



CANCER-RELATED FATIGUE IN CHILDREN WITH CANCER

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ABSTRACT

Introduction: Children with cancer are susceptible to experiencing symptoms of anxiety, nausea, vomiting, nutrition, fatigue, sleep disorders and pain. Children often experience fatigue during the treatment process. not much is known about other factors that influence the experience of fatigue
Aim: This study aimed to determine fatigue data in children with cancer that explains aspects of the experience of fatigue, with a focus on interoceptive awareness and emotional vulnerability.
Method: This research uses a cross sectional study approach. The subjects of this study were 64 people with the inclusion criteria of children with cancer, respondents aged 6-18 years, patients who signed informed consent, were willing to be respondents, and were undergoing treatment. This Research used accidental sampling using 64 respondents. were measured using the FAS (Fatigue Assessment Scale) PedsQol Cancer Module 3.0. In data analysis using chi square. Findings: The results of the research were that there was a relationship between fatigue and quality of life in children with cancer ($p=0.000$), and showed that 20 children (31.2%) experienced severe fatigue, while 18 children (28.1%) had quality of life. Conclusion and recommendation: based on this research that.

Keywords: *Children, Cancer, Fatigue, Quality Of Life, Children*

Introduction

Increasingly sophisticated medical technology and life-extending therapies children with life-limiting illnesses are living longer. Longer survival means more children are living with chronic and progressive illness or long-term medication toxicity. Pediatricians in primary care play a critical role in the medical team for these children; they build relationships with families, provide support, coordinate care, and establish a medical home that adapts to the patient's complex needs. Pediatricians in primary care can learn more about the scope of PPC, how to implement it into the hospital, and what to do if subspecialty PPC services are limited in their community. Palliative care clinicians have

an expanded toolbox of strategies for managing intractable symptoms such as pain, fatigue, nausea/vomiting, anxiety, insomnia, and dyspnea (Superdock & Madni, 2024). The Institute of Medicine (IOM) (2006) in Potter & Perry (2010) states that cancer is a chronic disease because of the late effects it causes. This disease can attack all ages, genders and races (Potter & Perry, 2010). Cancer is a serious disease that threatens children's health in the world. The threat of cancer throughout the world is very large, because there is an increase in the number of new cancer sufferers every year. Cancer sufferers every year and of all existing cancer cases it is estimated that around 4% of them are childhood cancers



(National Cancer Institute, 2009). Patients undergoing treatment in palliative care units often complain of symptoms such as nausea, anxiety, sleep disturbances and pain. (Uysal & Aykar, 2024). In 2018, the World Health Organization affirmed that providing palliative care to patients, families, and communities is at the core of the role and identity of primary care clinicians. It is important to build capacity in providing a palliative approach to care in the primary care setting to keep general practitioners (GPs) engaged in end-of-life (o) care (Driller et al., 2024). Patients undergoing treatment in palliative care units often complain of symptoms such as nausea, anxiety, sleep disturbances, and pain. For individuals with life-threatening or limiting critical illnesses, effectively managing these symptoms is crucial to improving their quality of life, regardless of the time remaining. Due to the diversity of symptoms observed in palliative care patients, treatment approaches rely on multidisciplinary collaboration, combining traditional support and specialized palliative care, including complementary and integrative therapies. (Uysal & Aykar, 2024).

Fatigue is one of the most frequent symptoms in palliative care patients, reported in .80% of cancer patients and in up to 99% of patients following radio- or chemotherapy. fatigue has received more attention in recent years, as quality of life is increasingly used as an endpoint in oncology trials (Radbruch et al., 2008). Fatigue and tiredness are considered to be the most common complaints of cancer patients during treatment and after treatment is completed. Manifestations of fatigue can be physical, cognitive, and emotional. However, the exact determinants of fatigue are still unknown (Strebkova, 2020).

