

Fatigue In Children With Cancer Who Receive Chemotherapy

Sri Hendrawati, Fanny Adistie, Nenden Nur Asriyani Maryam

Faculty of Nursing, Padjadjaran University

Email: sri.hendrawati@unpad.ac.id

Abstract

Fatigue in children with cancer is a physical, mental, and emotional experience characterized by reduced energy, decreased physical activity, and increased feelings of fatigue. So far, health workers have assumed that fatigue is a subjective feeling and is not life-threatening. If not handled properly, fatigue can reduce the quality of life. This study aimed to identify the level of fatigue in children with cancer. This research used a descriptive quantitative method. According to the inclusion criteria: 1) the respondents are children with cancer aged 6-18 years; 2) the children is undergoing treatment or medication, and 3) the general condition of the children is good. Technique sampling used consecutive sampling to get 74 children with cancer. The instruments used were the Childhood Fatigue Scale (CFS) to measure the level of fatigue in children and the Fatigue Scale-Adolescent (FSA) to measure the level of fatigue in adolescents. Data analysis using the mean value and frequency distribution. The results showed that based on the fatigue questionnaire of children with cancer who receive chemotherapy, most of them had a severe fatigue scale of 56 people (75.7%). Meanwhile, a small proportion of children had a mild fatigue scale of as many as 18 people (24.3%). In this study, all children with cancer experienced fatigue. It interrupts or limits their daily activities and significantly influences different aspects of personal life. Children can still felt fatigued even after chemotherapy is over. Nurses as health workers who have the most frequent contact with children must provide appropriate nursing interventions for cancer to minimize fatigue.

Keywords: Cancer, chemotherapy, children, fatigue.

Introduction

Cancer is a term for a disease in which cells divide abnormally without control and can attack the surrounding tissue (National Cancer Institute, 2009). Cancer can strike all ages, including children. According to data World Health Organization (WHO) (2017), the prevalence of cancer in children is around 4%, and 90,000 child deaths in the world are caused by cancer. Each year, the number of cancers in children increases by around 110 to 130 cases per one million children, and 80% of children diagnosed with cancer are in developing countries (International Agency of Research Cancer, 2017). According to data from the Union for International Cancer Control (UICC), there are approximately 176,000 children diagnosed with cancer each year. The majority come from low and middle-income countries (Ministry of Health Republic of Indonesia, 2015).

Ministry of Health Republic of Indonesia (2017) states that cancer is the second leading cause of death in children aged 5 to 14. The incidence of childhood cancer in Indonesia is around 2-4% (Ministry of Health Republic of Indonesia, 2015). Each year, there are 11,000 cases of cancer in children, and 10% of them cause death. The Indonesian Child Cancer Foundation also said that the prevalence of cancer in children increased by seven percent every year (Widodo & Amanda, 2018). Based on Dr. Hasan Sadikin Bandung Hospital in 2016 stated that chemotherapy in cancer patients was the highest number of cases in the Department of Pediatrics, namely 1,412 patients. Meanwhile, from January to October 2017, there were 952 cases of cancer in children aged 0-18 years at Dr. Hasan Sadikin Bandung Hospital. The Indonesian Children's Oncology Foundation (Yayasan Onkologi Anak Indonesia, 2017) states that the types of cancer in children include leukemia, brain tumors, retinoblastoma, lymphoma, neuroblastoma, Wilms tumor, rhabdomyosarcoma, and osteosarcoma. Meanwhile, the most common types of childhood cancer in Indonesia are leukemia and retinoblastoma. It is also in line with study conducted by Nurhidayah et al. (2020) which shows that most types of cancer occur in children and require treatment and hospital

care, namely leukemia.

