# Sleep Disturbances and Fatigue in Adolescents with Cancer Receiving Chemotherapy

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## **Abstract**

Sleep disturbances and fatigue are frequently complained by adolescents with cancer. These problems will lead to a variety of changes that may affect adolescents' development. However, there is very limited data concerning adolescents with cancer in Indonesia. The research aimed to explore sleep disturbances and fatigue in adolescents with cancer who are receiving chemotherapy. The research applied a qualitative design with phenomenology approach. Data were collected using in-depth interviews with seven adolescents with cancer in Jakarta, Bogor, and Bekasi. The interviews involved open questions on seven aspects, consisting of level of fatigue, responses to psychological drives, sleep disturbances, sleep disruption due to illness and chemotherapy, disruptions in some aspects of daily life, responses to problematic situations, and general perspective on life. Participants stated that chemotherapy induced sleep disturbances and fatigue, and this situation greatly influenced their overall quality of life. These problems are interrelated to each other and may affect the success of chemotherapy program. In terms of nursing, this research also shows the importance of developing a more effective system for managing sleep disturbances and fatigue during chemotherapy program.

## **Abstrak**

Gangguan Tidur dan Kelelahan pada Remaja Pengidap Kanker yang Menjalani Kemoterapi. Gangguan tidur dan kelelahan seringkali dikeluhkan oleh para remaja yang mengidap kanker. Keluhan ini mengakibatkan timbulnya berbagai perubahan yang dapat memengaruhi pertumbuhan remaja. Namun, data tentang remaja penderita kanker di Indonesia masih sangat terbatas. Penelitian ini bertujuan untuk menyelidiki keluhan-keluhan berupa gangguan tidur dan kelelahan yang diderita oleh remaja pengidap kanker yang sedang menjalani kemoterapi. Penelitian ini menerapkan rancangan kualitatif dengan pendekatan fenomenologis. Pengumpulan data dilakukan dengan mengadakan wawancara mendalam mengenai tujuh aspek yang terdiri dari tingkat kelelahan, reaksi terhadap dorongan-dorongan psikologis, gangguan tidur, tidur tidak nyenyak karena penyakit dan kemoterapi, gangguan pada sejumlah aspek dalam kehidupan sehari-hari, reaksi terhadap keadaan yang menyulitkan, dan pandangan hidup secara umum. Para responden menyatakan bahwa kemoterapi menimbulkan gangguan tidur dan kelelahan. Selain itu, mereka juga menyatakan bahwa situasi ini sangat memengaruhi kualitas hidup mereka secara umum. Masalah-masalah ini berkait satu sama lain dan dapat memengaruhi kesuksesan program kemoterapi yang mereka jalankan. Dari segi keperawatan, penelitian ini juga menunjukkan pentingnya merancang sebuah sistem yang lebih efektif untuk menghadapi gangguan tidur dan kelelahan selama program kemoterapi.

Keywords: adolescents, cancer, chemotherapy, fatigue, sleep disturbances

## Introduction

Cancer is an accumulation of abnormal cells formed by continuously and endlessly reproducing cells, which are uncoordinated with their surrounding tissue and have no physiologic function. Cancer now has become a serious threat to people's health because the ever increasing number of cancer-related incidents and death each year.

According to an estimation published by the National Cancer Institute or NCI, 4% of all cancer cases occur in children. In Indonesia, the leading cause of cancer-related deaths among children is leukemia.<sup>2</sup> High quality system for managing children with cancer must be developed in order to control the number and growth of cancer cells. Hockenberry and Wilson<sup>3</sup> encouraged chemotherapy as the most effective way to treat children with cancer,

especially those who suffer from leukemia. In principle, chemotherapy works by rapidly killing the growing cancer cells, but it also creates an adverse effect by indiscriminately killing healthy cells along with the cancer cells.

Some of the side effects of chemotherapy are vomiting, anorexia, myelosuppression (suppression of blood production), fatigue, sleep disturbances, hair fall, and mucocytis (oral ulceration). The side effects of chemotherapy on children are graded from mild to severe. Among various side effects of chemotherapy, fatigue and sleep disturbances have been identified as two of the most disturbing and most frequent problems complained by patients with cancer. Incidents of fatigue in children and adolescents reach almost 50% of the total patients, whereas 45% are estimated to suffer from sleep disturbances.

