Evaluation of questionnaires measuring quality of life in children and adolescents undergoing cancer treatment

Avaliação de questionários para mensurar qualidade de vida de crianças e adolescentes em tratamento oncológico

Evaluación de cuestionarios para medir calidad de vida en niños y adolescentes en tratamiento oncológico

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RESUMO

Objetivo: Este estudo visa identificar, apresentar e discutir instrumentos amplamente utilizados para avaliar a qualidade de vida relacionada à saúde (QVRS) em crianças e adolescentes com câncer, além de analisar suas características. Método: Trata-se de uma revisão integrativa da literatura com artigos publicados entre 2000 e 2020 nas bases PubMed, SciELO, SCOPUS e LILACS, nos idiomas português, inglês e espanhol. Estudos focados em populações adultas, idosos, dissertações, teses e artigos de opinião foram excluídos. Além disso, buscas manuais em sites de instituições desenvolvedoras dos instrumentos foram realizadas. Resultados: Foram identificados cinco instrumentos principais para avaliar a QVRS, categorizados como genéricos ou específicos. Características analisadas incluíram número de itens, dimensões avaliadas, faixa etária, respondentes, ano de criação e adaptação cultural ao português. Dentre os cinco instrumentos identificados, três se destacam: PedsQL 4.0, PedsQL 3.0 e KIDSCREEN-52. Esses instrumentos possuem propriedades psicométricas adequadas, são de fácil aplicação e adaptados culturalmente ao contexto brasileiro. Conclusões: A revisão revela a predominância de instrumentos internacionais adaptados e a escassez de ferramentas desenvolvidas no Brasil, destacando a necessidade de mais pesquisas nessa área no contexto nacional.

Descritores: Adolescente; Criança; Neoplasias; Qualidade de vida; Inquéritos e Questionários.

ABSTRACT

Objective: This study aims to identify, present, and discuss widely used instruments for evaluating health-related quality of life (HRQoL) in children and adolescents with cancer, as well as analyze their characteristics. Method: This is an integrative literature review including articles published between 2000 and 2020 from the PubMed, SciELO, SCOPUS, and LILACS databases in Portuguese, English, and Spanish. Studies focused on adult or elderly populations, dissertations, theses, opinion articles, and other types of reviews were excluded. Manual searches on the websites of institutions that developed the instruments were also conducted. Results: Five main instruments for assessing HRQoL were identified, categorized as generic or specific. The analyzed characteristics included the number of items, evaluated dimensions, target age range, respondents, year of creation, and cultural adaptation to Portuguese. Among the five identified instruments, three stood out: PedsQL 4.0, PedsQL 3.0, and KIDSCREEN-52. These instruments have adequate psychometric properties, are easy to administer, and have been culturally adapted to the Brazilian context. Conclusions: The review highlights the predominance of adapted international instruments and the scarcity of tools developed in Brazil, emphasizing the need for further research in this field within the national context.

Descriptors: Adolescent; Child; Neoplasms; Quality of life; Surveys and Questionnaires.

RESUMEN

Objetivo: Este estudio tiene como objetivo identificar, presentar y discutir los instrumentos ampliamente utilizados para evaluar la calidad de vida relacionada con la salud (CVRS) en niños y adolescentes con cáncer, además de analizar sus características. Metodo: Se trata de una revisión integrativa de la literatura con artículos publicados entre 2000 y 2020 en las bases de datos PubMed, SciELO, SCOPUS y LILACS, en los idiomas portugués, inglés y español. Se excluyeron estudios centrados en poblaciones adultas, personas mayores, disertaciones, tesis, artículos de opinión y otros tipos de revisiones. Además, se realizaron búsquedas manuales en sitios web de las instituciones que desarrollaron los instrumentos. Resultados: Se identificaron cinco instrumentos principales para evaluar la CVRS, categorizados como genéricos o específicos. Las características analizadas incluyeron el número de ítems, las dimensiones evaluadas, el rango de edad objetivo, los encuestados, el año de creación y la adaptación cultural al portugués. Entre los cinco instrumentos identificados, tres se destacaron: PedsQL 4.0, PedsQL 3.0 y KIDSCREEN-52. Estos instrumentos tienen propiedades psicométricas adecuadas, son fáciles de aplicar y están adaptados culturalmente al contexto brasileño. Conclusiones: La revisión revela la predominancia de instrumentos internacionales adaptados y la escasez de herramientas desarrolladas en Brasil, destacando la necesidad de más investigaciones en esta área dentro del contexto nacional.

