Fatigue assessment in children and adolescents undergoing oncology treatment

Avaliação da fadiga de crianças e adolescentes em tratamento oncológico

Danielle Pletes dos Santos; Daniele Botelho Vinholes; Juliana dos Santos Barbosa; Ana Cristina Wesner Viana; Lucas Paulo de Souza; Danielle Pletes dos Santos; Gisele Pereira de Carvalho

Abstract

Objective: To evaluate the fatigue of children and adolescents undergoing cancer treatment.

Methods: A cross-sectional study with 31 children and adolescents aged 5-17 years, undergoing cancer treatment. Data collection was carried out in the period January-August 2022 in a large pediatric hospital in Southern Brazil. There, the Pediatric Quality of Life Inventory™ Multidimensional Fatigue Scale questionnaire was applied to assess fatigue and collect clinical and sociodemographic data. In descriptive statistics, measures of central tendency and dispersion were used. Categorical variables were presented using absolute and relative frequencies. In inferential statistics, we used the Pearson or Spearman correlation tests with a significance level of 5%.

Results: The prevalence of males (n=19; 61.3%) was observed. The mean age was 10.6±3.64 years and the mean treatment time was 6.0±3.3 months. Acute lymphoblastic leukemia (n=9; 29%) and central nervous system tumors (n=5; 16.2%) were the most prevalent oncological diseases. Chemotherapy was the most prevalent treatment modality (n=17; 54.8%) in participants; the combined modalities of chemotherapy with radiotherapy or surgery were those that caused the greatest increase in fatigue.

Conclusion: Fatigue was present in all participants in this study. The tiredness dimension relative to sleep and/or rest was the one that presented the lowest scores, justifying the low scores also found in the general tiredness dimension.

Resumo

Objetivo: Avaliar a fadiga de crianças e adolescentes em tratamento oncológico.

Métodos: Estudo transversal com 31 crianças e adolescentes de 5-17 anos, em tratamento oncológico. A coleta de dados foi realizada no período janeiro-agosto de 2022 em um hospital pediátrico de grande porte no Sul do Brasil; lá, o questionário Pediatric Quality of Life Inventory™ Multidimensional Fatigue Scale foi aplicado para avaliar a fadiga e coletar dados clínicos e sociodemográficos. Na estatística descritiva, foram usadas medidas de tendências central e dispersão. As variáveis categóricas foram apresentadas usando frequências absoluta e relativa; na estatística inferencial, usamos os testes de correlação de Pearson ou Spearman com um nível de significância de 5%.

Resultados: Foi observada prevalência do sexo masculino (n=19; 61,3%). A idade média foi 10.6±3,64 anos e o tempo médio de tratamento foi 6,0±3,3 meses. A leucemia linfóide aguda (n=9; 29%) e os tumores do sistema nervoso central (n=5; 16,2%) foram doenças oncológicas mais prevalentes. Quimioterapia foi a modalidade de tratamento mais prevalente (n=17; 54,8%) nos participantes; as modalidades combinadas de quimioterapia com radioterapia ou cirurgia foram as que mais causaram aumento na fadiga.

Conclusão: fadiga estava presente em todos os participantes deste estudo. A dimensão cansaço em relação ao sono e/ou descanso foi a que apresentou os menores escores, justificando os baixos escores também encontrados na dimensão cansaço geral.

Resumen

Objetivo: Evaluar la fatiga de niños y adolescentes en tratamiento oncológico.

Métodos: Estudio transversal con 31 niños y adolescentes de 5 a 17 años, en tratamiento contra el cáncer. La recolección de datos se llevó a cabo en el período enero-agosto de 2022 en un gran hospital pediátrico del sur de Brasil; allí, se aplicó el cuestionario Pediatric Quality of Life Inventory™ Multidimensional Fatigue Scale para evaluar la fatiga y recoger datos clínicos y sociodemográficos. En la estadística descriptiva se utilizaron medidas de tendencia central y dispersión. Las variables categóricas se presentaron utilizando frecuencias absolutas y relativas; en estadística inferencial utilizamos las pruebas de correlación de Pearson o Spearman con un nivel de significación del 5%.

