

THE MEANING AND PERFORMANCE OF SELF-CARE BY ADOLESCENTS WITH LEUKEMIA

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ABSTRACT:

Background: “Self-care” is an essential component for adolescents with leukemia to cope with the illness and chemotherapy. Pediatric clinicians, especially nurses, need to create method to support self-care practice of adolescent with leukemia. Because the current literature contains little evidence concerning self-care in adolescents with leukemia during their chemotherapy period, studies on the meaning of self-care from the experience of adolescents with leukemia are needed.

Method: The qualitative method was applied in this study to describe the meaning of self-care from the experience of adolescents with leukemia. Data were collected by in-depth interview of 11 adolescents with leukemia. In addition, field note and observation note were written on the reflections, ideas, and meaning of self-care during the data collection process. All data were analyzed by using thematic analysis method.

Results: Two themes reflected the meaning of self-care from the perspective of adolescents, including 1) “*Learning self-care*”: Adolescents with leukemia must “learn” many things about living with chemotherapy and maintaining their way of life, and 2) “*Performing self-care in daily life*”: were the strategies to performing self-care to fit with the daily life.

Conclusion: Both themes emphasized the point of “self-care” that adolescents with leukemia took in terms of learning self-care and the variety of self-care activities that they practiced and modified for the goodness of integration with daily living. The findings help provide a clear picture of self-care in this group, and can help pediatric nurses and clinicians create intervention to support self-care for adolescents with leukemia.

Keywords: Self-care, Adolescents, Leukemia, Thailand

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INTRODUCTION

The diagnosis of leukemia can be devastating for patients and their families at any age, but coping with the effects of the disease and its treatments may be particularly difficult for adolescents. Smith, Seibel [1] observed that because the incidence of cancer is high and the survival rates are increasing [2], it is important to examine how adolescents are coping. Adolescents with leukemia must often learn to cope with demands that are not part of their normal repertoire of skills and knowledge [3]. The coping skills that are required for adolescents with leukemia are also different from those that are needed to cope with more acute self-limitation illnesses [4]. A model proposed by Craig and

Edwards [5] and Golchin, Sharifi [6] suggests that “self-care” is a basic component through which cancer patients cope with the crisis of their disease. “Self-care” is a problem-solving technique [7], the main focus of which is individual care with help from the family within a nursing context. In addition, self-care in this context can be seen as a specific set to learn activities or protocols encouraging individuals to act in a particular way in a given situation.

One of most common problems that adolescents with leukemia face is experiencing chemotherapy side effects. Most of adolescents with leukemia confront the side effect of chemotherapy after two times of chemotherapy. The side effects of chemotherapy such as nausea, vomiting, fatigue, infection and hair loss made the physical condition became worsening [8]. In addition, the side effect

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will be severe when the chemotherapy was continuing. The adolescents with leukemia will receive the supportive treatment to decrease the severity of the side effect. If the adolescents with leukemia need to get better from side effect of chemotherapy, they need to adjust their activity, meal, and taking adequate rest. Docherty, Sandelowski [9] indicated that patients who experience more severe side effects in response to chemotherapy have a reduced ability for self-care, particularly in adolescents with leukemia, who are treated with high-dose chemotherapy. Adolescents with leukemia frequently report fatigue, which is not only a common symptom but also highly disruptive and distressing [10]. Fatigue can hamper an individual's capacity for self-care [11]. Moreover, adolescents with leukemia have reported that fatigue interferes with their daily living. The feeling of "no power" decreased their mood and limited their self-care activities. The patient's response to fatigue includes sleeping and cancelling activities [12, 13].

In contrast, Kupst [2], Schulman [14] followed the families of children with acute leukemia for periods of two and nine years. They found that most of the families were coping well with self-care when the family supported its performance and that children with cancer can survive with a high quality of life. In adolescents who are newly diagnosed with cancer, some research has found that they can cope well by adjusting their routine. Self-care ability paves the way for adjusting life [6, 15], Landier, Hughes [16] studied the process of adherence oral chemotherapy in adolescents with leukemia. They noted that adolescents with leukemia often have good self-care behavior in terms of taking control of their oral chemotherapy treatment. However, the researchers did not provide sufficient detail about the self-care activity that could be used to support self-care in adolescents with leukemia. Some conclusions can be drawn, even if the adolescents are diagnosed by leukemia and have chemotherapy side effects in terms of their self-care strategies.

