required to support for adolescents with leukemia [12]. Obtaining appropriate knowledge or advice help assist children with cancer to gain knowledge and understanding leading to better quality of life among them [13].

The need for care to relieve the symptoms

Due to the treatment of leukemia in Thailand using the TPOG guidelines chemotherapy-based treatments together with radiation therapy, it causes complications that greatly affect the quality of life of young patients [6]. This is related to the severity of the adverse reactions occurring such as nausea and vomiting. It's the most painful symptom patients could experience [14]. Adolescents need care to relieve symptoms either from a nurse or a primary caregiver. The findings of this study showed that mother plays a vital role in providing primary care and support the needs of adolescents. Mothers provide caring and something to eat to relieve nausea and vomiting, and help arranging postures to relieve pain. Moreover, mothers encourage and provide emotional support enabling adolescents with leukemia to move past the undesired experiences. Mother is one of the most important factors for the quality of life among pediatric patients, especially for mental health [15].

The need for education

Adolescents have limitations from the illness and the treatment such as physical, mental and emotional conditions. Because of this, they are unable to attend school as normal. The findings of this study showed that adolescents need to continue their education even they are in the treatment phase. Adolescents responded to their need through family school arrangements. Family members coordinated with the sub-district school so that the adolescents with leukemia could still attend the school and maintain close relationship with teachers and friends. Adolescents are able to catch up with their coursework and exam so that they do not have to leave school system. For those adolescents who took a long break from school and dropped out of the educational system, they would find alternative school that support their situations when the treatment is complete and the symptoms are stable. Moreover, adolescents with special physical needs, such as deformed legs, disabilities from leg surgery, vision impaired are able to still go to school as usual. Even though they are unable to perform their study as same as their classmates, in return adolescents need a supportive environment for learning for them to return to school [12]. School management for children with cancer should concern two factors including 1) Physical needs such as seats, cabinets for school supplies and 2) Cognitive needs such as proper learning arrangements, home bound teacher, keeping track of workloads that are not excessive and facilitated by extending the school year for children [16]. According to the National Education Act of Thailand, children with chronic illness need care that meets the requirements such as education should be provided to persons with physical, mental, intellectual, emotional, social, communication and learning deficits. Children with physical disability or disabled persons who are unable to rely on himself or without a caregiver or underprivileged must have special rights and opportunities to receive basic and special education [17]. Young adolescents need understanding and assistance in learning from teachers and peers. Moreover, adolescence is an important age that is valuable to human resource for the development of the country. Therefore, they should receive a comprehensive and equal education that transcends health constraints.

The need for having a career

The adolescents in this study used universal health coverage which is a medical welfare provided by the government for Thai people. Even the primary caregivers do not have to pay for medical expenses. However, with a long treatment, it was found that there were still many expenses including costs for commuting, meals, and transportation. Most of adolescents participated in this study come from middle income to poor income family; as a results, it causes extra expenses for many families of these adolescents. If family has enough income, they are able to get their basic needs, and it will reduce the stress and improve quality of life of the family [18]. With adolescence age is being a responsible age, they have rational thinking and aware of family financial problems. Therefore, they want to alleviate family expenses by finding work doing what their physical condition can do, such as selling things through online channels, serving food and beverages, and do factory work. However, there are some physical limitations that are unable them to work continuously. Due to their health problem, they have to go back to the hospital for continuous treatment. With the situations, they worry about the impact on work and the recurrence of the disease symptoms. For this situation, this makes adolescents to become mature about how to live their life. Adolescents will start looking for a job and face challenges due to their inability to find the job they want. There could be discrimination against chronic illness people in the workplace; so that many people choose to disclose that they have cancer and decide to go on job [12].

The needs to live a normal teenage life

These adolescents with leukemia need to live a normal life. However, the illness and the treatment using chemotherapy and radiation therapy have impacted their physical body which prevents them from having a life they want with family and peers. Adolescence is an age that needs social attention such as an attention from the opposite sex, and the need to participate in social activities with friends. Maintaining relationships with peers and gaining attention from the opposite sex are very challenging for those adolescents with leukemia, especially for those who have to be in and out of the hospital for a long time. It is a huge challenge for teenagers living with cancer to live their lives defined as a normal. Adolescents who have already completed the course of treatment may start experiencing a life with family and friends [12].

Limitations of the Study

The study employed a gatekeeper approach in selected hospital. This process may limit the chances of meeting the new key informants for the study.

Conclusion and Implication for Health Personnel Practice

Nurses, families, schools and communities should take part in the holistic care for adolescents with leukemia. In order to achieve all stages of health, the recommendations are as follows:

Nursing practice

Nurses should design nursing care based on the perspectives and needs of adolescents with leukemia, and encourage the mothers or primary caregivers of those adolescents to participate in care.

Education

Educational institutions should coordinate with hospitals that provide care for pediatric cancer patients; so that the adolescents with leukemia will be able to continue their study. Moreover, schools should develop an appropriate teaching and learning model for adolescents with leukemia who have to go through hospitalization process by using educational technology to support and to create conductive learning for adolescents. This will enable equal learning environment in the 21st century.

Policies

Local government should play important role in providing welfare for adolescents with physical limitations; for instance, career, transportation, and social support group in the community.

Community and schools should formulate policy to support and follow-up the adolescents with leukemia who have to leave school for hospitalization.

Conflict of Interests

The authors no conflicts of interest.

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