Conclusion: Fatigue was present in all participants in this study. The tiredness dimension relative to sleep and/or rest was the one that presented the lowest scores, justifying the low scores also found in the general tiredness dimension.

Keywords

Fatigue; Oncology; Pediatrics; Child health; Nursing; Pediatric nursing

Descritores

Fatiga; Oncologia; Pediatría; Saúde da criança; Enfermagem; Enfermagem pediátrica

Descritores

Fatiga; Oncología; Pediatría; Salud infantil; Enfermería; Enfermería pediátrica

How to cite:


1 Universidade Federal de Ciências da Saúde de Porto Alegre, Porto Alegre, RS, Brazil.

Conflict of interest: * manuscript extracted from the Completion Work of Multidisciplinary Residency in Childhood Cancer Care presented at Universidade Federal de Ciências da Saúde de Porto Alegre.

Submitted: March 28, 2023 | Accepted: December 21, 2023

Corresponding author: Lucas Paulo de Souza | E-mail: lucaspdesouza1995@gmail.com

DOI: 10.31508/1676-379320230031
Fatigue assessment in children and adolescents undergoing oncology treatment

Introduction

Currently, childhood cancer is the first cause of death from the disease in the population aged 1-19 years in the South, Southeast and Central-West regions of Brazil. National estimates point to around 7,930 new cases each year in the 2023-2025 period. Males were the most prevalent, with 4,230 (53.3%) new cases per year, followed by females, with 3,700 (46.7%) new cases per year. In childhood and adolescence, the most common neoplasms prevalent are leukemias, followed by Central Nervous System (CNS) tumors and lymphomas.

Children and adolescents undergoing cancer treatment show signs and symptoms of cancer-related fatigue (CRF), which interfere both with adherence to treatment and children’s quality of life when left untreated. They often find their involvement in typical childhood daily activities compromised due to incapacitation resulting from the nature of the disease.

With progress in cancer treatment, the entire process can become more arduous when accompanied by symptoms of psychological stress. Therefore, it is important that the entire care team can identify the first signs and symptoms, providing patients with a more detailed assessment of how they and their families can support themselves in the context of a serious illness like childhood cancer.

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR), the term fatigue is defined as “a state (also called exhaustion, fatigue, lethargy, dejection, languor, lassitude and apathy) generally associated with the weakening or depletion of physical and/or mental resources, ranging from a general state of lethargy to a specific burning sensation in the muscles induced by work. Physical fatigue leads to an inability to continue functioning at individuals’ normal activity level. In contrast, cognitive fatigue manifests itself as drowsiness”.

CRF is a subjective experience characterized by a feeling of fatigue that is not relieved by sleep or rest, being a factor that causes a reduction in quality of life. The signs and symptoms of CRF can vary in both intensity and duration, reducing patients’ ability to carry out daily activities and their functional capacity. Its appearance may be related to the natural course of the disease and the harmful effects of treatments, and may also be related to the uncertainty of the future, the risk of death and family strain, which generate stress and may be related to the state of chronic fatigue.

Oncological fatigue is a complex finding considering the multicausal magnitude of the symptom. Therefore, it is important to think that it goes beyond the psychological aspect, including the context in which patients are inserted. Therefore, a global assessment of patients is important, identifying possible potentiators for CRF and adopting strategies to prevent and treat them.

The guiding question of this study was the following: Is the sign of fatigue present in the oncological treatment of children and adolescents? Therefore, this research aimed to assess the presence of fatigue in children and adolescents during cancer treatment.