Sleep disturbances and fatigue experienced during chemotherapy may have significant impacts on physical and psychological conditions of adolescents with cancer, as well as their overall wellbeing, which pose a great challenge in their daily lives. However, a large number of patients, especially children, do not voice their complaints because they think that such disturbances are only temporary side effects of the medication that they are undertaking.8 Parents and healthcare providers also tend to dismiss such complaints as common symptoms, given the fact that the patients are still able to play and do their daily activities. In fact, fatigue and sleep disturbances may be a very important issue in adolescent with cancers' lives, affecting all aspects of their lives and eventually decreasing their overall quality of life. Nevertheless, there are many parents and medical team members who have not given their full attention to these disturbances and have not considered them when providing treatment for cancerous adolescent patients. No data has been collected concerning adolescent with cancers in Indonesia who suffer from fatigue and sleep disturbances during chemotherapy.

## **Methods**

This research utilizes the descriptive phenomenology method which emphasizes on daily experiences. This method can provide a larger and more detailed picture of the experiences of adolescents with cancer who are receiving chemotherapy, in terms of sleep disturbances and fatigue.

Seven participants were selected by applying purposive sampling technique. Their profiles were obtained from Dharmais Cancer Hospital Jakarta with an inclusion criterion of adolescent patients with cancer aged between 12 to 18 years who were receiving chemotherapy, were able to speak Indonesian fluently, and were willing to participate. In addition to that, consent from parents or caregivers were also obtained prior to data collection. Research proposal has been approved by the Ethical

Committee of Nursing Research of the Faculty of Nursing, Universitas Indonesia. This research also applies a set of ethical principles which consist of self-determination, privacy and dignity, anonymity and confidentiality, protection from discomfort and harm, and justice.

Data collection was conducted in February 2013 in Jakarta, Bekasi, and Bogor. The method of data collection was in-depth interviews by addressing open questions and conducting observation using field notes. Interviews were conducted at time and place agreed upon by the participants. Data collection for each participant was conducted in 2 to 3 meetings for 40 to 60 minutes per individual meeting to obtain more detailed information about their experiences of sleep disturbances and fatigue during chemotherapy. Each interview was closed when all necessary information related to research purpose had been obtained, i.e. when the data has reached saturation or no further data can be obtained from the participants. Instruments of data collection consisted of the researcher, interview guidelines, field notes, and a recorder.

These are the main questions included in the interview guidelines: (1) can you tell me what you think about fatigue? (2) how can you describe fatigue? (3) when you are tired or unenergetic, what do you usually do to make yourself more comfortable? (4) what do you think about your sleep pattern? and (5) with this current condition, what do you think about your own life?

Interview transcripts were produced by replaying the recordings and typing the words verbatim. Field notes, which were used to make a written record the participants' non-verbal responses during interviews, were also integrated in the transcript. The transcript data was the analyzed manually using the Colaizzi method (1978, in Speziale & Carpenter, 2003). Data analysis was conducted to identify some themes related to the research objectives which consist of research keywords, categories, subthemes, and themes. The data validity of this research is based on the criteria of credibility, dependability, confirmability, and transferability. <sup>10</sup>

## **Results and Discussion**

Interviews were conducted with seven participants consisting of five males and two females who had been diagnosed with cancer. The types of cancer include synovial sarcoma, nasopharyngeal cancer, retinoblastoma, and acute lymphocytic leukemia. As many as seven themes have been identified to describe sleep disturbances and fatigue in adolescents with cancer during chemotherapy, which are as follows.

**Feeling of fatigue.** Fatigue caused by chemotherapy is marked by the presence of various body responses

which are perceived as reducing their physical comfort. Such responses are stiffness muscles, tiredness, weariness, exhaustion, lethargy, malaise, and pains. Such feelings are expressed by these following statements.