Thus, it is worth studying whether self-care in adolescents with leukemia is effective or difficult in practice. Moore and Beckwitt [17] performed a pioneer study on self-care and dependent-care practice in children with cancer. They found that supportive education nursing interventions were needed and suggested that more data on children with cancer-specific self-care activities should be explored to create an intervention that can support self-care. Because of the minimal evidence that exists in the literature concerning self-care in adolescents with leukemia during their chemotherapy period, studies on the nature of self-

care from the experience of adolescents with leukemia are needed. The findings can provide a clear picture of self-care in this group and can help pediatric nurses and clinicians develop treatment plans to support self-care in adolescents with leukemia.

METHODOLOGY

Qualitative methods were used in this study to describe the meaning of self-care from the experience of adolescents with leukemia. Participants in this study were adolescents with leukemia aged 12-19 year olds and receiving chemotherapy at Thammasat University Hospital. These adolescents had to know of their diagnosis and had to have been treated with more than 6 months of chemotherapy because adolescents with leukemia often confront the side effects of this treatment within this timespan.

The study proposal, in-depth interview questions, information sheet, and consent form were reviewed and approved by The Ethics Review Committee for Research Involving Human Research Subjects, Thammasat University Hospital (IRB NO 5/2557). The researcher asked the permission for data collection process from the parents (or caregiver). If the parents allow, the researcher gave the information sheet to the participants. When the participants expressed their intention to join the study, all participants and parents (or caregiver) were gave informed consent and sign in. The appointments were made by the researcher to meet the participants for the in-depth interview. The chosen place for interview was also selected on mutual agreement between the researcher and the participants.

Data were collected during January to September 2014. All interviews were conducted in the participants' residences and asked to recall how they were diagnosed and how they tolerated treatment. The two main open-ended questions for the in-depth interview were "Could you tell me about what do you do for caring yourself?" and "What are the effects of Leukemia and Chemotherapy and how do you deal with them?" Each interview lasted an average of 50-60 minutes and was recorded using a digital device. Field note and observation note were conducted by researcher during data collection process. The audio-recordings were transcribed verbatim into Word documents. Thematic analysis was the method of data analysis and included the following: familiarization with the data, coding data, searching for themes, reviewing themes, defining and naming themes, and producing the rapport [18]. To enhance the trustworthiness of this study, the researcher selected the appropriate participants by using rigorous the inclusion criteria. The researcher

attempted to establish a good relationship with the participants in order to build trust and rapport in the data collecting process. The data collecting methods were used various sources, such as in-depth interviews, field note and observation note, to increase the credibility. The researcher described the results of this study based on the participants' information. In addition, eight participants were selected because of they can meet the researcher again for confirming the meaning of self-care was the same as they had experienced.

RESULTS

After we collected and analyzed the data from the 11 participants, the pattern of the themes emerged and saturated. Throughout the study, field notes and observation note were written on the reflections, ideas, and meaning of self-care from the data. At the end of the study, the field notes were used when producing the report because field notes confirm the data and help the researcher recall the participants' experience.

The participants of this study included 11 adolescent patients who were between the ages of 13 and 18 years and had 9 to 15 years of leukemia and chemotherapy experience. All of them had periodically stopped going to school while they were treated with chemotherapy and attempted to return to school after their side effects improved.

Two themes reflected the meaning of self-care from the perspective of adolescents, including 1) "*Leaning self-care*" and 2) "*Performing self-care in daily life*." Both themes emphasize a point of "self-care" with components that reflect the meaning of self-care that adolescents with leukemia must learn and perform. Adolescents with leukemia must "learn" many things about living with chemotherapy and maintaining their way of life. Physical limitations were one of the potential long-term consequences of chemotherapy, but adolescents with leukemia did not surrender or let the limitation interrupt their self-care learning. They had to learn according to the limitations of learning self-care. A variety of self-care activities were practiced and modified for the goodness of fit with daily living.

In addition, adolescents with leukemia has the cognitive development refers to the development of the ability to think and reason, that why they can learning self-care to caring themselves. The strategies of self-care included adjusting life to fit in with living with leukemia. Performing self-care activities was similar to having good health behavior. The leukemic adolescents performed self-care to live as normal adolescents. The support from parents, friends, nurses and doctors was important to

maintaining self-care in daily life.