Cancer in children must get quality treatment. Treatment of cancer in children aims to control the number and spread of cancer cells. According to the National Cancer Institute (2009), cancer treatment in children includes chemotherapy, biological therapy, radiation therapy, cryotherapy, bone marrow transplantation, and peripheral blood stem cells. However, chemotherapy is the main treatment option in children with cancer. Although it is one of the therapeutic modalities that can help the child's healing process, chemotherapy can also cause some side effects that make children uncomfortable. Some of the side effects of chemotherapy in children with cancer include fatigue, pain, nausea and vomiting, anorexia, alopecia, neuropathy, sleep disorders, puberty disorders, gastrointestinal dysfunction, and kidney function disorders (Marilyn J. Hockenberry & Wilson, 2018; Kaushal et al., 2013; Potts & Mandleco, 2012). Also, the research results of Hendrawati et al. (2019) showed that one of the effects of chemotherapy is injuries of the lips and mouth or mucositis. Ismuhi et al. (2020) show that nausea and vomiting are also side effects of chemotherapy. However, various studies have reported that the physical problem in children with the highest prevalence is fatigue (Allenidekania et al., 2012; Crichton et al., 2015; Yilmaz et al., 2016).

Cancer-related fatigue has been described as the most prevalent symptom in pediatric cancer patients, affecting between 36% and 93% of the cases, with a higher level of fatigue among patients submitted to chemotherapy, affecting between 70% and 100% of the cases. Children and adolescents consistently report fatigue as the most persistent, anguishing, uncomfortable and stressful symptom of cancer and its treatment (da Silva et al., 2016). Fatigue in children with cancer is a physical, mental, and emotional experience characterized by reduced energy decreased physical activity, and increased feelings of fatigue (Hockenberry-Eaton & Hinds, 2000; Mahdizadeh et al., 2020). According to the National Cancer Institute (2009), cancer-related fatigue is a state of distressing, persistence, and subjective feelings of physical, emotional, and cognitive tiredness

or exhaustion related to cancer or cancer treatment or disproportionate activities can reduce a person's functional status. That is why fatigue must be concerning symptom for family members of children and adolescents with cancer as well as health professionals (da Silva et al., 2016).

The prevalence of fatigue in children with cancer is still a matter of debate because currently, there is no consensus on the exact incidence of fatigue. However, according to Mahdizadeh et al. (2020), fatigue is a common complaint in children with cancer with an estimated 80-100%. Meanwhile, in the United Kingdom (UK), about 70% of children with cancer who undergo chemotherapy experience fatigue (Crichton et al., 2015; Macmillan Cancer Support, 2013). While in the United States (US), 96% of children experience fatigue, and as many as 50% of them experience severe fatigue (Ullrich et al., 2010). It is related to pain, dyspnea, anorexia, nausea, vomiting, diarrhea, anxiety, and fear experienced by children during the treatment period. In Indonesia, there have not been many studies to identify the incidence of fatigue. However, the research results by Allenidekania et al. (2012) showed that the prevalence of fatigue in children with cancer in Jakarta alone reached 44.2%.

So far, health workers have assumed that fatigue experienced by children is a subjective feeling and is not life-threatening (da Silva et al., 2016). It is considered that fatigue is an unavoidable consequence of cancer therapy (Yilmaz et al., 2016). Even though if not appropriately handled, fatigue can reduce the quality of life of children (Mahdizadeh et al., 2020; Nunes et al., 2017; Nurhidayah et al., 2016). The effects of fatigue on children who are declared cured of cancer include growth problems, memory loss, short-term memory limitations (forgetfulness), learning difficulties, hormonal changes, and other complications, including getting secondary cancer. Fatigue can also be a mental health-related problem in patients with children. Some of the common symptoms of fatigue can be mistaken for indications of depression (Hockenberry-Eaton & Hinds, 2000; Nunes et al., 2017).

Excessive fatigue in children with cancer will impact the decreased quality of life (Keener,

2018; Nunes et al., 2017; Rosenberg et al., 2016). So it is essential to identify fatigue early in children with cancer because it is crucial for nurses to understand fatigue in children with cancer to determine the proper intervention according to the child's condition. Thus, it is necessary to study the level of fatigue in children with cancer. This study aimed to identify the level of fatigue in children with cancer who receive chemotherapy.

Research Method

This study used a quantitative descriptive research design. This research was conducted at a public hospital in West Java Province in February 2018. According to predetermined inclusion criteria, sampling was carried out by consecutive sampling so that 74 child respondents with cancer were obtained. The sample inclusion criteria in this study were: 1) this study was conducted on pediatric patients with cancer aged 6-18 years; 2) pediatric patients who receive chemotherapy; and 3) the general condition of the pediatric patient is stable. The exclusion criteria in this study were children with cancer whose hemodynamic condition was unstable.

