# Analysis of the quality of life in children and adolescents undergoing cancer treatment

Análise da qualidade de vida em crianças e adolescentes sob tratamento oncológico

Análisis de la calidad de vida en niños y adolescentes en tratamiento oncológico

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## Resumo

**Objetivo:** Avaliar a qualidade de vida de crianças e adolescentes em tratamento oncológico.
**Métodos:** Este estudo transversal foi realizado em um hospital pediátrico no Sul do Brasil. A amostra foi não-probabilística por conveniência, e 31 pacientes de 5-17 anos participaram do estudo. Foram coletados dados clínicos e sociodemográficos com posterior aplicação de um questionário específico para avaliar a qualidade de vida. Na estatística descritiva, foram usadas medidas de tendência central e dispersão, e as variáveis categóricas foram apresentadas usando frequências absoluta e relativa.
**Resultados:** O sexo masculino mostrou prevalência (61,3%; n=19), a idade média foi 10,6±3,6 anos e os pacientes com diagnóstico de leucemia linfoide aguda predominaram (29.1%; n=09). A redução na qualidade de vida foi um achado presente em todos participantes, e quimioterapia foi a modalidade de tratamento que mais impactou a qualidade de vida (escore: 65.9±14,3).
**Conclusão:** Quimioterapia foi a modalidade de tratamento que causou maior redução na qualidade de vida dos pacientes.

**Keywords**
Quality of life; Oncology; Pediatrics; Adolescent; Nursing; Pediatric nursing

## Abstract

**Objective:** To assess the quality of life of children and adolescents undergoing cancer treatment.
**Methods:** This cross-sectional study was carried out in a pediatric hospital in southern Brazil. The sample was non-probabilistic for convenience, and 31 patients aged 5-17 years participated in the study. Clinical and sociodemographic data were collected with subsequent application of a specific questionnaire to assess quality of life. In descriptive statistics, measures of central tendency and dispersion were used, and categorical variables were presented using absolute and relative frequencies.
**Results:** The male sex showed prevalence (61.3%; n=19), the mean age was 10.6±3.6 years and patients diagnosed with acute lymphocytic leukemia predominated (29.1%; n=09). The reduction in quality of life was a finding present in all participants, and chemotherapy was the treatment modality that most impacted quality of life (score: 65.9±14.3).
**Conclusion:** Chemotherapy was the treatment modality that caused the greatest reduction in patients' quality of life.

**Descritores**
Qualidade de vida; Oncologia; Pediatria; Adolescente; Enfermagem; Enfermagem pediátrica

## Resumen

**Objetivo:** Evaluar la calidad de vida de niños y adolescentes en tratamiento oncológico.
**Métodos:** Este estudio transversal se realizó en un hospital pediátrico del sur de Brasil. La muestra fue no probabilística por conveniencia y participaron en el estudio 31 pacientes con edades entre 5 y 17 años. Se recogieron datos clínicos y sociodemográficos con la posterior aplicación de un cuestionario específico para evaluar la calidad de vida. En la estadística descriptiva se utilizaron medidas de tendencia central y dispersión, y las variables categóricas se presentaron mediante frecuencias absolutas y relativas.
**Resultados:** Predominó el sexo masculino (61,3%; n=19), la edad promedio fue 10,6±3,6 años y predominaron los pacientes con diagnóstico de leucemia linfocítica aguda (29,1%; n=09). La reducción en la calidad de vida fue un hallazgo presente en todos los participantes, y la quimioterapia fue la modalidad de tratamiento que más impactó la calidad de vida (puntuación: 65,9±14,3).
**Conclusión:** La quimioterapia fue la modalidad de tratamiento que provocó la mayor reducción en la calidad de vida de los pacientes.