1. Learning self-care

Adolescents with leukemia developed "*Learning self-care*" to live with chemotherapy and maintain their lives through the following three forms of learning: 1) learning with side effects and managing side effects, 2) learning health promotion and prevention, and 3) learning self-care according to the limitations.

1.1) Learning with side effects and managing side effects

This is the first skill to learn for self-care after receiving chemotherapy. Adolescents with leukemia expanded their ability to learn by "learning from information" that they obtained from health care providers. The physician provided information about the side effects of chemotherapy, such as nausea, vomiting, and abdominal discomfort. When the adolescents first heard the word "chemotherapy," but the adolescents then learned what to expect when confronting the side effects. The learning from information turned in to "learning from direct experience." In this learning tactic, the nursing staff stepped forward to encourage the leukemic patients to learn how to manage their side effects. Additionally, the nurses provided information about the next side effect, such as hair fall, fatigue and infection. Subsequently, adolescents with leukemia paid attention and learned to manage the side effects by themselves. One adolescent with leukemia asked their parents to cut their hair before it fell out. Another patient who was aware that they might stop growing taller compared with their healthy friend, stated

"It was the side effect of chemotherapy that I could see in other patients because they are short like me"

At this point, they transitioned to "Learning from observing other patients." In this learning tactic, adolescents with leukemia learned from meeting other leukemic patients. The leukemic adolescents could observe the pallor face, small body and baldness in others. They realized that side effects occurred in all patients and that they would eventually have side effects in the future. They did not ask questions or talk to each other. One adolescent said,

"I just see and only observe. We do not chat about the side effects"

The side effects of chemotherapy were always present with treatment. The adolescents with

leukemia reported nausea, vomiting and tiredness. They learned to manage their side effects by themselves before asking for help. One adolescent said,

"I feel tired after chemotherapy. It was easy to sleep, but I could not sleep for a long time. I must eat some food and rest without sleeping in daytime. It can make be better, but if not, I ask the nurse for help."

1.2) Learning health promotion and health prevention

In this learning tactic, learning health promotion and prevention was directed at the problem of leukemia that affected the patient's daily life. For preventing health, leukemic adolescents had to learn about the risk of infection. Moreover, they learned how their immune system had been damaged. Leukemic adolescents had to know that they would more easily experience sickness compared with healthy children. To promote health, adolescents with leukemia learned about the benefits of sleep and eating good food. They learned how to feel "good" and maintain life while receiving chemotherapy.

1.3) Learning according to the limitations

Leukemia causes physical limitations. Adolescents with leukemia assessed their overall health status in a process called "*learning the limitations to living*." They realized that they were not healthy anymore because they had to undergo chemotherapy. With these limitations, typical self-care is not helpful.

"Chemotherapy made me sicker. I have fever every time after treatment, and paracetamol does not help. I found that if I shower with hot water after chemotherapy, it can help."

Chemotherapy not only causes physical limitations, but it "*disturbs*" the ability to learn. The adolescents found that their thought was slow and they felt "heavy" in the head; however, they were not pausing to learn because they needed to go back to school as usual. As one participant said,

"I can't read the school books because my head does not feel good. I start to read a poem, and write some poems with pictures. And I will continue this because I need to go back to school."

All leukemic adolescents reported more positive feelings than negative ones because they

were still living and undergoing treatment.

When leukemic adolescents realized their health status, they "tested the limitations" of their health by undertaking heavy exercise, playing football, and watching television programs until late at night. All such testing of limitations was performed at home after chemotherapy. After that, adolescents with leukemia learned "what they can do."

One patient stated the following:

"I go back home after chemotherapy. I go out as usual to play football. After that, I am very tired. I sleep for 2 days. I know what can I do; I play football again but not in the same way."

2. "Performing self-care in daily life"

Adolescents with leukemia have to stay in the hospital for chemotherapy and then return home to recover. The learning of self-care was advanced by practicing and modifying self-care actions to obtain a better goodness of fit with daily living. Two strategies were used to perform self-care, and the effectiveness outcome was living with both the illness and the treatment regimen. The first strategy was "*adopting and applying advice*" for performing self-care, and the second strategy was "*taking self-care in daily life*." All strategies were aimed at achieving the major aim of adjusting their life to fit into the new identity of being patients with leukemia.

