

REALIZING BEING A LEUKEMIC PATIENT: THE STARTING POINT OF RETURNING TO NORMALITY IN THAI ADOLESCENTS

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ABSTRACT:

This grounded theory discovers the experience of adolescents undergoing chemotherapy for leukemia. Participants were 20 leukemic adolescents, aged between 12-19 years old. Data were collected through in-depth interview, and we observed their experience while receiving chemotherapy. The constant comparative method was used to analyze the data. "Realization being a leukemic patient" was identified as the first stage in the basic social process of "returning to normality". This stage was the starting point of the process to living with chemotherapy in leukemic adolescents. Three subcategories comprised the adolescents' experiences: having alarming symptoms, knowing the diagnosis, and accepting leukemic patients' role. All the adolescents in this study realized they were leukemic patients and they accepted chemotherapy as a treatment. The choice to be cured was apparent in leukemic adolescents. Chemotherapy was considered a task for them to endure. These findings will be useful for nurses, clinicians, and parents to identify interventions for leukemic adolescents during chemotherapy. This research also has implications for future study in this field.

Keywords: Leukemia, Adolescent, Chemotherapy, Thailand

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INTRODUCTION

Advances in chemotherapy have transformed leukemia from a deadly disease to a curable disease, but chemotherapy must begin early in treatment [1]. Leukemia symptoms, especially infection and bleeding, that occur in adolescents are more severe than in any other age group. Leukemia symptoms become worse if adolescents delay treatment and can threaten their survival.

Despite improved survival rates because of chemotherapy, the side effects of treatment pose substantial problems for adolescents with leukemia. Chemotherapy is a lengthy treatment (2-3 years of treatments) and is complex and demanding. Pain from invasive procedures and discomfort from the cytotoxic drug can cause distress. The adolescents' lives and routines are disrupted, and school attendance is interrupted during chemotherapy. Adolescents with leukemia experience fear about the future. Distress, sadness, anger and the need to

stop treatment have been reported [1, 2].

Additionally, adolescents associate the word "chemotherapy" with "leukemia" in their understanding of the severity of the illness. The meaning of death makes them afraid to die while suffering from chemotherapy. Loss of control and increased dependency are particular responses that have been observed in adolescents with leukemia [3]. Some patients choose to delay chemotherapy, but they finally choose to undergo chemotherapy because of the severity of leukemia symptoms. Hymovich [4] indicated that cancer can alter physical characteristics, self-concept, feelings, and life-style, as well as result in a loss of support and need for information. The coping abilities of adolescents with leukemia decrease during chemotherapy.

The adolescent is central to their care and ability to cope. They need to adapt to daily life during the chemotherapy treatment period. The suffering and distress experienced by the patients during chemotherapy challenges the adolescents to maintain self-care that is required during their

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treatment [5]. A study employed grounded theory method with the aim to gain more knowledge of how leukemia adolescents living with chemotherapy. The finding of the study will specific explore the basic social process of adolescents with leukemia when they receiving chemotherapy that can generalized, and use as the middle range theory [6, 7].

The adolescents "returning to normality" was the basic social process of living with chemotherapy in adolescents with leukemia [8]. This process is composed of four major stages: realizing being a leukemic patient, accepting chemotherapy as a key to normal life, learning self-care related to chemotherapy, and pursuing the best self-care. In addition, leukemic adolescents looking forward to a bright future as a key for help them to returning to the normally. The concept of normalization has emerged as the result of numerous studies addressing how families response to child with chronic illness [9-11]. The findings in this study was the emic view of adolescents with leukemia, the action that they solving the problem in their life during chemotherapy. This is the specific new knowledge for guiding the appropriate nursing care for adolescents with leukemia.

Only one stage, "*realization being a leukemic patient*", will be presented in detail in this paper, because the data in this stage relates to the actions that leukemic adolescents use to resolve issues after beginning chemotherapy. It was the starting point of the process of returning to normality. If the leukemic adolescents are not passing this stage they cannot live as leukemic patients and accept chemotherapy. Moreover, this stage is important for nurses to use as basic knowledge about the practice during the leukemic adolescents who start their chemotherapy.