Identification of fatigue in children aged 6-12 years in this study was conducted using the Childhood Fatigue Scale (CSF) instrument designed by Hockenberry et al. (2003). The CSF instrument consists of 14 questions with Yes or No answers. If the child answers Yes, then how much the complaint is felt starting from the following ranges: never with a score of 1; rarely with a score of 2; sometimes with a score of 3; often with a score of 4; and always with a score of 5. If the child answers no to the question, then a score of 0. The total score ranges from 0 to 70. Meanwhile, identifying fatigue in adolescents aged 13-18 years in this study was carried out using the Fatigue Scale for Adolescents (FS-A) designed by Hinds et al. (2007). This instrument consists of 14 questions using a Likert scale with ranges: never with a score of 1; rarely with a score of 2; sometimes with a score of 3; often with a score of 4; and always with a score of 5. The score ranges from 14 to 70. The higher the score, the heavier the fatigue level in children

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and adolescents.

The CSF and FSA instruments used in this study are available in English. The researcher carried out the back translation process of the CSF and FSA instruments to fulfill the content validity. The validity and reliability test of the instrument obtained the results of the validity test with the r item value of 0.509-0.884 and the reliability test with the results of Cronbach's alpha 0.948. It shows that this instrument is valid and reliable to use.

Data collection was carried out after the child received chemotherapy. Before collecting the data, the researcher gave informed consent to the children and their families beforehand. If the child and family are willing, the researcher asks the child to answer several CSF or FSA instruments for about 10-15 minutes. The filling process is assisted and accompanied by the researcher; if the child experiences problems filling out the questionnaire, the researcher interviews according to the instruments.

Data analysis in this study used univariate analysis to identify respondent characteristics

and describe the incidence of fatigue in children with cancer. The results of the fatigue score for the CFS and FSA instruments are normally distributed, so the fatigue score is assessed based on the mean value. Based on the research results, CFS has a mean value of 50.51, while the FSA instrument has a mean value of 51.81. Children are categorized as having a mild fatigue level if they have a score $<$ the mean value, and children have a severe fatigue level if they score \geq the mean value. Research data are described in terms of frequency and percentage.

This study received approval from the Health Research Ethics Committee of the hospital where the research was conducted with letter number LB.04.01/A05/EC/240/VIII/2018 and obtained permission with letter number LB.02.01/X.2.2.2/16053/2018. The research was carried out by considering the principles of research ethics that fulfill The Five Rights of Human Subjects in Research in Polit and Back (2012), including respect for autonomy, privacy or dignity, confidentiality, justice, and beneficence, and non-maleficence.

Research Results

The characteristics of the respondents in this study can be described in the following table.

Table 1 Characteristics of Respondents of Children with Cancer who Receive Chemotherapy (n = 74)

No.	Characteristics	Frequency (n)	Percentage (%)
1.	Age		
	6 – 12 Year Old (School Age)	51	68.9
	13 – 18 Year Old (Adolescence)	23	31.1
2.	Gender		
	Boy	44	59.5
	Girl	30	40.5
3.	Types of Cancer		
	Leukemia	64	86.5
	Non-Leukemia	10	13.5
4.	Cancer Severity		
	Stage I	18	24.4
	Stage II	26	35.1
	Stage III	9	12.1
	Stage IV	21	28.4
5.	Duration of Therapy		
	$<$ 1 Year	46	62.3
	1 – 3 Year	22	29.7

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> 3 Year

6

8.0

Table 1 shows the majority of children aged 6 to 12 years (school age), namely 51 children (68.9%), and most of the children are boys as many as 44 children (59.5%). In table 1, it appears that as many as 64 children (86.5%) had leukemia. According to the severity of cancer suffered by children, almost half, as many as 26 children (35.1%) had stage II cancer, and 21 children (28.4%) had to stage IV cancer. Table 1 also shows that most children, as many as 46 children (62.3%), had just undergone therapy for less than one year.

Table 2 Level of Fatigue in Children with Cancer who Receive Chemotherapy (n = 74)

Level of Fatigue	Frequency (n)	Percentage (%)
Mild Fatigue	18	24.3
Severe Fatigue	56	75.7

Table 2 regarding the level of fatigue in respondents shows that most children with cancer who receive chemotherapy treatment experience mild fatigue, as many as 18 people (24.3%). As for most children with cancer, as many as 56 people (75.7%) experienced severe fatigue.