Methods

This was a cross-sectional study with a quantitative approach. Data collection was carried out at a large pediatric philanthropic hospital in southern Brazil from January to August 2022. It is one of the most modern pediatric care centers in southern Brazil, being a national reference for the treatment of patients with congenital heart disease, pediatric oncology, etc.
The study population was made up of children and adolescents aged 5-17 years undergoing cancer treatment. Inclusion criteria included children who had developed understanding and language. Exclusion criteria included patients who had an unstable clinical condition (pain, nausea, vomiting, etc.) and/or were in immunobiological and/or infectious isolation. The sample adopted was non-probabilistic for convenience. All eligible patients identified during the data collection period were invited to participate in the study. Figure 1 shows the details of patients screened, included and excluded (with their respective causes).

<table>
<thead>
<tr>
<th>Screened patients</th>
<th>n=43</th>
<th>Excluded patients</th>
<th>n=12</th>
<th>Patients without clinical conditions to participate</th>
<th>n=02</th>
<th>Patients on precaution for infectious disease</th>
<th>n=10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Included patients</td>
<td>n=31</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Data were entered by two researchers into a spreadsheet (Excel program), and any inconsistencies identified were corrected. Data analysis was performed using the Statistical Package for the Social Sciences (SPSS; v. 25.0) for Windows.

Data symmetry was verified using the Shapiro-Wilk test. In descriptive statistics, measures of central tendency (mean and median) and dispersion (range, interquartile range and standard deviation) were used according to the distribution of the quantitative variable. Categorical variables were presented as absolute and relative frequencies.

In inferential statistics, Pearson’s or Spearman’s correlation tests were used between the PedsQL-MFS dimensions (depending on data symmetry), adopting a significance level of 5%. Regarding the magnitude of correlation, low (0.10-0.30), moderate (0.30-0.50) and high (0.50-1.00) magnitudes were considered. The internal consistency of responses to the instrument was measured by Cronbach’s alpha coefficient, adopting the following classification: $\alpha < 0.30$: very low; $0.30 < \alpha \leq 0.60$: low; $0.60 < \alpha \leq 0.75$: moderate; $0.75 < \alpha \leq 0.90$: high; and $\alpha > 0.90$: very high.

The project was approved by the Research Ethics Committee of the proposing institution (CAAE: 53237921.6.1001.5335; Opinion: 5.222.280), in accordance with Resolution 466 (2012) and the General Data Protection Law 13.709 (2018).

**Results**

A total of 31 patients participated in the study. The mean age was 10.6±3.6 years. The mean treatment time was 6.0±3.3 months, with a minimum time of 1 month and a maximum of 13 months. Table 1 presents the frequencies of participant characteristics such as sex, age group, education and self-declared color.
In relation to oncological pathology, data were collected on neoplastic diagnoses, treatment modality and antineoplastic protocols used at the time of data collection. Table 2 presents the frequencies of these findings.

Table 2. Frequency of oncological diagnoses and treatment modality used (n=31)

<table>
<thead>
<tr>
<th>Oncological diagnoses and treatment modality used</th>
<th>n(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnoses</td>
<td></td>
</tr>
<tr>
<td>Non-Hodgkin’s lymphoma</td>
<td>3(9.7)</td>
</tr>
<tr>
<td>Hodgkin’s lymphoma</td>
<td>1(3.2)</td>
</tr>
<tr>
<td>Wilms tumor</td>
<td>3(9.7)</td>
</tr>
<tr>
<td>Bone tumors</td>
<td>2(6.5)</td>
</tr>
<tr>
<td>Central Nervous System tumors</td>
<td>5(16.2)</td>
</tr>
<tr>
<td>Soft tissue sarcomas</td>
<td>1(3.2)</td>
</tr>
<tr>
<td>Germ cell tumors</td>
<td>1(3.2)</td>
</tr>
<tr>
<td>Acute lymphoid leukemia</td>
<td>9(29)</td>
</tr>
<tr>
<td>Desmoid fibromatosis</td>
<td>1(3.2)</td>
</tr>
<tr>
<td>Ganglioneuroblastoma</td>
<td>1(3.2)</td>
</tr>
<tr>
<td>Acute promyelocytic leukemia</td>
<td>1(3.2)</td>
</tr>
<tr>
<td>Osteosarcoma</td>
<td>2(6.5)</td>
</tr>
<tr>
<td>Malignant peripheral nerve sheath tumor</td>
<td>1(3.2)</td>
</tr>
<tr>
<td>Types of treatment</td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>17(54.8)</td>
</tr>
<tr>
<td>Radiotherapy + chemotherapy</td>
<td>5(16.2)</td>
</tr>
<tr>
<td>Surgery + chemotherapy</td>
<td>5(16.2)</td>
</tr>
<tr>
<td>Radiotherapy + chemotherapy + surgery</td>
<td>4(12.8)</td>
</tr>
</tbody>
</table>