**Descriptores**
Calidad de vida; Oncología; Pediatría; Adolescente; Enfermería; Enfermería pediátrica

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## Introduction

An oncological diagnosis has an important impact on the lives of patients and their families. In Brazil, it ranked first among the causes of death in children aged 0-4 years, being the main cause of death in the age group 1-19 years in 2022 (Ministry of Health data). In adults, environmental factors are the main risk factors for cancer, whereas in the pediatric population, the risk is linked to inherited genetic factors or mutations of uncertain cause.[1-3]

The Brazilian National Cancer Institute (INCA - *Instituto Nacional de Câncer*) estimated the incidence of pediatric cancer in the 2023-2025 period, predicting around 7,930 new cases in the child and adolescent population each year. There were an estimated 4,230 (53.3%) new cases in males and 3,700 (46.7%) in females. These values correspond to an estimated risk of 140.50 new cases per million male children and 128.87 per million female children. The most common pediatric types are leukemias, followed by Central Nervous System tumors and lymphomas.[1,3]

Adherence to treatment is arduous and difficult not only for children but also for their families as everyone must adapt to a new routine for consultations, tests, medications, including hospitalization. During this adaptation, children and adolescents may present various signs and symptoms that interfere with quality of life (QoL), generating emotional stress due to fear and uncertainty about the prognosis.[2,4]

According to the World Health Organization, QoL is "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".[5] In the health area, the concept of QoL has influenced both public policies and care practices and treatment protocols, as the determinants and other conditions of the health-disease process are complex and multifactorial factors.[6]

For Seidl *et al*.,[6] health and disease are processes understood as a continuum that are related to economic and sociocultural aspects as well as individual lifestyles. In this regard, improved QoL has become one of the expected results in the areas of health promotion and disease prevention.

The way children will face the disease is reflected not only in their adherence to treatment, but also in the way they will express themselves in the face of the challenges of being an oncology patient. This process can generate emotional reactions such as anxiety, guilt about being sick, depression, etc. Multidisciplinary action is essential for patients to have a good QoL throughout treatment. This is part of the construction and security of humanized care centered on patients and their families, which can help them promote autonomy, improve QoL and adjust to new needs in their own environment.[2,7]

Thus, pediatric patients' QoL becomes compromised not only because they are sick but also because they need to reorganize themselves into a new routine. The main objective is to ensure the best possible QoL for patients and their families despite difficult-to-control circumstances, offering choices about the most appropriate places for care and assistance.[2,7]

The quest to study and work on children's QoL has been growing over time. One of the questionnaires used for this purpose is the Pediatric Quality of Life InventoryTM Cancer Module v. 3.0 (PedsQL). This instrument was developed by Varni *et al*. to measure the QoL of children and adolescents undergoing cancer treatment.[8-10] The questionnaire was translated into Brazilian Portuguese and validated.[11]

A Brazilian study applied the PedsQL to 35 children and/or adolescents undergoing oncological monitoring and showed that different factors affected QoL in each age group in which it was applied.[12] This finding draws attention to the importance of multidisciplinary teams directing their care and interventions according to each patient's needs. Another study carried out by Portuguese nurses applied the PedsQL to 75 children and/or adolescents; it drew attention to the agreement found between age groups regarding the "worry" and "nausea" dimensions that most generated a reduction in QoL in study patients.[13]

The guiding question of this research was the following: Did pediatric patients undergoing oncology treatment experience a reduced QoL? Hypotheses H0 and H1 about patients undergoing cancer treatment were, respectively, "They had a reduction in QoL" and "They did not have a reduction in QoL".

To answer the research question, this study aimed to assess the QoL of children and adolescents undergoing oncological treatment, as treatment is multicausal and can have implications for patients.

## Methods

This was a cross-sectional study with a quantitative approach described based on the STROBE checklist.[14] Data collection was carried out at a large pediatric hospital in southern Brazil from January to August 2022. It is a philanthropic hospital that is stands out in areas of high pediatric complexity, being a reference in pediatric oncology treatment. The study population consisted of patients aged 5-17 years who were undergoing cancer treatment. Children who had well-developed understanding and language were included. Patients with an unstable clinical condition (e.g., agitation) and those in infectious and contagious isolation were excluded. A non-probabilistic convenience sample was adopted; all eligible patients identified during the data collection period were invited to participate in the study. Figure 1 shows patient screening.

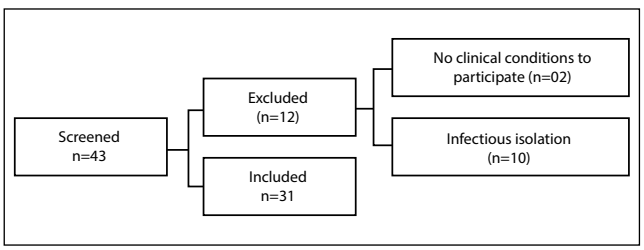


**Figure 1.** Sample selection

Collection was carried out at the bedside in pediatric inpatient units or in individual boxes in the pediatric oncology outpatient clinic. Sociodemographic data (age, sex, self-declared skin color and education) were collected, followed by the application of PedsQL and subsequent consultation of patients' electronic medical records to collect their health history (type of neoplasm, modality and treatment protocols).