The details of the basic social process and the additional stage will be presented in another paper [11]. According to Kearney [12] who described the level and application of qualitative research, argues that the categories of qualitative findings can be selected to present only one category. Moreover, DeSantis and Ugarriza [13] suggested that data categories in qualitative research can be used to develop nursing science because categories from qualitative research can explain the experiences of patients, which can lead to more helpful approaches to care.

METHODS

The participants in this study were adolescents diagnosed with leukemia. Two types of purposeful sampling were used: open sampling, which is

related to open coding, and theoretical sampling, which is related to selective coding and category building. The inclusion criteria were the following: 1) Thai boys and girls aged 12-19 years old with a diagnosis of leukemia; 2) awareness of the diagnosis and 3) treatment with chemotherapy. Participants in various phases of treatment were included to gain an overall picture of the chemotherapy treatment experience. Thammasat university hospital was the setting of this study. This tertiary hospital has a pediatric cancer unit that provides care for leukemic patients. The treatment protocol for leukemia consisted of remission, consolidation, re-intensification, central nervous system leukemia therapy, and maintenance chemotherapy. All protocols involved giving multiple drugs at high doses. One caregiver was allowed to stay with a patient in the hospital.

Prior to data collection, the proposal, interview guide, information sheet, and consent form were reviewed and approved by the Ethics Review Committee for Research Involving Human Research Subjects of the research filed. The researchers gave the information sheet to the parents and ask the permission of the data collection with the adolescents (participants). If the parents allow, the researcher gave the consent form for sign in and gave the research information to the participants and ask them for made a decision to join the study. When the participants express their intention to join the study willingly they were sign in the consent form. The data collection period was from October 2013 – February 2014.

Semi-structured interviews were used to collect data. The researcher obtained spontaneous descriptive information about leukemic adolescents by actively listening and allowing the adolescents to tell their stories. The adolescents were interviewed 1-2 times for 40-60 minutes at a place convenient for the participant. Interviews were recorded by a digital device, transcribed, and analyzed by using constant comparative method. After the data analysis began, the next data collection and interview was guided according to the emerging themes. Theoretical sampling was applied to seek and collect pertinent data to elaborate and refine the data into categories. The interviews became more specific as our understanding of adolescents with leukemia developed. The interview process ended after data saturation had been reached.

RESULTS

Data saturation was reached with 20 participants. The age of participants ranged from

12 to 19 years old with a mean of 16.4 years old. Four participants (20%) were 14 years old. Ten (50%) were 15-17 years old, and six (30%) were 18-19 years old. All were Thais and Buddhists. The majority finished junior high school (60%, N=12); two finished elementary school (10%), two were studying at a vocational study program; and three were studying for a bachelor's degree. Ten participants withdrew from school because of illness, but all planned to return. Three participants died in February 2014.

Realization being a leukemic patient

"Realization being a leukemic patient", was the first stage that reflected how adolescents are becoming leukemic patients and living with chemotherapy. The three subcategories of having alarming symptoms, knowing the diagnosis, and accepting leukemic patients' role were found as the subcategories that supported this stage.

The adolescents began life as healthy children, and they became leukemic patients by realizing they had an illness after the aggressive symptoms of leukemia affected their routine life. Additionally, the adolescents questioned their life because of the severe symptoms, which led them to stop a normal routine. They believed that the symptoms of leukemia could be relieved by going to see the doctor. This belief reflected that adolescents participated in the decision process and chose the best way to solve the illness.

The realization of being a leukemic patient was important to establish and highlight a substantial step forward in the adolescents understanding of how their health was changed by illness. The need to return to normal living as a teenager forced leukemic adolescents to receive chemotherapy. Moreover, physicians told patients that chemotherapy was the best way to treat leukemia. The three subcategories of this realization process are described in the following.

Having alarming symptoms

The adolescents' symptoms of leukemia varied over time, and they experienced differing degrees of concern about these changes. However, each adolescent observed changes in his or her physical performance. As the adolescents described how they came to sense something had changed in their body, their stories highlighted visible and acute signs or symptoms, including extreme pain, tiredness, bleeding, excessive sweating, and high fever. The symptoms had usually happened before, but they were *'unfamiliar and unrelenting'*. For example, one adolescent shared how he recognized the extreme pain in legs as a sign, and he was

tempted to stay home from school when it briefly subsided:

"I usually feel pain in my legs after I play basketball. At night the pain was severe, it was like a bone pain, pain inside the bone. I could not move my leg and could not walk. I let my parents know. I stopped going to school on that day."