2.1) "Adopting and applying advice"

The time to admission in the hospital was important for adolescents with leukemia such that they could gain knowledge about care and taking action for self-care in daily life. "*Adopting advice*" was the mechanism used to learn the self-care that they observe in the cancer unit. Adopting the advice was easy and useful for adolescents with leukemia. In addition, the self-care actions that adolescents with leukemia "adopted" directly benefitted their health. Wearing a hygienic mask, hand washing, skin care by applying lotion and using easy relaxation techniques (i.e., listening soft music and breathing) were self-care actions that adolescents with leukemia performed by adopting advice. Moreover, adolescents with leukemia did more to perform self-care by "*applying advice*." This action was performed by knowing that the advice was good and then applying the advice according to their individual needs. Adolescents with leukemia not only used self-care in the hospital, but they continued using it at home. Self-care strategies that patients with leukemia developed included

preparing boiled water to drink and use for eye care, ventilating the bedroom with an open window at noon, and using olive oil to prevent skin itching after chemotherapy.

"In the hospital, the nurse uses some special equipment and antiseptic solutions. But at my house, we do not have it. I use boiled water to clean my eyes because I have discharge in the morning. I boil the water every morning and then use it all day."

2.2) "Taking self-care in daily life."

"Taking self-care in daily life" was a self-care activity that adolescents performed to alleviate the side effects of chemotherapy and manage their lives.

Adolescents with leukemia knew that maintaining a "strong body" was important to living with the illness. "Taking physical care" was the first tactic used to perform self-care activities. Leukemic adolescents transitioned to eating more protein and high-calorie diets, including eggs, milk and peanuts with every meal. In addition, adolescents with leukemia ate five meals to maintain food intake. They added some liver or green vegetables at lunch to increase their iron consumption. All physical care increased their frequency of good behavior, and adolescents were encouraged to engage in activities that they had never done before.

"I started to eat green vegetables and liver because my body needs the nutrition. I don't like it, but I'm changing."

Adolescents with leukemia had to "slow down" to undertake activities in their daily life to maintain their energy, and they took naps during the day. They maintained strict activity regimens, particularly before the next chemotherapy appointment. Some adolescents with leukemia stated:

"My body needs to rest before chemotherapy, which can help me get better."

Infection was another problem for adolescents with leukemia. Engaging in physical care to "prevent infection" was a self-care tactic. Adolescents with leukemia "restricted visits", particularly with sick people. They chose to stay at home as much as possible after chemotherapy and to go out only when they knew, as the result of a checkup, that their white blood cell counts were normal. Adolescents with leukemia said that

"I can wait to meet friends because I have a

risk of infection."

Leukemia used to be an acute illness, but it has become a chronic condition with which adolescents can live. Discomfort symptoms, such as body pain, sweating more, and feeling drowsy, have been identified. Adolescents with leukemia in this study "relieved" such symptoms with a hot bath and body massage. They did not use medication to relieve the symptoms.

"Having a good body and good mind was important", one participant said.

Adolescents with leukemia knew that "taking psychological care" was important. The tactic of psychological care was related to the "keeping the spirit of adolescents". All of the adolescents with leukemia wanted to return to studying and being with their friends. To do so, adolescents with leukemia stayed connected with their friends at school by telephone and occasionally went to school. Adolescents with leukemia expressed the feeling of "I am the same" and maintained their spirits. In addition, adolescents with leukemia had a good time with their families during illness, according to the activities in which they engaged with their families, such as shopping, going to a picnic at the park, and watching movies. One adolescent stated that

"I have a happy time with family. It was not a big activity. It was simple, but I feel happy and feel the same."

Adolescents with leukemia had a difficult time with the illness.

"Sometimes I was sad and wanted to give up."

They "used psychological strategies" to cherish themselves. Leukemic adolescents maintained a "positive attitude" when confronting a hard time.

"I laugh when I feel bad. It is just a little pain. I still have to live. It is just a little."

Most of the adolescents with leukemia were peaceful and in a good mood. Many of the adolescents with leukemia went to the temple with their parents when they had the chance. In addition, "praying" was a new form of psychological care for some adolescents with leukemia. They started to pray when they were admitted to the hospital because praying could help them sleep with the use

of mindfulness. The nursing staff informed them of how to pray before going to bed. A prayer book was provided if the adolescents with leukemia needed one.