The PedsQL is an instrument[8-10] to assess the perception of patients and their families regarding the impact of cancer treatment on children's and adolescents' QoL. It consists of a questionnaire validated for Brazilian Portuguese[11] with a Likert-type scale grouping the age groups 5-7, 8-12 and 13-18 years old and their guardians for the same age groups. We emphasized that in this study only data related to patients' perception were collected.

The instrument consists of five answer options ranging from "never" to "always", and is structured into 27 items distributed across the following eight dimensions: 1. pain and hurt (2 items); 2. nausea (5 items); 3. procedural anxiety (3 items); 4. treatment anxiety (3 items); 5. worry (3 items); 6. cognitive problems (5 items); 7. Perceived physical appearance (3 items); and 8. communication (3 items).[8-11]

In PedsQL analysis, options are reverse scored and transformed into a 100-0 scale: 0 (never): 100; 1 (almost never): 75; 2 (sometimes): 50; 3 (almost always): 25; and 4 (always): 0. Thus, the score can be added and divided by the total number of answers. In interpretation, the lower the score, the lower the self-perceived QoL of children and/or adolescents.[8-11] Authorization for free use of PedsQL was obtained through contact with the Mapi Research Trust through ePROVIDE™ (https://eprovide.mapi-trust.org/).

The data were entered into spreadsheets (Excel program) by two different researchers, and possible inconsistencies were corrected. The analysis was carried out using the Statistical Package for the Social Sciences (SPSS 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 are presented as absolute and relative frequencies.

In inferential statistics, Pearson's or Spearman's correlation tests were used (between the PedsQL 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.[15] The internal consistency of answers to the instrument was measured by Cronbach's alpha coefficient, adopting the following classification: very low ($a \leq 0.30$); low ($0.30 < a \leq 0.60$); moderate ($0.60 < a \leq 0.75$); high ($0.75 < a \leq 0.90$); and very high ($a > 0.90$).[16]

The project was approved by the institution's Research Ethics Committee and is in accordance with the Brazilian Resolution on research involving human beings (466/2012) and the General Data Protection Law (13.709/2018)/ CAAE 53237921.6.1001.5335/ REC 5.222.280.

# Results

A total of 31 patients were included, with a mean age of 10.6±3.6 years (min.-max: 5-16). The mean treatment time was 6.0±3.3 months (min-max: 1-13). Table 1 presents patient sociodemographic data.

**Table 1.** Sociodemographic data of patients undergoing cancer treatment (n=31)

| Sociodemographic data | n(%) |
|---|---|
| Sex | |
| Male | 19(61.3) |
| Female | 12(38.7) |
| Age group (years) | |
| 5-7 | 08(25.8) |
| 8-12 | 13(41.9) |
| 13-18 | 10(32.2) |
| Education | |
| Preschool to 5th grade in the initial grades | 14(45.2) |
| 6-9th grade | 12(38.7) |
| High school | 5(16.1) |
| Self-declared skin color | |
| White | 22(70.9) |
| Black | 4(12.9) |
| Yellow | 1(3.3) |
| Brown | 4(12.9) |

Concerning the disease, data were collected on diagnosis, type of treatment and antineoplastic protocol in use at the time of collection, and Table 2 presents these findings.

**Table 2.** Antineoplastic treatment diagnoses and regimens (n=31)

| Clinical data | n(%) |
|---|---|
| Diagnoses | |
| Non-Hodgkin's lymphoma | 3(9.7) |
| Wilms tumor | 3(9.7) |
| Bone tumors | 2(6.5) |
| Central Nervous System tumors | 5(16.1) |
| Acute lymphoid leukemia | 9(29.1) |
| Osteosarcoma | 2(6.5) |
| Others* | 7(22.4) |
| Types of treatment | |
| Chemotherapy | 17(54.9) |
| Radiotherapy + chemotherapy | 5(16.1) |
| Surgery + chemotherapy | 5(16.1) |
| Radiotherapy + chemotherapy + surgery | 4(12.9) |
| Treatment protocols | |
| BFM† 2009 protocol | 06(19.4) |
| Glato‡ protocol | 02(6.4) |
| Others§ | 23(74.2) |

*Others correspond to neoplasms with a frequency of 3.2% (n=1); †Berlin-Frankfurt-Munich; ‡Latin American Osteosarcoma Treatment Group protocol; § Others correspond to protocols with a frequency of 3.2% (n=1) of patients.