Based on Riskesdas data, cancer in Indonesia shows an increase from 1.4 per 1000 population in 2013 to 1.79 per 1000 population in 2018. Meanwhile, data from the

World Health Organization (WHO) records that the total number of cancer cases in Indonesia in 2020 reached 396,914 cases. and total deaths of 234,511 cases. During the treatment process they underwent and after the treatment ended, some of the symptoms included fatigue (fatigue), pain, feeling lethargic, changes in mood and behavior, depression, anxiety, uncertainty about the outcome of the disease, fear, and feelings about the stigma of "children with cancer" (Ruland, Hamilton & Schjodt-Osmo, 2009, in Singh, 2016). However, fatigue is the most common problem experienced because fatigue not only occurs because of the side effects of chemotherapy but is also caused by the course of the disease. Cancer children experience fatigue because cancer cells continue to divide abnormally so that energy is needed for cell division (Prisani & Rahayuningsih, 2017).

According to research (Chiang et al., 2009) shows that children in all age groups often say the word fatigue. Patients in different age groups describe fatigue differently. Young adult It is important for nurses, parents, foundation administrators to understand the quality of life of children with cancer, so they can determine appropriate interventions according to the child's condition, including by focusing on the psychosocial and social welfare of children which is expected to help improve the child's physical condition. Currently, there is still not much research regarding the quality of life of children with cancer with an Indonesian cultural background. Previous research was more often conducted in other Asian countries, America and Europe. Thus, it is necessary to study the quality of life in children with cancer quantitatively so that it is more objective, especially in Indonesia with different backgrounds and characteristics of children. Based on data from the Cahaya Kota Padang Community Foundation from 2018-





2022, 363 children with chronic diseases were recorded, including 181 children with ALL leukemia, 13 children with retinoblastoma, 2 children with leukemia, 10 children with retinal blastoma, 1 child with hemangioma, 2 children with LCH, Hodgkin's lymphoma 4 children, Skin cancer 1 child, Abdominal tumor 2 children, Leukemia AML 20 children, Epithelioid Glioblastoma 1 child, Wills tumor 11 children, Osteosarcoma 17 children, Clearcell Sarcoma 1, Intra Abdominal Tumor 2, Liver cancer 2. And according to the results of an initial survey conducted by researchers by interviewing parents of children with chronic diseases (cancer) at the Cahaya Kota Padang Community Foundation, it was found that children who had chronic diseases (cancer) experienced a decline in their quality of life, especially children at school age. Cancer children experience poor quality of life because they experience side effects during treatment, namely pain, nausea, procedural anxiety, management anxiety, worry, cognitive and physical problems. The problems experienced by children with cancer can influence and hinder daily activities, so it is necessary to carry out research to examine the quality of life of children with cancer so that children, parents and caregivers can improve the quality of life of children with cancer.

Fatigue in cancer and non-cancer palliative care patients is under-recognized, under-assessed and under-treated. Fatigue is one of the most frequent symptoms of cancer and cancer treatment. Fatigue (84%), weakness (66%) and lack of energy (61%) were three of the five most frequent symptoms in a study of 1000 patients in an American palliative care program.¹⁹ Fatigue has been reported in 99% of patients after radiotherapy or chemotherapy (review in^{11,20}). Seventeen to 56% of long-term survivors report fatigue as one of the main symptoms impairing quality of life even months after treatment

ends (review in¹¹). In interviews with parents of children who died of cancer, fatigue was the most common symptom affecting 57% of patients (Radbruch et al., 2008)

Aim This study aimed to determine fatigue and quality of life in cancer patients

Methods Design

This research was conducted in a halfway house unit in Padang City. This research was carried out in stages: quantitative stage. The quantitative phase of this research carried out data collection by distributing questionnaires and assessing the quality of life of children of cancer patients. This research was conducted from September 2023 to March 2024, a total of 64 cancer patients who met all inclusion criteria. The inclusion criteria for selecting participants are as follows: 1) Children with cancer aged 6-18 years at the Padang City Light Community Foundation. 2) A cancer child who has undergone 2 chemotherapy sessions at the Cahaya Kota Padang Community Foundation. 3) Patients who sign informed consent and are willing to become respondents. 4) Currently undergoing treatment. 5) Patients with childhood cancer. 6) Children with cancer who are in the Padang City Light Community Foundation shelter home

PedsQL Cancer Module 3.0

PedsQL Cancer Module 3.0 is a standard generic questionnaire that is valid and has been tested in various studies as a reference for quality of life research. Cancer Module 3.0 is an instrument specifically used in the population of children with cancer. The instrument consists of eight domains, namely pain (pain and hurt), nausea (nausea), procedures that cause anxiety (procedural anxiety), management or treatment that causes anxiety (treatment



anxiety), fear (worry), cognitive problems (cognitive problems), perception of physical disorders (perceived physical appearance).