"Fatigue is like tiredness, pains on my back here, near the spine ..., then it makes me feel so weary, exhausted, and such ... my body's kind a stiff ... it doesn't feel nice at all." (P1)

"Pains on my feet, my back. Tired, yes. Feels like hurt and painful, as if somebody just hit my bones, feels like being punched. Here, and on my knees." (here the participant showed the parts of his body which often feel painful). (P7)

The feeling of fatigue experiences by participants during chemotherapy is largely the side effects of the medication itself. However, fatigue may also be experienced because the participants were bored with chemotherapy protocols at the hospital, which is expressed by these following statements.

"Maybe it's because of the chemo ... perhaps because I got bored too ..." (P1)

"Yup ... that's because of the chemo." (P2)

Fatigue due to chemotherapy was perceived as an inconvenient experience by the adolescents. Other effects included reduced concentration, laziness, and reduced physical strength. These feelings are expressed as follows.

"... if I get tired, I can't do things. Like ... hard to concentrate ..." (P1)

"Yup. Feels like wanna sleep all the time, don't wanna do anything; don't wanna wake up even to reach the remote, usually just ask my brother or sister to do it." (P6)

"Tired, yes, that's right. Even holding a glass of water is difficult; my hand is like shaking. It feels like my hand loses its strength, tired." (P3)

**Psychological responses.** The cancer, as well as the whole treatment process, also affects the patients' psychological wellbeing. Psychological responses appear in the forms of boredom, melancholy, and grief over their current health condition. These are supported by these following statements.

"Talking about my mental condition, erm ... it's like fatigue, got bored being here, and such. The atmosphere is always the same every day. Mental fatigue at home is like ... erm, can't meet my school friends because I still need to rest." (P1)

"Yes, of course. I get emotional a lot; I tend to be emotional. I don't know why, I always get upset about many things, like wanna get angry." (P6)

"Yees ... I'm really mad. Mad at ... why my feet should become like this. Mad with my own feet. I once even thought this way: it'd be better if it were amputated." (P4)

**Experiences of** sleep disturbance. Sleep disturbances might also occur as the result of the disease itself and the effects of a long period of chemotherapy. Sleep disturbances might take some forms: difficulty in falling asleep, increased frequency of waking up during the night, and excessive sleepiness during the day. Below are some of the participants' statements concerning sleep disturbances.

"It's right that I often find it difficult to get asleep at night; it's still hard even though I've closed my eyes. I often stay awake until very late at night." (P5)

"Yes ... I often wake up at night. Sometimes two or three times in one night." (P1)

"... since chemotherapy, I often sleep during the day. It can be twice a day." (P6)

Such changes in sleep pattern were caused by various factors, some of which were physical discomfort, the effect of chemotherapy, and general disruptions at the hospital. Below are some of the supporting statements.

"Yup, very tiring. I'm so tired that it disrupts my sleep pattern." (P1)

"After chemo, it always upsets my stomach, making it difficult for me to get asleep." (P3)

"Yes, it's quite noisy around here. A lot of little kids are here, all together, so it's very difficult to sleep." (P5)

Faced by a high level of disturbance, participants have taken some measures to deal with their sleep problems, such as body massage, environment modification, and asking other people's companion. Below are some of the supporting statements.

"Usually, I listen to music while trying to sleep ... like, the slow ones, then wrap myself in my blanket." (P1)

"Yes, I love being massaged by my Dad, and my Granny, too." (P4)

"... sometimes it's hard for me to fall asleep. I usually ask my mother to accompany me in bed." (P6)

Various complaints due to disease and chemotherapy. In addition to causing fatigue and sleep disturbances, the disease itself (cancer) and the chemotherapy procedures have also brought negative effects on the participants. Such complaints may involve various physical problems and changes in the participants' self-image.

Below are some of the participants' statements concerning physical problems that they experienced:

"... lose my appetite. The food gone tasteless. Yes, and also stomachache. I vomited once, but the nauseous feeling remained." (P1)

"Pain in my stomach, yes, that's also true. And some headaches, too." (P2, P3)

The participants also underwent some physical changes due to their health condition, and this new situation affected their own perception of themselves. Some shifts in personal image were identified, such as feeling of embarrassment, dependence, powerlessness, and perception of themselves as different from others. Such perceptions were expressed in these following statements.