Data on the PedsQL questionnaire were grouped according to the corresponding age groups and are presented in Table 3.

**Table 3.** Quality of life scores of patients undergoing cancer treatment (n=31)

| Dimensions | PedsQL* | | |
|---|---|---|---|
| | 5-7 YEARS n=08 (25.8%) | 8-12 YEARS n=13 (41.9%) | 13-18 YEARS n=10 (32.3%) |
| | mean±SD | | |
| Pain and hurt | 50±42.25 | 74.03±20.70 | 56.25±33.97 |
| Nausea | 76.25±15.97 | 63.46±21.73 | 52±28.10 |
| Procedural anxiety | 60.41±44.48 | 56.41±37.60 | 79.16±27 |
| Treatment anxiety | 75±26.72 | 79.48±22.20 | 75.83±27.90 |
| Worry | 64.58±24.29 | 62.17±26.26 | 51.66±25.70 |
| Cognitive problems | 64.06±27.90 | 70.57±18.37 | 77±16.02 |
| Perceived physical appearance | 66.66±29.54 | 77.56±23.90 | 73.33±28.54 |
| Communication | 91.66±15.43 | 69.87±23.20 | 71.66±18 |
| Total score | 68.28±17.49 | 69.19±14.00 | 67.11±16.27 |

*Pediatric Quality of Life InventoryTM (Cancer Module v. 3.0); SD - standard deviation.

Table 4 presents data on QoL scores according to the treatment modality used.

**Table 4.** General quality of life scores according to the treatment modality used (n=31)

| Treatment modality | PedsQL*(n=31) mean±SD |
|---|---|
| Chemotherapy | 65.91±14.32 |
| Radiotherapy + chemotherapy | 66.30±16.12 |
| Surgery + chemotherapy | 68.39±13.48 |
| Radiotherapy + chemotherapy + surgery | 80.15±13.41 |

* Pediatric Quality of Life InventoryTM (Cancer Module v. 3.0); SD - standard deviation.

In Pearson's correlation, the general PedsQL score was correlated with the nausea (0.568; p<0.001), procedural anxiety (0.533; p<0.002) and cognitive problems (0.726; p<0.000) dimensions. The general PedsQL score was correlated with treatment time in months (0.384; p<0.33). In Spearman's correlation, time under treatment in months was correlated with the procedural anxiety (0.407; p<0.023), treatment anxiety (0.546; p<0.001) and perceived physical appearance (0.386; p <0.032) dimensions. The procedural anxiety dimension was correlated with the treatment anxiety (0.500; p<0.004) and perceived physical appearance (0.388; p<0.031) dimensions. The treatment anxiety dimension was correlated with the perceived physical appearance dimension (0.644, p<0.000). The internal con-

sistency of PedsQL, measured by Cronbach's alpha, reached = 0.905.

## Discussion

In this study, males predominated (n=19; 61.3%) according to INCA estimates.[1,3] This finding is also present in other national[12,17-19] and international[20-22] studies that applied the PedsQL.

The most common oncological diseases were acute lymphocytic leukemia (n=09; 29.0%), followed by Central Nervous System tumors (n=5; 16.1%), Wilms tumors and non-Hodgkin's lymphoma (n=3 ;9.7%) each. Leukemia was also the most common neoplastic disease in international[20-23] and national findings.[12,18]

As for treatment modality, chemotherapy (CT) (n=17; 54.8%) was the most prevalent in our findings; international[21,22] and national[19] studies also showed prevalence of CT as the main treatment modality. This data agrees with the prevalence of leukemias and hematological diseases found in this research and in the literature.[12,18,20-23] Furthermore, the CT treatment modality was the one that caused the greatest reduction in QoL in this research. A similar finding was present in two international studies.[20,21]