Table 3 Analysis Item of The Mean Value of The CSF and FSA Questionnaire

No.	Item of CSF	Mean	Item of FSA	Mean
	Skor Total	50.51	Skor Total	51.81
1	I have been tired	4.5	My body has felt tired	4.9
2	My body has felt different	3.5	My mind has felt worn out	3.9
3	I have been tired in the morning	3.3	I move more slowly	3.5
4	I have needed a nap	3.9	I want to rest more	4.3
5	I have been too tired to play	4.1	I sleep more often	4.1
6	I have been lying around	3.5	It's harder to keep up with schoolwork	3.9
7	I have been sad	2.7	I don't feel like doing much	4.1
8	I have been mad	2.5	My body hasn't kept up with others	3.5
9	I have had to stop and rest when walking	3.7	I am able to do my usual activities	1.5
10	I have been too tired to do my usual activities	4.7	I have felt angry	2.7
11	I have been too tired to run	3.9	I have not felt like talking	3.5
12	It has been hard to keep my eyes open	3.9	I need help to do my usual activities	4.3
13	I slept more at night	3.7	I don't feel like being with others	2.9
14	I have trouble thinking	2.5	I have to work harder to do my usual activities	4.7

Table 3 shows the analysis item of the mean value of the CSF and FSA questionnaire. In the CSF questionnaire, there are three items with the highest mean value, namely the item I have been too tired to do my usual activities (mean value = 4.7), I have been tired (mean value = 4.5), and I have been too tired to play (mean value = 4.1). Whereas in the FSA questionnaire, there are four items with the highest mean value, namely the item My body has felt tired (mean value = 4.9), I have to work harder to do my usual activities (mean value = 4.7), I want to rest more (value mean = 4.3), and I need help to do my usual activities (mean value = 4.3). The item with the highest mean value interpreted that children with cancer were exhausted, so it was difficult to carry out usual activities.

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Table 4 Crosstab Results of Fatigue Levels in Children with Cancer based on Respondent Characteristics (n = 74)

Level of Fatigue/ Characteristics	Mild Fatigue		Severe Fatigue		Total		Nilai p
	f	%	f	%	f	%	
Age							
6-12 Year Old (School Age)	16	31.37	35	68.63	51	100.00	0.000
13-18 Year Old (Adolescence)	2	8.70	21	91.30	23	100.00	
Gender							
Boy	15	34.09	29	65.91	44	100.00	0.000
Girl	3	10.00	27	90.00	30	100.00	
Types of Cancer							
Leukemia	14	21.88	50	78.13	64	100.00	0.000
Non-Leukemia	4	40.00	6	60.00	10	100.00	
Cancer Severity							
Stage I	7	38.89	11	61.11	18	100.00	0.000
Stage II	8	30.77	18	69.23	26	100.00	
Stage III	1	11.11	8	88.89	9	100.00	
Stage IV	2	9.52	19	90.48	21	100.00	
Duration of Therapy							
< 1 Year	11	23.91	35	76.09	46	100.00	0.000
1 – 3 Year	5	22.73	17	77.27	22	100.00	
> 3 Year	2	33.33	4	66.67	6	100.00	

Table 4 explains that adolescents have more percentage of experiencing severe fatigue, namely 91.30%. In terms of gender, girls have more percentage of experiencing severe fatigue, which is 90.00% compared to boys. Meanwhile, the type of cancer experienced by children shows that children with leukemia experience severe fatigue by 78.13%. Meanwhile, when viewed from the severity of cancer, it shows that children with cancer stage III and stage IV tend to experience severe fatigue, namely 88.89% and 90.48%, respectively. Furthermore, when viewed from the length of cancer therapy that children have carried out, it shows that children with a duration of therapy <1 year and 1-3 years experience severe fatigue, respectively 76.09% and 77.27%. Table 4 also shows a significant relationship between age, gender, types of cancer, cancer severity, and duration of therapy with the level of fatigue (p value = 0.000)