"Sometimes I got a hair fall. I'm so embarrassed; I feel shy when I'm playing with other friends."
(P2)

"It's difficult to walk around. I often need my mom's help. Yes, so ... I usually just stay in my bed." (P3)

"Yes, I have to wear mask if I wanna go to the mall. People find it weird, and look at me, they sometimes stare at M [the participant indicates her/his own name], as if there're something odd with me. It doesn't feel really nice, so I usually avoid going out of home." (P1)

Impacts on daily life. Stressors which were resulted from the disease and the medication taken have brought significant impacts on the participants' lives. Since their first diagnose, the participants have felt that (1) they have been given more attention from other people, (2) they were not as free as they had been, and (3) their pattern of social interaction has shifted. Below are some of the supporting statements.

"Erm ... I feel that people shower more attention to me, perhaps ... like, if I haven't taken my medicine, they always ask, 'have you taken your medicine?' or 'have you eaten?' That's what they always ask." (P6)

"... yup, I can't just go anywhere; I'm no longer free. I'm not as free as I was." (P1)

"Yes, but now everything is different. Everybody just drifts away. I feel like my friends are avoiding me." (P6)

Overcoming the situation. Having cancer and receiving chemotherapy pose a difficult situation for adolescent patients because they now have to develop their ability to adapt to their current condition in order to regain their normal pattern of life. Examples of such efforts were limiting their activities, maintaining their physical health, trying to do their daily activities by themselves, and doing various enjoyable activities to help them alleviate the burden. These are shown in these following statements.

"Just limit my activities. Erm ... like having more rest instead." (P7)

"If S [the participant indicates her/his own name] feels weak, S drink a lot, eat a lot, too." (P5)

"Yes, I stil can walk, but using a walking stick." (P3)

"Playing with my computer, it's quite fun, so I may forget my fatigue. Then, just rolling around in my bed. Oh, and yes, asking my Mom to do some massage." (P1)

"... for me, it's just a matter of diverting my attention. Like chatting with little kids, laughing with them; it makes me happy. Besides that, I usually play games." (P3)

Perspective on life. Each event in an individual's life influences her/his personal perspective on life in general and perception of the value of life. Our research participants redefined their concepts of life as soon as they were diagnosed with cancer and started receiving chemotherapy. Interestingly, they were found to have developed a more optimistic attitude towards their condition and the possibility of a recovery. Such a positive perspective on life is expressed in these following statements.

"Erm ... I'm very optimistic. There is still a chance of recovery. I wanna get well soon, and wanna be able to walk again." (P4)

"That never crosses my mind. S always think: just relax." (P5)

"Yes, don't think too much about your illness. When you think too much about it, you'll lose your spirit." (P7)

Our research participants were 13 to 18 years old, which meant that they were in their mid-adolescence period. A

chronic disease such as cancer must have posed a great challenge to adolescent patients. Cancer diagnosis and its treatment have greatly affected their lives. Those adolescents thought that chemotherapy brought negative impacts on their physical condition, which greatly affected their overall quality of life. 11 Gender, however, was not proven to be a factor affecting the participants' perception of what they feel about sleep disturbances and fatigue during chemotherapy. Therefore, gender does not seem to be a determining factor which causes fatigue in adolescent with cancers. Similar results were also reported in a study conducted by Paterson, Canam, Joachim, and Thorne<sup>12</sup> which found that fatigue had no demonstrable connection with the patients' gender, as well as their economic and social status. Another research by Allenidekania-which was conducted in Indonesia and involved children with cancer—showed that gender and age factors did not play any significant role in the patients' chances of experiencing fatigue.<sup>13</sup>

There are various types of treatments according to the types of cancer that the patients' are suffering from. Cancer diagnosis and treatment may trigger specific symptoms in adolescents. Fatigue and sleep disturbances are two of the most disturbing side effects complained by cancer patients. Research shows that fatigue may occur at all stages of the disease and its treatment for months or even for years until the end of the treatment. In addition to that, fatigue may also occur in all types of cancer treatment, including surgery, chemotherapy, radiation therapy, and biotherapy, even though there might be different patterns of fatigue, depending on the types of treatment received. Complaints of fatigue and sleep disturbances can bring disruption to all aspects of a cancer patient's life. In addition to the types of treatment received.