In the age group of 5-7 years (Table 3), the lowest scores were found in the pain and hurt (50.00±42.25) and procedural anxiety (60.41±44.48) dimensions. In the age group of 8-12 years, the lowest scores were found in the procedural anxiety (56.41±37.60) and worry (62.17±26.26) dimensions. In the 13-18 age group, the lowest scores were found in the procedural anxiety (15.83±27.90) and worry (51.66±25.70) dimensions. The procedural anxiety dimension presented a low score in all age groups, with the lowest score being in the 8-17 year old range. This is relevant data, as we know that cancer patients undergo several procedures during their treatment. In this same age group, attention is drawn to the fact that the worry dimension also reached low scores, and this differs from what was found in the 5-7 year old group, in which the pain and hurt dimension presented lower scores. These findings are present because individuals better understand the health-illness process as they grow and develop, and are therefore more concerned about the cure and the possible consequences that the disease and treatment can cause. In younger children, pain is caused not only by the disease but also by the necessary procedures (e.g., Portocath catheter puncture), thus being a limiting factor to their QoL.

In a Brazilian study[19] that analyzed the QoL of adolescents undergoing cancer treatment via PedsQL, the dimensions that achieved the lowest scores were worry followed by nausea. Differently, an African study[24] with children found lower scores in the procedural anxiety and communication dimensions. These findings indicate that each age group has its own perceived QoL and its reduction may also vary depending on the age group of patients. So, older patients better understand their disease, treatment and implications.

In the present research, different total PedsQL scores were found for the age groups of 5-7 years (68.28±17.49), 8-12 years (69.19±14.00) and 13-18 years (67 .11±16.27). These results suggest a reduction in QoL in all age groups. According to Cronbach's alpha, the internal consistency in our investigation was considered very high;[16] therefore, the PedsQL is a suitable instrument for measuring QoL in the pediatric oncology population. Regarding correlation magnitudes, seven correlations of high magnitude[15] and three of moderate magnitude were found,[15] agreeing with the multicausal concept of QoL that it can be affected by several determinants.

A Brazilian study[25] developed a nursing care instrument (based on the NANDA-I-NIC-NOC taxonomy) to assist the pediatric oncology population; in this instrument, nursing diagnoses and care aim to qualify nursing care by offering children care that is more focused on their needs. Instruments like this can be useful to identify each patient's weaknesses, offering individualized care with the potential to improve their QoL. Therapeutic toy is an alternative tool capable of relieving stress and increasing comfort during hospitalization.[26] Therefore, quality improvement studies are essential to test interventions like these, and can be adopted from the moment of diagnostic investigation to the maintenance phase of oncological treatment.

As a limitation of this study, we highlighted the high number of patients who were in infectious isolation at the time of data collection. This situation was worsened by the COVID-19 pandemic, limiting the sample for this study. Furthermore, our data show find-

ings from patients seen at a single pediatric treatment center. Multicenter studies could generate more representative results, providing a greater basis for healthcare professionals to think about other interventions and improve pediatric oncology patients' QoL. It was not possible to make associations and inferences about treatment protocols with QoL scores. However, we understand that all treatment modalities contributed to reducing patients' QoL, including those combined.

As contributions to nursing, this study highlighted the importance of including improvement in QoL as one of the care and assistance actions as the health-disease process is dynamic, multi-causal and can be influenced by the most diverse factors. Nurses, as agents of a multidisciplinary team, must encourage pediatric patients to express themselves and make decisions that help them maintain a high QoL, making them feel more encouraged to find personal and collective strategies to face the disease and its repercussions, thus improving their QoL and the way in which they will face treatment.

## Conclusion

Oncological treatment reduces QoL. CT is the treatment modality that most causes a reduction in QoL in children. Assessing pediatric oncology patients' QoL is important to identify possible interfering factors, plan care and strengthen their coping strategies. Patients' QoL must be reassessed during treatment to reduce possible damage as much as possible. Professionals must master the interventions that can improve QoL, readjusting them whenever necessary. Studies are recommended to evaluate the impact of interventions with strategies to improve QoL and periodic measurements to confirm the effectiveness of these interventions.

## Contributions

Santos SD, Souza LP, Viana AC, 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.

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