Discussion

Currently, the problem of cancer in children is a big enough problem. Cancer is the top ten diseases that cause death in children. Cancer in children must be treated with quality. The most common treatment for cancer in children is chemotherapy. Chemotherapy in children with cancer can cause several side effects, including fatigue. There is no consensus regarding the exact rate of fatigue incidence, so the prevalence of fatigue in children with cancer is still a matter of debate. Fatigue may result from the process of disease, or related treatments called cancer fatigue. It affects > 70% of the patients undergoing radiotherapy and chemotherapy. In most patients, cancer fatigue is so severe that it interrupts or limits their daily activities and significantly influences different aspects of personal life. Cancer fatigue influences the patients' quality of life and functional conditions by influencing their abilities to perform activities and play roles in significant life events (Mahdizadeh et al., 2020).

This study indicates that most children with cancer who receive chemotherapy treatment experience severe fatigue like 56 children (75.7%). As many as 18 children (24.3%) experienced mild fatigue. So that in this study, all children (100%) experienced fatigue, although to varying degrees. The results of this study are also in line with research conducted by Fernandes (2020) which shows that the prevalence of cancer in children who experience fatigue reaches 98%. It shows that children were undergoing chemotherapy experience fatigue. Meanwhile, the research conducted by Yilmaz et al. (2016) states that children with cancer who undergo chemotherapy treatment show fatigue, and Bastani et al. (2015) stated that about 40% of cancer patients who receive chemotherapy experience fatigue. The research in the United Kingdom (UK) shows that approximately 70% of children with cancer who undergo chemotherapy experience fatigue (Crichton et al., 2015). Also, in the United States (US), 96% of children experience fatigue, and as many as 50% of them experience severe fatigue (Ullrich et al., 2010). Previous research in Indonesia also showed that the prevalence of fatigue in children with cancer in Jakarta

alone reached 44.2% (Allenidekania et al., 2012).

Based on some of these studies, children who get chemotherapy can develop fatigue with varying incidence rates. That may occur because fatigue can be affected by age, gender, types of cancer, cancer severity, and duration of therapy (Fernandes, 2020; Utami et al., 2020). Fatigue occurs both in children who are receiving medication and in children who have finished their medication. This fatigue can be directly related to cancer or treatment and may continue in the following year after treatment is complete (Hockenberry et al., 2017). Based on the table 3, the item with the highest mean value interpreted that children with cancer were exhausted, so it was difficult to carry out usual activities.

Research conducted by Fernandes (2020) shows that the fatigue experienced by children with cancer occurs due to cancer cells that continue to divide abnormally so that the energy needed increases for cancer cell division. It causes children to lack energy, so they experience fatigue. Uzun and Kucuk (2019) also stated that chemotherapy treatment could disrupt the bone marrow to produce blood cells to reduce erythrocyte production. Chemotherapy drugs also work to damage the DNA of rapidly dividing cells, including blood cells. The fatigue felt by children with cancer will be severe because when the fatigue that is felt is still mild, the child and his family and health workers consider this to be something normal. Also, they think that when someone is sick, the sick person will experience fatigue. They also think that fatigue occurs as a result of cancer therapy. If this fatigue is not handled correctly, it can interfere with the child's daily activities and impact their quality of life.

Table 3 shows the analysis item of the mean value of the CSF and FSA questionnaire. In the CSF questionnaire, there are three items with the highest mean value, namely the item I have been too tired to do my usual activities (mean value = 4.7), I have been tired (mean value = 4.5), and I have been too tired to play (mean value = 4.1). Whereas in the FSA questionnaire, there are four items with the highest mean value, namely the item My body has felt tired (mean value = 4.9), I have to work harder to do my usual activities

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(mean value = 4.7), I want to rest more (value mean = 4.3), and I need help to do my usual activities (mean value = 4.3). This study is in line with Mahdizadeh's research (Mahdizadeh et al., 2020).