Fatigue, as experienced and complained by all participants in our research, was described as feeling of exhaustion, painful on muscles, tiredness, weariness, lethargy, malaise, and pains. This finding was the same as the description of fatigue as described in a study conducted by Gibson, Mulhall, Richardson, Edwards, Ream, and Sepion.<sup>11</sup> Adolescent patients involved in this research described fatigue as unpleasant feelings in the body, such as tiredness, powerlessness, and vulnerability, which affected all of their daily activities. The main factor causing the fatigue was attributed to the therapy itself.<sup>18</sup> Fatigue constitutes a real condition experienced by adolescents during and after receiving chemotherapy. 11 These statements support our research findings, in which all participants admitted that their fatigue was the effect or impact of the chemotherapy that they had been receiving.

Other factors causing fatigue are depression, pain, sleep problems, anemia, health decline, infection, nutritional problems, hypoxia, and side effects of medication.<sup>19</sup> Fatigue which occurs after chemotherapy may affect the

patients' physical, mental, and emotional capacities in doing their daily activities. In this research, various effects of fatigue were identified, such as reduced concentration, feeling of weakness, and lack of physical strength. Adolescent participants also stated that, when they felt the fatigue, they had no desire to do any activities and they only wanted to be in bed all day because of lack of energy. This finding conforms with the result of a study by Gibson, Mulhall, Richardson, Edwards, Ream, and Sepion<sup>11</sup> which showed that fatigue prevented adolescent patients from doing their daily activities because it reduced their strength, spirit, and motivation to do their usual habits.

Cancer and its treatment bring emotional consequences which are usually associated with chronic diseases. McCorkle indicated that physical symptoms due to therapy may influence the patients' psychological state.<sup>20</sup> Our research participants recounted some psychological responses that they felt due to diagnosis of cancer or effects of treatment, such as boredom and unstable emotion. Another response was a feeling of grief over their illness. Being diagnosed with cancer caused the adolescents to feel miserable because of the hardships that they had to endure. This research has also identified some expressions of grief shown by the adolescents, such as anger, sadness, depression, and denial of their condition. This finding conforms with a study conducted by Theofanidis which found that children who were diagnosed with chronic diseases were also prone to mental shock, stress, emotional instability, or anger, which might also be accompanied with a more intensified relationship with parents. Additionally, adolescents with chronic diseases also found it difficult to accept the diagnoses and the subsequent treatments that they had to undergo.<sup>21</sup>

Another problems complained by adolescents with cancer was sleep disturbances, which might be caused by various factors such as biochemical changes related to growth of neoplasm, anticancer medication, and accompanying symptoms of cancer such as pain, fatigue, and depression. Adolescents with cancer have to cope with greater challenges in terms of their sleep quantity and quality as the effects of their disease and its accompanying symptoms, as well as treatment procedures that they receive. Various sleep disturbances have been identified in adolescent with cancers, such as more frequent waking ups during the night, greater sleep difficulty, and excessive sleepiness during the day. Allenidekania found that there were only 7% of 73 children with cancer who could fall asleep in just 15 minutes, whereas 15% of them needed more than 60 minutes to fall asleep.

All those experts' findings support the results of this research. All of our adolescent participants admitted that their sleep pattern had changed ever since they started

receiving chemotherapy. Some of the changes were difficulty of falling asleep, frequent wake ups during the night, and restless sleep. According to our research participants, their sleeping problems were caused by various physical inconveniences such as fatigue, tiredness, muscle pains, or pains in their bodies. Such results conform to what was experienced by adolescents as reported by Gibson, Mulhall, Richardson, Edwards, Ream, and Sepion<sup>11</sup> in their research. They stated that their research participants experienced a difficulty of falling asleep due to anxiety over their illness, physical inconveniences, and frequent urination. They said that, despite being able to sleep during the night, they still felt tired when they woke up and had no desire to rise from their beds until lunchtime.