Cancer Module and Generic Core Scale scores except for the 'treatment anxiety' subscale for child report. Depression Self-Rating Scale for Children (DSRS-C) scores were significantly correlated with the emotional domain and cancer module total scores. Children who had undergone treatment for 12 months showed significantly higher scores than those who had undergone treatment. The second questionnaire is the Fatigue Assessment Scale (FAS) as a subjective questionnaire-based fatigue measurement tool that is most suitable for measuring fatigue. The FAS itself consists of 10 questions and its level of reliability is stated to be good in various studies (Vreis, Michelseon, and Van Heck, 2003). So the FAS with 10 question items can be used as an alternative, more concise measurement

instrument. However, the FAS itself is a questionnaire that uses English. So, if it is to be used as an instrument to measure fatigue for respondents in Indonesia, it needs to be validated and tested for reliability. The results of this questionnaire are calculated or measured using a Likert scale.

Sample and setting

The samples in this study were taken in the field where the data was collected. This research involved 64 people.

Ethical Consideration

This research was reviewed and approved by the Ethics Committee of Fort De Kock University, Bukittinggi, Indonesia, no 186/ KEPK/V/2023

Findings

All patients gave their consent to fill out the questionnaire. A total of 64 patients completed the

Table 1. Frequency distribution of types of disease in children with cancer
Type of disease Frequency

Type of disease	Frequency (f)	Percentage (%)
Leukemia ALL	24	68,8
Osteosarcoma	5	7,8
Brain cancer	1	1,6
Dysgerminoma	1	1,6
Hodgkin's lymphoma	2	3,1
Leukemia AML	8	12,5
Neuroblastoma	1	1,6
Tumor wilms	1	1,6
Retinoblastoma	1	1,6

Tabel 2. DATA ON THE FATIGUE OF CANCER CHILDREN IN THE COMMUNITY FOUNDATION

Fatigue Data	Never	Sometimes sometimes	Felt regular	Often experienced	Always experienced
I was very disturbed by the tiredness I felt.	14,1 %	28,1 %	31,3 %	21,9 %	4,7 %
I feel tired easily.	7.8 %	31.3 %	23.4 %	32.8%	4.7 %
I don't do much activity during the day.	6.3 %	37.5 %	28,1 %	14.1 %	14.1 %
I feel like I have enough energy to carry out my daily activities.	6.3 %	12.5 %	32.8 %	39.1 %	9.4 %
Physically I feel tired	6.3 %	18.8 %	37.5 %	28.1 %	9.4 %
I find it difficult to start doing something.	23.4 %	32.8 %	17.2 %	20.3 %	6.3 %
I find it difficult to think clearly.	26.6 %	26.6 %	23.4 %	20.3 %	3.1 %
I feel lazy to do various activities	18.8 %	29.7 %	26.6 %	17.2 %	7.8 %
Mentally I feel tired	34.4 %	20.3 %	23.4 %	18.8 5	3.1 %
When I am doing activities, I can easily concentrate fully	4.7 %	12.5 %	32.8 %	40.6 %	9.4 %

Pathophysiology of fatigue

Primary fatigue is hypothesized to be related to the tumor itself. This may occur through peripheral mechanisms such as energy depletion or through central mechanisms such as dysregulation of the hypothalamic-pituitary-adrenal (HPA) axis or

serotonin metabolism. These mechanisms may ultimately be associated with high levels of cytokines. Cancer-related syndromes and comorbidities such as anemia, cachexia, fever, infection or metabolic disorders as well as sedation to control symptoms may cause secondary fatigue. The pathophysiology of



cancer fatigue is not fully understood. In most patients, throughout the course of the disease, many different causes contribute to the onset of fatigue.⁵⁵ For a systematic approach, the expert group suggested a distinction between primary fatigue, which may be related to a high cytokine load and secondary fatigue. Fatigue in palliative care patients¹⁷ from cancer- or treatment-related syndromes and comorbidities (Radbruch et al., 2008).