DISCUSSION

One effect of chemotherapy is a reduction in an individual's self-care ability [9]. In this study, adolescents with leukemia had chemotherapy side effects, such as nausea and tiredness. However, the side effect of chemotherapy did not decrease their self-care activities. However, adolescents with leukemia can use the information about the side effects and their direct experiences to manage their side effects by themselves. Parents and nurses can also help adolescents with leukemia. In addition, adolescents with leukemia may be open to the directed learning by observing other patients in the cancer unit. This finding showed that they learned about side effects by "picking up information and learning from it." This finding supported the notion that proactively obtaining information about the side effects of chemotherapy can be used to support self-care [19]. An interesting result of this study was that having side effects can help adolescents with leukemia learn about self-care. Shrivastava et al. [20] found that when patients realize the nature of the problem, their self-care abilities can be promoted. This finding was supported by the observation that the side effects of chemotherapy increased the self-care ability in adolescents with leukemia.

Leukemic adolescents showed the cognitive ability to be able to care for themselves by learning self-care and creating self-care activities that were specific to the individual. Self-care was an action used to adjust their lives around the disease and treatment. Self-care activities promoted good health behaviors. Adolescents with leukemia performed self-care so they could live as normal adolescents. This finding is consistent with the study by Woodgate and Degner [21], who reported that adolescents with cancer have a spirit as "being normal" and that they keep this spirit alive. The children seem to "keep the spirit of I'm the same and the illness is extra" and use that spirit to guide self-care activities [22, 23]. Leukemic adolescents perform self-care with the effective outcomes of living with both their illness and the treatment. The perspective of "doing things easily" was a form of encouragement to follow the good self-care behavior that leukemic adolescents could see and perceive from the nursing staff in the cancer unit. This issue reflected the way in which adolescents learn self-care when they perceive that a self-care

activity is easy to adopt [24, 25]. Moreover, leukemic adolescents apply advice to caring for themselves. The action of self-care is not only used in the hospital during chemotherapy, but it is also used at home when leukemic adolescents are discharged. The adolescents can adapt such self-care actions following any changes in their symptoms and side effects, such as altering the timing of meals or modifying their nutrition.

However, leukemic adolescents are dependent on "chemotherapy" because chemotherapy is an essential treatment regimen for achieving remission in leukemia. All of the adolescents with leukemia in this study continue to undergo chemotherapy. However, they have "psychological care" as part of this process. The psychological care consists of the following: maintaining school life, keeping the spirit of adolescence, and cherishing the good times. Hokkanen, Eriksson [26] supported the finding that adolescents with cancer focus on the here and now. The adolescents use resources that they recognize as making life easier and can thus maintain a positive attitude during their illness.

Nurse and health care providers could change their view of adolescents with leukemia as people with a severe illness who have limitations in learning self-care. The assessments must evaluate "what adolescents know about self-care and what they need to creating self-care" for supported self-care by nurses and health care providers.

Self-care programs with the objective of encouraging leukemic adolescents to learn self-care based on advice from nurses are needed. Nurses need to work with patients to help them understand their physical limitations. In addition, nurses must be open to learning from the experiences of leukemic adolescents. Adolescents with leukemia can observe such health care behavior from the nursing staff in the cancer unit and from the self-care behavior of other leukemic patients. An effective self-care program might include this feature by allowing leukemic patients to learn via the group method. Posters summarizing self-care activities for leukemic patients can be placed in cancer units to motivate self-care practices.

LIMITATIONS

The researcher make no claim about the generalization of the results, but the results of this study provide the emic view of self-care from adolescents with leukemia. Sample selection was limited by the homogeneity of participant who attended the cancer care unit at one tertiary hospital in Bangkok. Most participants lived in Bangkok and Patumthani, central region of Thailand.

CONCLUSION

In this study, the findings address the study question “How do adolescents with leukemia care for themselves?” The explanation of this study was “They can learn and perform self-care in their daily lives.” The findings showed that adolescents with leukemia must learn to care for themselves following the illness trajectory. The adolescents used the information obtained from their experience with the illness to learn self-care.

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