In Pearson’s correlation, the sleep/rest fatigue dimension showed a correlation with the general fatigue dimension (R=0.589; p<0.00). The internal consistency of PedsQL-MFS reached 0.892 according to Cronbach’s alpha.

Table 3. Pediatric Quality of Life Inventory™ Multidimensional Fatigue Scale scores (n=31)

<table>
<thead>
<tr>
<th>Types of fatigue</th>
<th>5-7 YEARS n=8(25.8%)</th>
<th>8-12 YEARS n=13(41.9%)</th>
<th>13-18 YEARS n=10(32.2%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>General fatigue</td>
<td>77.0±19.7</td>
<td>75.6±18.1</td>
<td>62.0±18.8</td>
</tr>
<tr>
<td>Sleep/rest fatigue</td>
<td>52.0±22.6</td>
<td>63.7±18.5</td>
<td>47.5±21.0</td>
</tr>
<tr>
<td>Cognitive fatigue</td>
<td>78.1±19.8</td>
<td>77.2±18.8</td>
<td>78.7±25.7</td>
</tr>
<tr>
<td>Total score</td>
<td>69.0±17.7</td>
<td>72.2±15.8</td>
<td>62.7±17.4</td>
</tr>
</tbody>
</table>

Table 4. Fatigue scores and cancer treatment modalities (n=31)

<table>
<thead>
<tr>
<th>Treatment modality</th>
<th>PedsQL-MFS mean±SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemotherapy</td>
<td>71.3±12.2</td>
</tr>
<tr>
<td>Chemotherapy + radiotherapy</td>
<td>57.2±21.6</td>
</tr>
<tr>
<td>Chemotherapy + surgery</td>
<td>57.2±19.5</td>
</tr>
<tr>
<td>Chemotherapy + surgery + radiotherapy</td>
<td>83.6±10.1</td>
</tr>
</tbody>
</table>

In Pearson’s correlation, the sleep/rest fatigue dimension showed a correlation with the general fatigue dimension (R=0.589; p<0.00). The internal consistency of PedsQL-MFS reached 0.892 according to Cronbach’s alpha.

Discussion

There was a prevalence of male patients (n=19; 61.3%), diagnosed with acute lymphoid leukemia (ALL; n=9; 29.0%), followed by CNS tumors (n=5; 16.2%). These findings agree with national and international literature, where ALL is the most common type of neoplasm in children and adolescents\(^{11-14}\) and its incidence is higher in males.\(^{11-16}\) Furthermore, these findings are in line with annual estimates from the Brazilian National Cancer Institute (Instituto Nacional de Cáncer) for the 2023-2025 triennium, when it was expected that the number of new cases of childhood cancer would be 7,930 (males: 4,230; 53.3%; females: 3,700; 46.7%).\(^{11}\)

The mean age was 10.6±3.6 years. Patients aged 8-12 years (n=13; 41.9%) prevailed, followed by 13-18 years (n=10; 32.3%) and 5-7 years (n=8; 25.8%). In all age groups, the lowest fatigue score was found in the sleep/rest fatigue dimension. This finding was previously found in another national study,\(^{12}\) highlighting the factors limiting sleep and/or rest in this popula-
Another Brazilian study carried out in Acre applied the PedsQL-MFS to 37 children and adolescents undergoing cancer treatment and found lower scores in the general fatigue dimension. In another Brazilian study, the dimension with the lowest score was cognitive fatigue.