It is reasonable to assume that the difference between relatives of institutionalized patients and relatives of patients treated at home is due to the fact that hospitalized patients are closer to death. The functional status of the patient is associated with impending death. Therefore, when the patient is mostly bedridden, the care will be physically and mentally strenuous and fatigue is greatly affected by anticipated grief. Symptoms of fatigue displayed by respondents at the level of severe fatigue include feeling bothered by the fatigue they feel, feeling tired easily, not doing many activities during the day, feeling like they don't have enough energy to carry out daily activities, feeling physically tired, finding it difficult to start, doing something difficult to think clearly, feeling lazy to carry out activities, feeling mentally tired, and unable to concentrate fully. According to researchers, based on research results, the average age of respondents in this study is in the school age range, school age children feel tired or lack energy more easily because children do a lot of activities at school and with their peers, children are also unable to concentrate at school, and often lie in bed. Based on the results of research on children with cancer undergoing treatment.

The result was 31.2%, this shows that children undergoing treatment experienced fatigue, almost half as many as children with cancer undergoing chemotherapy treatment. This is in accordance with research (Anggraeni et al., 2022) where the prevalence of fatigue in children with cancer in Jakarta, Indonesia reached 44.2% (n=73). Fatigue or exhaustion is felt by almost all cancer patients. Fatigue occurs as a result development of cancer and the effects of therapy. Fatigue can be felt before or after therapy is completed and can interfere with physical, psychological, mental and social functioning. Fatigue that is not treated appropriately can reduce a child's quality of life. The impact of fatigue on children who are declared cured of cancer includes children experiencing growth disorders, decreased memory, limited short-term memory (easily forgotten), learning difficulties, activity difficulties (Muz & Taşçı, 2017), hormonal changes, and other disease complications including get secondary cancer. Quality of Life of cancer children undergoing treatment at the Cahaya Kota Padang Community Foundation. Quality of life is a subjective assessment of physical and mental health, which is greatly influenced by the values and culture of the surrounding environment and socio-economic aspects of each individual.

Although 70–100% of patients treated for cancer experience cancer-related fatigue, which can be more distressing and disruptive to daily activities than the pain associated with the disease.^{1–4} However, individuals are often reluctant to report fatigue, and cancer care providers often do not screen because they are unsure about how to treat the condition.³ Evidence shows that high levels of





fatigue during treatment can lead to significant reductions in physical function and quality of life,⁵⁻⁸ however the causes are still poorly understood (Jim & Jacobsen, 2008).

Severe fatigue experienced by cancer children was 31.2% who experienced symptoms of feeling tired easily, not doing much activity during the day, feeling physically tired, having difficulty thinking clearly and having difficulty concentrating. Meanwhile, 68.8% of cancer children who felt mild fatigue did not feel too tired and did not feel too many symptoms of fatigue. Fatigue is the most dominant thing felt by cancer children. namely not doing many activities during the day because of the fatigue he experiences. According to researchers, based on research results, physical problems caused by cancer in children are problems that disrupt the quality of life of children, whether they are receiving treatment or children who have completed treatment. The physical disorders experienced by children are not only due to side effects from treatment but also from side effects from the course of the disease itself, because cancer cells continue to divide abnormally so that the energy needed by the body increases and causes the body to lack energy and fatigue. This is something that is often experienced by children with cancer, when I am doing activities, I easily concentrate fully (40.6%) and I don't do many activities during the day as much as (14.1%)

Conclusion and Recommendation

Fatigue can be felt before or after therapy is completed and can interfere with physical, psychological, mental and social functioning. Fatigue that is not treated appropriately can reduce a child's quality of

life. Fatigue is something that is often experienced by cancer children, when I am doing activities, I easily concentrate fully (40.6%) and I don't do much activities during the day (14.1%).