The side effects of chemotherapy may also have physical impacts. In adolescent patients, these impacts may manifest in actual fatigue and physical lethargy, which are partly due to changes in their sleep pattern. Such physical disadvantages make it difficult for the adolescents to do their daily activities. Physical and psychological changes related to their condition also affect their perception of themselves. Some participants revealed some changes in their perception of themselves, such as embarrassment, dependency, powerlessness, and feeling that they were different from other people. This result demonstrated that our adolescents had to cope with some difficulties because of physical changes that they have to experience, which were resulted from the cancer and the side effects of their treatment. As the side effects of cancer treatment, hair fall and facial skin problems make them feel embarrassed of themselves and feel that other people look at them differently. In addition to that, adolescents may also develop feelings of vulnerability and dependency on other people due to their limited physical strength and capacity resulted from their disease. They responded to such problems by focusing more on maintaining their physical health and on the completion of their treatment. Our adolescent patients tended to make more effort to do their activities independently and to continue their treatment, which are considered as positive attitudes towards their condition.

Adolescents who are suffering from chronic diseases such as cancer and have to undergo chemotherapy procedures also consider their lives to be more difficult and stressful than healthy adolescents do; they feel that adolescents with cancer have more limitations and restrictions in their lives. They also consider the side effects of their treatment to be the factor most affecting their quality of life, which require them to make huge adjustments in order to maintain their normal pattern of life.

The effects of chemotherapy, both at acute and subsequent stages, affect adolescents' lives in various ways. All of our research participants said that their

lives have changed ever since they were diagnosed with cancer and started receiving chemotherapy. Some of those changes were that (1) they received more attention from other people, (2) they had to limit their activities, (3) they became less independent than when they were still healthy, and (4) their pattern of social life were disrupted. On the one hand, deeper attention from family members, especially from their mothers, was considered as a positive influence since it greatly supported those adolescents in coping with their problems. On the other hand, such attention might also be perceived as a sign of their increased dependence, which might impair their self esteem. Till [25]<sup>25</sup> reported that adolescents with cancer felt protected, were given much attention, and were carefully watched due to their delicate condition. This statement also supports the results of our research because some of our participants felt that their peers paid more attention to them since their diagnosis. Conversely, there were also some adolescents who felt that they were being avoided by friends who had been relatively close to them. Besides that, they also find it increasingly difficult to cope with being an object of ridicule because of their physical limitations resulted from their cancer treatment.

Various strategies are used by adolescents to live normally with their physical condition and limitations. To deal with the fatigue, they choose to reduce their activities and take more rest. Another effort is by focusing on maintaining their health, which comes from their desire to preserve their bodily functions, so they may avoid more adverse effects of their condition. Besides that, adolescents might also engage themselves in fun activities that they consider as entertaining and enjoyable to divert themselves from the feeling of fatigue.

Every moment in an individual's life affects her/his perspective on life and teaches different values of life. After diagnoses and undergoing chemotherapy procedures, our research participants still viewed their lives in a generally positive way, which was indicated by good hopes, high spirit, and optimism for recovery.

Cancer and its therapy bring long-lasting effects on the patients. In adolescent patients, experience of having cancer and receiving chemotherapy has a temporary effect on their life hopes. However, care must be given to distinguish hope from desire. Cancer patients' hope is more related to aspiration for receiving treatment. High hopes in adolescents with cancer during the early stages of treatment may serve a protective function. <sup>27</sup>

Our research showed that adolescent participants expressed a great hope for returning to their healthy condition before they were diagnosed with cancer. Such hopes were related to their experience with cancer and psychosocial relationships, such as hopes for speedy recovery, for not ever getting the same disease, for

being able to perform school activities and to play like before, for no longer becoming a burden to their relatives, for no longer being dependent on other people, for no longer relying on medication to keep healthy, and for being able to perform various activities like normal and healthy adolescents do.

The presence of such hopes revealed that our participants still had a high level of optimism in their lives after cancer diagnoses and chemotherapy. This attitude was also shown by a belief that God would heal them. Therefore, they kept their high spirit during chemotherapy and obeyed all advice from healthcare providers and their parents in order to achieve a complete recovery. Their main sources of motivation were positive attitude towards life, confidence in their personal strength, belief in God's intervention, and strong desire to overcome the disease.<sup>28</sup>

This research found that the most significant problems experienced by adolescents with cancer were sleep disturbances and fatigue following chemotherapy. Like a cycle, fatigue might occur due to sleep disturbances during chemotherapy, while problems and changes in sleep pattern were factors causing fatigue in adolescent with cancers. Fatigue might have some impacts on the adolescents' physical condition, their parents' mental wellbeing, and the family's economy due to expensive treatment. Fatigue might also impair their ability to engage in physical and emotional interactions with their peers, family members, and healthcare providers.