Descriptores: Adolescente; Niño; Neoplasias; Calidade de Vida; Encuestas y Cuestionarios.

Introduction

The World Health Organization (WHO) defines Quality of Life (QoL) as the individual's perception of their position in life, considering their cultural context, values, goals, expectations, and concerns. It is a comprehensive and complex concept, influenced by physical health, psychological state, personal beliefs, social relationships, and environmental characteristics. Because it is subjective and multidimensional, QoL is difficult to measure, varying between people and similar contexts due to its dynamic and individual organization.[1-3]

The National Cancer Institute (INCA) describes cancer (CA) as a group of more than 100 diseases caused by genetic mutations, characterized by the disordered and invasive growth of cells that form tumors and can metastasize. Cancer results from the interaction between endogenous and exogenous factors, but most of the causes of childhood tumors are still unknown. Clinically, pediatric tumors tend to develop rapidly and be more aggressive, although they respond better to treatment.[4-7]

In Brazil, it is estimated that there will be 704 thousand new cases of AC between 2023 and 2025. With early diagnosis and appropriate treatment, 80% of children and adolescents diagnosed can be cured or have a good quality of life. The combined use of different treatments has contributed to the longevity of patients. As in developed countries, childhood and adolescent CA is the leading cause of death from diseases, accounting for 8% of all deaths among children and adolescents aged 1 to 19 years.[8]

In pediatric oncology, QoL is often reduced due to the physical and emotional immaturity of children and adolescents. Treatments such as chemotherapy, radiation therapy, surgery, and bone marrow transplantation not only impact physical health but also cause significant adverse effects. These challenges require specialized and humanized care to improve the QoL of children and their families.[9-13]

Measuring Health-Related Quality of Life (HRQoL) is crucial to understanding how patients perceive their own quality of life and the impact of therapies. With the advancement of research and the development of specific tools for pediatrics, the assessment of HRQoL in children considers their understanding of the issues and the disease. Recent instruments favor children's self-reporting, with generic questionnaires assessing HRQoL broadly and specific questionnaires addressing the impact of specific diseases.[15]

The present study aims to identify, present and discuss instruments widely used to assess Health-Related Quality of Life (HRQoL) in children and adolescents with cancer, as well as to analyze its characteristics based on recent literature.

Method

It is an integrative literature review, a method that enables the synthesis of research results on a theme or delimited issue, contributing to the deepening of the investigated theme.[16]

The study focused on the "Analysis of instruments used to measure the quality of life of children and adolescents undergoing cancer treatment", with the objective of identifying the instruments applied in this context. The research question was formulated using the PICo strategy, where 'P' represents the population (children and adolescents), 'I' the interest (quality of life instruments), and 'Co' the context (cancer).[17]

After establishing the guiding question, the following databases were used as a source for surveying the studies: Scientific Electronic Library Online (SciELO), Medical Literature Analysis and Retrieval System Online (MEDLINE/PubMed) and SCOPUS. A search was also carried out on the Virtual Health Library (VHL) portal, specifically in the following databases: Latin American and Caribbean Literature on Health Sciences (LiLACS) and MEDLINE.

The controlled descriptors were pre-established, based on the consultation of the VHL, in the Health Sciences Descriptors (DeCS) and Medical Subject Headings (MeSH). The search for articles was carried out in April 2020, using advanced search of the databases, crossing the descriptors with each other through the Boolean operators "AND" and "OR". The search strategy involved different combinations of the following keywords: "quality of life", "health-related quality of life", "child", "adolescent", "cancer", "neoplasms" and "self-perception". The searches were carried out with the terms in English, as this increases the number of results retrieved, since the scientific literature is mostly published in English. To meet the inclusion criteria, the following filters were also used: English, Portuguese and Spanish. The compound terms were searched in quotation marks, because in search attempts without this resource, most of the articles found addressed topics that were not of interest to this review.