When the adolescents had symptoms, they asked their parents for help and tried to alleviate the symptoms by themselves. The basic home medication was used, but often, the medicine did not help. Adolescents became aware that the symptoms were not normal because every symptom was *'unresolved by the regular treatment'*. The adolescents realized that their symptoms were serious if the commonly used pain medication did not improve their symptoms. An adolescent said:

"I take paracetamol and cold pack to relieve my fever, but my body seemed like I have a fire inside. My parents gave me the traditional herb to drink but it did not help. The simple medication can help."

Beyond these signs of concern, the adolescents were particularly attentive to changes that persisted, interfered with their normal living, and were perceived as *'severe and progressive.'* All symptoms lacked a clear explanation because they occurred suddenly and were severe and progressive. Some adolescents, for example, became concerned when they began to notice a "trend" of worsening symptoms, such as severe tiredness after exercise and powerlessness the next day. Another adolescent explained his growing concern about the persistent pain he felt. He believed that the symptoms were progressive in a bad way.

The adolescents realized quickly that they had an unfamiliar sickness. Every adolescent that participated in this study could not maintain their normal routine. They could not do basic activities, such as walking, because of the severe pain. Some adolescents could not eat because they had severe fatigue and high fever. The symptoms transformed the illness to a severe sickness, and it affected the adolescents' routine life. All basic activities

stopped, and a social life outside the family did not exist. The adolescents were alarmed by the symptoms of their illness.

Knowing the diagnosis

When adolescents had particular symptoms, such as bleeding, excessive sweating, and high fever, they were unable to continue routine life. They could not resolve the illness by themselves. Every adolescent is going to hospital.

'Having a series of investigations' was mentioned as the approach to explain the adolescents' symptoms. Moreover, this method was used to find the appropriate treatments that were specific to the sickness. The adolescents saw several physicians for physical exams and received appropriate medication. The initial tests at the first hospital visit included complete blood count, chest x-ray, blood chemistry, and urinalysis. The adolescents felt like patients because their health was being evaluated. Additionally, some adolescents who had severe symptoms were admitted to the hospital for observation. After abnormal results were found from the initial evaluation, another physician explained that a specific test would be needed. An adolescent recalled the special test very clearly: *"The doctor tells me that he will give me a special test. Bone marrow aspiration was the procedure."* The adolescents who underwent bone marrow aspirations had a variety of emotions, including fear, frustration, and anxiety. An adolescent said: *"I am really anxious and a little afraid because this is a special procedure. I have no idea about the result."* Full evaluation took two or three days. Some adolescents had to go to the hospital more than once.

'Guessing of having cancer' emerged as the point at which they transitioned from a normal adolescent to a leukemic patient. A series of abnormal results were found, and the parents of the adolescents were the first to hear the diagnosis of leukemia. All the adolescents were excluded from the discussion that occurred between the physician and parents. The adolescents noticed other people's strange expressions as the cues that something was wrong. The parents' responses after hearing that their child had leukemia were not concealed from the teenagers. An adolescent explained: *"My parents had a discussion with the doctor without me. After they discussed, I saw my mom crying. I knew I had a severe illness."*

Some parents tried to calm down and avoid talking to their children about the diagnosis that they just discovered. However, the adolescents

observed strange signs from their parents, such as cool hands, different tone of speaking, and facial expressions. The signs confirmed that "something bad happened", but the parents tried to calm down and avoided telling the adolescent about the diagnosis. A girl described the experience in the following way: *"My father held my hand. I felt his hands were cool. He looked so sad, I had a severe illness. He smiled with the red eyes and he tried to not cry. I knew something bad happened."*

In informing the adolescents about medication treatment, physicians used the word "chemotherapy". Adolescents knew this word and an adolescent explained that he thought *"I guess that I have cancer because cancer patients receive chemotherapy."* Additionally, when adolescents heard the term "blood disease", they were doubtful and tried to ask the doctor for more details. The doctor explained some details, such as "your white blood cells are more productive and not under control. It makes you sick." The adolescents were suspicious, and one adolescent had guessed: *"The illness is not only a blood disease. I think it is severe, maybe it is cancer in my blood."*

'Being informed by parents or by physician'