Fatigue and sleep disturbances caused by cancer and chemotherapy pose significant challenges in adolescents' lives, affecting all aspects in their lives. Adolescents who were diagnosed with chronic diseases such as cancer and have to receive chemotherapy tended to view their lives as more burdensome than healthy adolescents do; they also felt that adolescents with cancer had more limitations and restrictions. They considered that the side effects of their medication, especially fatigue and sleep disturbances, were the factors most affecting their overall quality of life, which required them to make great adjustments in order to maintain their normal pattern of life. These two challenges might also affect the success of their chemotherapy.

The main strength of this research is its capacity for providing a deeper and more thorough understanding of the experiences of Indonesian adolescent patients with cancer in dealing with fatigue and sleep disturbances. Nevertheless, it also admits a limitation in which interview results are not totally verifiable due to the difficulty of contacting the participants for clarification after the interviews. Efforts of validation have been made to verify the findings via telephone in order to achieve a more credible data.

Implications of this research include (1) the improvement of several aspects in nursing service, (2) the expansion of nursing theory, and (3) the development of nursing research. This research provides important information about the types of problems most affecting adolescents due to their cancer and chemotherapy. The principal stressors were sleep disturbances and fatigue. Pediatric nurses play a strategic role in supporting the adolescents in coping with their sleep problems, as well as their root factors. Broader understanding of various factors which can cause fatigue and sleep disturbances in adolescents with cancer enables nurses to provide the most appropriate treatment management to help improve their patients' physical and psychological comfort during chemotherapy. Some measures can be taken, such as creating a more comfortable environment for treatment, so that adolescents can be more motivated to undergo their regular treatment.

In addition to that, information presented in this research can serve as inputs and references for nursing scholars to expand their knowledge about the nursing intervention to adolescent patients with cancer during chemotherapy. Included in this knowledge are more effective strategies or efficient management systems to help adolescents overcome their health problems.

## **Conclusions**

Sleep disturbances and fatigue are two problems most frequently experienced by adolescents with cancer who are also receiving chemotherapy. Those two problems are strongly related to and affecting each other. Fatigue affects the adolescents' physical, psychological, and social aspects, which eventually bring adverse impacts on their overall quality of life. Nurses have to acquire a broader understanding of factors causing sleep disturbances and fatigue in adolescents with cancer during chemotherapy. Equipped with such knowledge, the nurses are expected to be able to provide the most appropriate nursing intervention to improve the patients' physical and psychological comfort during chemotherapy. More extensive research should be conducted to examine the extent of nurses' understanding of the problems encountered by adolescent with cancer patients during chemotherapy.

## References

- 1. Price SA, Wilson LM. *Patofisiologi: Konsep proses*proses penyakit. Jakarta: EGC; 2005.
- IARC. International Agency for Research on Cancer: *Incidence of cancer in Indonesia*, 2005. (internet) [cited 2012 November 10]. Available from: http://globocan.iarc.fr/.
- Hockenberry MJ, Wilson D. Wong's essential of pediatric nursing (8<sup>th</sup> edition). Missouri: Mosby Company; 2009.