Mahdizadeh et al. (2020) stated that fatigue is a common complaint experienced by children with cancer with an estimated 80-100%. Fatigue can also be related to pain conditions, dyspnea, anorexia, nausea, vomiting, diarrhea, anxiety, and fear experienced by children during the treatment period (da Silva et al., 2016). Based on complaints from cancer children who experience fatigue, children report that the weakness they feel makes it difficult for children to open their eyes so that it makes the child feel like he always wants to sleep, but the weakness or fatigue does not disappear with rest or sleep throughout the day. Fatigue can still be felt even after the treatment is finished. Almost all children complained about difficulties in carrying out activities and not playing with their friends. Most children reported that they could not go to school because they felt tired and weak, which made it difficult for children to do school work and decreased concentration on learning. Almost all parents report that fatigue can also make children emotionally unstable, irritable, irritable, and sad (da Silva et al., 2016; Keener, 2018; Yilmaz et al., 2016).

Yilmaz et al. (2016) shows that the general characteristics of fatigue consist of constant verbal expression due to energy loss and being unable to maintain or perform daily living activities. While the unique characteristics of fatigue consist of: 1) needing extra energy to fulfill or perform daily living activities, 2) increasing physical complaints, 3) unstable emotions or becoming more sensitive, 4) decreased or lost the ability to concentrate, 5) decreased appearance, 6) lethargy, 7) withdrawing from the environment, 8) unable to carry out social activities, and 9) unable to restore energy even after resting or sleeping throughout the day.

Various factors can cause victims to children with cancer who receive chemotherapy. According to Allenidekania et al. (2012), there are three factors related to records in children with cancer, sleep problems, and hemoglobin levels. As Yilmaz

et al. (2016) explained, chemotherapy, anemia, psychological, nutritional problems, sleep problems, and radiotherapy contribute to the incidence of fatigue in children with cancer.

The results of this study explain that adolescents have more percentage of experiencing severe fatigue. So based on this study, it appears that adolescents have a higher fatigue score than school-aged children. It is in line with Fernandes's research (2020) which also shows that the fatigue felt by adolescents is heavier than school-aged children. In terms of gender, girls have more percentage of experiencing severe fatigue than boys. It may occur related to the emotional and development stage of adolescents. Besides, it may also occur because girls usually pay more attention to appearance than boys, so changes in body image due to cancer in girls are very influential. It can affect the psychological changes in children that can cause fatigue (Utami et al., 2020).

Meanwhile, the type of cancer experienced by children shows that children with leukemia experience more fatigue. Leukemia is a malignancy that attacks the blood and bone marrow. This cancer has a more virulent and aggressive nature, making it more difficult to cure when compared to other types of cancer (Yu et al., 2017). The side effects of chemotherapy that children can feel can be heavier, including fatigue. Meanwhile, when viewed from the severity of cancer, it shows that children with cancer stage III and stage IV tend to experience more fatigue. Furthermore, when viewed from the length of cancer therapy that children have carried out, it shows that children with a duration of therapy <1 year and 1-3 years experience severe fatigue. It may occur because the higher the severity of cancer, the heavier the fatigue experienced. Also, in the early stages of treatment, the fatigue experienced will be even heavier because the child is still in the adaptation stage to the treatment. The length of therapy contributes to fatigue in children. The longer the child has undertaken the therapy, the more the child will adapt to the fatigue he experiences (Fernandes, 2020).

Fatigue will increase during chemotherapy and will continue to increase after receiving chemotherapy (Yasin & Al-hamad, 2015).

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Fatigue is a complex phenomenon that can significantly affect the quality of life of children during treatment, after treatment, and in the survival phase (Kestler & LoBiondo-Wood, 2012). So that in this case, the role of nurses is needed in conducting nursing interventions in children with cancer who are undergoing chemotherapy appropriately to reduce or overcome the side effects of chemotherapy they are undergoing. Also, family-centered care emphasizes the importance of synergy between parents and nurses in caring for children with cancer (Nurhidayah et al., 2020).

Conclusion

Fatigue is the most common side effect of chemotherapy in children with cancer. The results showed that children with cancer who receive chemotherapy mostly had a severe fatigue scale and a small portion had a mild fatigue scale. Nurses as health workers who are most frequently in contact with children with cancer should be able to improve nursing care for children with cancer to minimize fatigue. Nurses can take some actions to minimize fatigue, including monitoring fluid intake that is suitable for children, controlling pain with both non-pharmacological and pharmacological therapies, preventing anemia, controlling nausea and vomiting, controlling constipation, controlling infection, planning a diet, meeting needs rest and sleep, increase activities according to children's tolerance, conserve energy, and maintain interactions with family and friends.

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