References

- Chiang, Y. C., Yeh, C. H., Wang, K. W. K., & Yang, C. P. (2009). The experience of cancer related fatigue in Taiwanese children. *European Journal of Cancer Care*, 18(1), 43–49. <https://doi.org/10.1111/j.1365-2354.2007.00884.x>
- Driller, B., Talseth-Palmer, B., Hole, T., Strømskag, K. E., & Brenne, A. T. (2024). Cancer patients have a reduced likelihood of dying in hospital with advance care planning in primary health care and a summarizing palliative plan: a prospective controlled non-randomized intervention trial. *Scandinavian Journal of Primary Health Care*, 42(3), 471–482. <https://doi.org/10.1080/02813432.2024.2346131>
- Prisani, D. Y., & Rahayuningsih, S. I. (2017). Common Symptoms in Children with Cancer Undergoing Chemotherapy in the Pediatric Oncology Center Room. *Student Scientific Journal*, 2(3), 1–8.
- Jim, H. S. L., & Jacobsen, P. B. (2008). Assessment and management of cancer-related fatigue. *Cancer Supportive Care: Advances in Therapeutic Strategies*, 362, 13–30. <https://doi.org/10.3109/9781420052909.002>
- Muz, G., & Taşçı, S. (2017). Effect of aromatherapy via inhalation on the sleep quality and fatigue level in





- people undergoing hemodialysis. *Applied Nursing Research*, 37(1), 28–35. <https://doi.org/10.1016/j.apnr.2017.07.004>
- Radbruch, L., Strasser, F., Elsner, F., Gonçalves, J. F., Løge, J., Kaasa, S., Nauck, F., & Stone, P. (2008). Fatigue in palliative care patients - An EAPC approach. *Palliative Medicine*, 22(1), 13–32. <https://doi.org/10.1177/0269216307085183>
- Superdock, A., & Madni, A. (2024). *Pediatric palliative care What the general pediatrician needs to know*. June, 24–30.
- Servaes, P., Verhagen, S., & Bleijenberg, G. (2002). Determinants of chronic fatigue in disease free breast cancer patients: A cross-sectional study. *Annals of Oncology*, 13(4), 589–598. <https://doi.org/10.1093/annonc/mdf082>
- Strebkova, R. (2020). Cancer-related Fatigue in Patients with Oncological Diseases: Causes, Prevalence, Guidelines for Assessment and Management. *Medicinal leaves*, 62(4), 679–689. <https://doi.org/10.3897/folmed.62.e50517>
- Uysal, D. A., & Aykar, F. S. (2024). Effect of Music and Aromatherapy Applied in Palliative Care on Symptom Management: A Systematic Review. *International Journal of Caring Sciences*, 17(1), 179–184. https://www.proquest.com/scholarly-journals/effect-musicaromatherapy-applied-palliative-care/docview/3025294588/se-2?accountid=13771%0Ahttps://media.proquest.com/media/hms/PFT/1/8zGoX?_a=ChgyMDI0MDUxNjAxNTkzMDA3NzozOTI4NTYSBtk3ODM1GgpPTkVfU0VBUkNIIg40NS4
- Uysal, D. A., & Aykar, F. S. (2024). Effect of Music and Aromatherapy Applied in Palliative Care on Symptom Management: A Systematic Review. *International Journal of Caring Sciences*, 17(1), 179–184. https://www.proquest.com/scholarly-journals/effect-music-aromatherapy-applied-palliative-care/docview/3025294588/se-2?accountid=13771%0Ahttps://media.proquest.com/media/hms/PFT/1/8zGoX?_a=ChgyMDI0MDUxNjAxNTkzMDA3NzozOTI4NTYSBtk3ODM1GgpPTkVfU0VBUkNIIg40NS4
- Wang, Y., Zanden, S. Y. Van Der, Leerdam, S. Van, Tersteeg, M. M. H., Kastelein, A., Michel, S., Neefjes, J., Meijer, J. H., & Deboer, T. (2022). *Induction of Fatigue by Specific Anthracycline Cancer Drugs through Disruption of the Circadian Pacemaker*.