The adolescents received information about their illness and learned of the leukemia diagnosis by their parents or physician. The information that the adolescents received was consistent with their suspicion of having cancer. After hearing their diagnosis, the adolescents did not panic, and they used the information they received about leukemia to decide to receive chemotherapy treatment. However, they asked for clarification about chemotherapy because they needed more information. One adolescent described: *"I need to know more about chemotherapy. Does it help me to get rid of leukemia?"* Physicians and parents gave more information about chemotherapy, but the adolescents asked for more details and directly asked the physician about the chemotherapy, using questions such as *"Can you tell me more about chemotherapy?"* The doctor then explained the treatment more directly. The adolescents focused most on the possibility that chemotherapy could cure their leukemia. Many adolescents stated: *"Chemotherapy is the choice of treatment. I was bright in my mind."* All the leukemic adolescents in this study desired to have chemotherapy because of the chance of being cured.

Leukemic adolescents were to summarize

their information and knew the truth of the illness happening with their life. The conclusion in mind that they had leukemia became real. "Leukemia was a logical conclusion" as adolescents, shared:

"The doctor told me the diagnosis of my illness. Everything concluded that I was diagnosed with blood cancer. It was a truth and real. I became a patient having leukemia"

In learning of their disease, the first lesson for the adolescents was to becoming leukemic patient. Deliberations was over the meaning of symptoms, the medical diagnosis, and the completed conclusion of every cue. Every teenager felt "numb," and "hot flush on face," on the time that they completely knew the diagnosis.

Accepting leukemic patients' role

After the adolescents realized their diagnosis, treatment began as soon as possible. The leukemic adolescents 'accepted chemotherapy as a treatment'. This was a large step towards realizing their role as a leukemic patient. The time they spent in the hospital for chemotherapy allowed the adolescents to learn more about leukemia and chemotherapy because they could ask for more information from the physicians and nurses that spent time with them. Information, such as the cause of leukemia and the chance to be cured, showed that leukemia was different from other types of cancer. This belief process was a strategy that leukemic adolescents used to reflect on the opportunity to live. It was the starting point for leukemic adolescents to think "What should I do after having leukemia?"

"Leukemia is a cancer of white blood cells. It's a cancer but I know it has a chance to be cured by chemotherapy. Because nowadays, many children with leukemia are cured. This is a different form of cancer. Maybe my leukemia can be cured and I know what I can do when I have leukemia. I will take care of myself."

Leukemic adolescents referred to themselves as a "leukemic patient" when they spoke with health professionals. Additionally, they described that they merged their understanding of the illness with the realization of being a leukemic

patient. They demonstrated their understanding of the cause of leukemia and accepted that staying in the hospital was an important part of treatment. An adolescent said:

"I'm a leukemic patient. I know that leukemia is the cancer of the white blood cells. My white blood cells are too high and the white blood cells make me sick. Every leukemic patient must understand this topic because it is the basic information for going on with treatment for decreasing the white blood cells."

Moreover, the adolescents had to tell the significant people in their life about the illness. This task was not complicated but needed to be done at the right time. For leukemic adolescents, the significant people they had to tell about their leukemia were close friends. Most of the leukemic adolescents in this study called their close friends to share this information.

Many leukemic adolescents sought not only the information about illness and chemotherapy by asking the doctor questions but also looked for information by themselves. Since the leukemic adolescents had ability to explore the information; "reading the medical book about leukemia and chemotherapy" was done to explain the disease to themselves. The leukemic adolescents would find the source of medical books by themselves. For example, some leukemic adolescents found the resource of medical information in textbooks by asking for help from friends who had brother studying in medicine to borrow a medical book, especially in cancer and chemotherapy. When the leukemic adolescents read the medical book, they merged the information that they received from doctor with the information that they read. The understanding of chemotherapy was important for the leukemic adolescents, and it would become more than the understanding. Since chemotherapy was an essential part to cure and every patient must rely on chemotherapy. The chemotherapy would be an important task for the leukemic adolescents.