Possible explanations for such low fatigue scores in the sleep/rest fatigue dimension may be recurrent and prolonged hospitalization, changes in routine that patients face, fear of the uncertain prognosis of the disease, etc., which often leads them experiencing sleep disorders. Therefore, it is important that nurses adapt the nursing care routine (e.g., grouping care and interventions) to the treatment and context of each patient, allowing each of them to have more rest time with fewer care interruptions. Furthermore, it is also important to encourage patients to express their feelings and communicate their symptoms, finding strategies to deal with signs of fatigue that they may present.

Regarding treatment modalities, chemotherapy was prevalent in participants (n=17; 54.8%), as it partly represents the prevalence of leukemia diagnoses in this study. However, the lowest fatigue scores were found in chemotherapy treatment modalities combined with radiotherapy (57.2±21.6) or surgery (57.2±19.5).

In this research, the PedsQL-MFS value reached a high internal consistency (0.892) according to Cronbach’s alpha, being a suitable instrument for the global measurement of fatigue in the pediatric oncology population. In Pearson’s correlation, the sleep/rest fatigue dimension showed a correlation with the general fatigue dimension (0.589; p<0.00), being considered a correlation of high magnitude. With the sample size of this study, it was not possible to extrapolate further inferences; all other dimensions and variables reached low correlation magnitudes, and none of them reached moderate magnitude.

According to Nursing Diagnoses (ND), the fatigue diagnosis is an oppressive sensation sustained by exhaustion and decreased ability to perform physical and mental work at the usual level. A study (with 100 pediatric oncology patients) conducted by Brazilian nurses applied the NANDA-I taxonomy to identify the most prevalent NDs in this population during hospitalization in a pediatric ward. In this study, fatigue was an ND present in patients (n=31; 31.0%). According to NANDA-I, compromised concentration, increase in rest requirements, fatigue, inability to maintain usual levels of physical activity or routines, among others, are among the defining characteristics of fatigue. All of these defining characteristics are inserted in the PedsQL-MFS dimensions and in all of them the score indicates the presence of fatigue.

A group of Brazilian nurses developed a booklet with guidelines for pediatric patients undergoing cancer treatment where fatigue (synonymous with fatigue) is present in the guidelines. It is important that all professionals are aware of the magnitude of pediatric oncology treatment (in which systemic cytotoxic drugs are often used) and do not underestimate the signs and symptoms of fatigue. Studies and materials like this booklet are recurrent and important in the education of pediatric oncology patients; they allow patients to be taught a little more about the context in which they will be inserted, making them leaders in their treatment and care process.

Finally, we listed all phases of oncological treatment that this research covered as limitations and risk of bias, as they may have exacerbated the fatigue findings. Another important limitation was the high number of patients who were taking precautions for infectious diseases, a situation that was worsened by the COVID-19 pandemic and limited the sample number.

Nursing has the role of offering pediatric patients centered and individualized care not only in terms of their diagnosis, but also the reality and specificities of each patient and their family. Allowing them to be the leaders of their care does not exempt the care teams from responsibility. On the other hand, this allows them to feel encouraged to find personal and collective strategies to face the disease and its repercussions, including the presence of fatigue.

**Conclusion**

Fatigue occurs in all age groups. The feeling of fatigue increases with a reduction in sleep and/or rest time. It is up to nurses, as leaders of nursing teams, to identify risk factors for the emergence of fatigue in pediatric oncology patients, applying nursing care centered on each person’s individuality as a form of prevention and treatment.
Contributions

Santos DP, Souza LP, Viana ACW, Barbosa JS, Vinholes DB, Carvalho GP declare to have participated in the project design, data analysis and interpretation, article writing, relevant critical review of intellectual content and final approval of the version to be published.

References