- 4. Bowden VR, Dickey SB, Greenberg CS.. *Children and their families: The continuum of care*. Philadelphia: W.B. Saunders Company; 1998.
- Ahlberg K, Ekman T, Gaston-Johansson F, Mock V. Assessment and management of cancer-related fatigue in adults. *Lancet* 2003;362,640-650.
- Collins JJ, Devine TD, Dick GS, Johnson EA, Kilham HA, Pinkerton CL, et al. The measurement of symptoms in young children with cancer: The validation of the memorial symptom assessment scale in children aged 7-12. J Pain Symptom Manag 2003;23:10-16.
- National Cancer Institute/NCI (2010). Sleep disorders. (internet). [cited 2013 Pebruari 25]. Available from: www.cancer.gov/cancertopics/pdg/supportivecare/sleepdi sorders/healthprofessional.
- 8. Davies B, Whitsett SF, Bruce A, McCarthy P. A typology of fatigue in children with cancer. *J Pediatric Oncol Nursing*, 2002;19:12-21.
- Speziale HJ, Carpenter DR. Qualitative research in nursing: Advancing the humanistic imperative. (3<sup>th</sup> edition). Philadelphia: Lippincott Williams & Wilkins, 2003.
- 10. Afiyanti Y. Validitas dan reliabilitas dalam penelitian kualitatif. *J Keperawatan Indonesia*, 2008;12: 137-141.
- 11. Gibson F, Mulhall AB, Richardson A, Edwards JL, Ream E, Sepion BJ. A phenomenologic study of fatigue in adolescent receiving treatment for cancer. *Oncol Nursing Forum*, 2005;32(3):651-60.
- 12. Paterson B, Canam C, Joachim G, Thorne S. Embedded assumptions in qualitative studies of fatigue. *Western J Nursing Res.* 2003;25:119.
- Allenidekania, Kusumasari, Lukitowati. Influenced factors to cancer related fatigue in hospitalized children in Jakarta. Paper presented at The 3<sup>rd</sup> international nursing conference, bringing current research into nursing practice for improving quality of care, Bandung, Indonesia, 2012.
- 14. Roscoe JA, Kaufman ME, Matteson-Rushy SE, Palesh OG, Kohli S. Cancer-related fatigue and sleep disorders. *The Oncologist*, 2007;12(Suppl 1):35-42.
- 15. Lovely MP, Miaskowski C, Dodd M. Relationship between fatigue and quality of life in patients with glioblastoma multiformae. *Oncol Nursing Forum*, 1999;26:921-25.

- Schwartz AL, Nail LM, Chen S, Meek P, Barsevick AM, King ME, et al. Fatigue patterns observed in patients receiving chemotherapy and radiatiotherapy. *Cancer Investigation*, 2000;18:11-19.
- Alexander S, Minton O, Andrews P, Stone P. A comparison of the characteristics of disease-free breast cancer survivors with or without cancer-related fatigue syndrome. *European J Cancer*, 2009;45:384-92.
- Richardson A. A critical appraisal of the factors associated with fatigue. In J. Armes, M. Krishnasamy, I. Higginson (Eds), *Fatigue in cancer*, 29-50. Oxford: University Press; 2004.
- Berger A. Treating fatigue in cancer patients. The Oncologist, 2003;8:10-14.
- McCorkle R, Grant M, Stromborg FM, Baird BB. Cancer nursing. (2<sup>nd</sup> edition). Philadelphia: WB. Saunders Company; 1996.
- Theofanidis D. Chronic illness in childhood: Psychosocial adaptation and nursing support for the child and family. *Health Sci J*, 2007;1:1-9.
- Erickson JM. Fatigue and sleep disturbances in adolescent receiving chemotherapy. *Proquest Dissertation and Theses*, 2008.
- Gedaly-Duff V, Lee KA, Nail LM, Nicholson S, Johnson KP. Pain, sleep disturbance, and fatigue in children with leukemia and their parents: A pilot study. *Oncol Nursing Forum*, 2006;33:641-46.
- Hinds PS, Hockenberry-Eaton M, Rai SN, Zhang L, Razzouk BI, McCarthy K, et al. Nocturnal awakenings, sleep environment interruptions, and fatigue in hospitalized children with cancer. *Oncol Nursing Forum*, 2007; 34(2):393-402.
- Till T. Coping with cancer: The adolescent experience. Australian Catholic University, 2004.
- Otto ES. Oncology Nursing. (4<sup>th</sup> edition). Philadelphia: Mosby; 2001.
- 27. Ritchie MA. Self-esteem and hopefulness in adolescent with cancer. *J Pediatric Nursing*, 2001;16(1):35-42.
- Kyngas H, Mikkonen R, Nousiainen E. Coping with onset of cancer: Coping strategies and resources of young people with cancer. *European J Cancer Care*, 2001;10: 6-11.