"I called to my friend who had brother studying in medicine. I asked him for borrowing the book about cancer and chemotherapy from his brother. I knew from the book about the

importance of chemotherapy. It could cure leukemia, especially in children. The chemotherapy was important that is why the doctor told me to admit for having chemo on hospital”

The data of chemotherapy that the leukemic adolescents were receiving and seeking were indicated as the knowledge of leukemia. This knowledge was used to support the adolescents with leukemia to moving on during chemotherapy. Most of the leukemic adolescents who were interviewed had similar understanding of leukemia that can be cured by chemotherapy. The leukemic adolescents “knew that chemotherapy was the best way for cure.” They “wanted to be cured”, “wanted to get rid of cancer” and “wanted to start treatment as soon as possible.” In interviewing the leukemic adolescents, it became clear that chemotherapy was common, and the leukemic adolescents were likely to accept the treatment.

DISCUSSION

The “Realization of being a leukemic patient” was consistent with the formation of identity in the adolescents’ development. The identity of the leukemic adolescents was to remain rooted in reality while the illness happened. The chemotherapy was a new experience for the adolescents. They established a new identity by accepting their role as a leukemic patient and did not deny the illness.

Having been diagnosed as leukemia was the crisis event, interrupting of the normal process of identity formation and disrupting the normal life [14]. The leukemic adolescents were developing new identity to stay with leukemia because they had a healthy norm. The self-identified formation was influenced by leukemic symptoms and the starting of chemotherapy. Being leukemic patients was substituted for the identity of healthy adolescents. In the other hand, Madan-Swain, Brown [15] stated that a chronic illness may negatively influence identity formation in adolescents. Gavaghan and Roach [16] found that adolescents diagnosed with cancer were identified as having fewer achievements compared to healthy adolescents. A future study to explore the perception of adolescent when they know the diagnosis of leukemia is needed to make a conclusion and setting the appropriate nursing intervention.

However, the findings from this study came from 20 leukemic adolescents that were not

compared to healthy adolescents. The study showed that the leukemia symptoms may affect the adolescent’s self-care ability. The adolescents suffered, especially if the symptoms were severe and unresolved by regular treatment. However, the symptoms were warning signs that alarmed the adolescents to consider their health. It was important to highlight how the adolescents perceived that their health had been changed by illness. This finding can be used to encourage a positive perception of symptoms in leukemic adolescents to establish self-care interventions for leukemic adolescents in the future.

We determined that the leukemic adolescents accepted chemotherapy “as a method to be cured” because they sought and received chemotherapy information by asking physicians, and seeking information by themselves, which indicated they gained knowledge about leukemia and its treatments. This knowledge of leukemia was used to support their journey during chemotherapy treatment. Most of the leukemic adolescents who were interviewed had a similar understanding that leukemia can be cured by chemotherapy. They “wanted to get rid of cancer” and “wanted to start treatment as soon as possible.” Chemotherapy was the primary treatment for the leukemic adolescents. They had to accept and endure their new identity as leukemic patients.

In this study, all the leukemic adolescents were questioned about their illness. They were informed of the diagnosis of leukemia before receiving chemotherapy. Adolescents should be prepared before they are informed of a leukemia diagnosis because they are observant individuals. Additionally, nursing staff must assess the adolescent’s psychological needs such as, fear, anxiety, and past experience with invasive medical procedures [17] at the time of having special procedures – such as bone marrow aspiration – and again when adolescents are admitted to the hospital for chemotherapy. Several studies show that adolescents with cancer have depression and need help, and some patients think about death because death is a possibility, and they need to express this feeling [3, 18, 19].

The findings of this study show that adolescents can accept an illness and realize the chance to be cured by chemotherapy, but detailed information about leukemia and chemotherapy must be provided at the time of diagnosis. It is important that the health professional consider the type and format of information that leukemic adolescents need. In this study, we found that a direct explanation with appropriate timing was

important. Additionally, the leukemic adolescents need to ask about their health care. However, the appropriate format to give information about leukemia and chemotherapy needs further study.

Future studies on the topic of how leukemic adolescents adjust to life after being diagnosed with leukemia is needed to clarify their responses. Because the adolescents in this study displayed positive adjustments after first confronting the side effects of chemotherapy, our next study will focus on the side effects of chemotherapy and how they affect the adolescent's life.

CONCLUSION

The leukemia disturbed the lives of the adolescents. All the adolescents in this study realized they were leukemic patients. Chemotherapy was considered a task for them to endure. The conclusion to become a leukemic patient was clear, and they accepted chemotherapy as a treatment. The choice to be cured was apparent in the adolescents of this study.

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