The inclusion criteria were: scientific articles available in full in Portuguese, English and Spanish, with abstracts available; published and indexed in the relevant databases; between 2000 and 2020. Out-of-scope articles, such as dissertations, theses, case reports, opinion articles, and reviews that included out-of-focus groups, such as adults or the elderly, were excluded. The bibliographic material resulting from the search was subjected to a thorough reading to ensure that the articles contemplated the guiding question of the review.

Once the instruments were identified, a new search was performed in the SciELO database to analyze each instrument found. The following search strategy was used: "Questionnaires" AND ("quality-of-life" OR "quality of life" OR "QoL" OR "health-related-quality-of-life" OR "health related quality of life" OR "HRQOL") AND ("child" OR "adolescent"). The references of each article were also checked to obtain articles that could help in the review and that were not identified in the search through the keywords. Manual searches directed to the website of the institution developing the instrument were also included.

The searches in the databases captured 589 references, of which 344 came from MEDLINE (PubMed), 222 from SciELO, 21 from SCOPUS, and 2 from the VHL in the LILACS information base. Of these, 530 articles were excluded. After the deletion of 45 duplicates, 14 studies were selected for full reading, all of which were included in the results of this review.

Results

Six different questionnaires were used in the studies included in this review. It is observed that some studies used more than one instrument to assess QoL. Eight studies used the Pediatric Quality of Life Inventory version 4.0 (PedsQL 4.0) questionnaire for QoL, while two studies used the AC module of the Pediatric Quality of Life Inventory version 3.0 (PedsQL 3.0). Three studies used the KIDSCREEN-52 questionnaire. One study used the European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire (EORTC QLQ-C30 and EORTC QLQ-ELD15). Finally, three questionnaires were used independently, one in each study, to assess the quality of life of children and adolescents. These questionnaires are: Youth Quality of Life Instrument Facial Differences (YQOL-FD), Pediatric Outcomes Data Collection Instrument (PODCI), and Child Health Questionnaire (CHQ). The characterization of the selected studies, according to variables of interest, is shown in Chart 1.

Table 1. Characterization of the selected articles, according to variables of interest. Brasília, DF, 2020.

Year Author, Country, Area of expertise	Title	Objective(s)	Sample	Age Range	Questionnaires
2000 Calaminus *et al.* Estados Unidos Medicina	Quality of life in children and adolescents with cancer. First results of an evaluation of 49 patients with the PEDQOL questionnaire	To assess how children with AC reflect on their QoL compared to healthy children of the same age. And to find out if there are significant differences in QoL between children with hematological disorders and children with solid tumors, which domains are affected.	49 children	8-18 years	PEDQOL
2007 Dijk *et al.* Holanda Psicologia	Health-related quality of life of child and adolescent retinoblastoma survivors in the Netherlands	To evaluate HRQoL in children and adolescents who survived retinoblastoma (RB), using the KIDSCREEN-52 and the proxy-report version.	65 children and adolescents	8-18 years	KIDSCREEN-52
2007 Frances *et al.* Estados Unidos da América Medicina	What is quality of life in children with bone sarcoma?	To evaluate the perceived QoL of children undergoing surgical treatment for primary bone sarcoma.	43 children and adolescents	11-18 years	PODCI
2009 Speyer *et*	Agreement between	To determine the level of agreement in	58 children	9-18 years	CHQ

al. França Medicina	children with cancer and their parents in reporting the child health-related quality of life during a stay at the hospital and at home	HRQoL reports between parents of children with AC and the children themselves during a hospital stay and a stay at home.	and 21 parents	and	
2012 Li *et al.* China Enfermagem	A descriptive study of the psychosocial well-being and quality of life of childhood cancer survivors in Hong Kong	To describe the psychosocial well-being and QoL of Chinese survivors of childhood CA in Hong Kong.	137 survivors of childhood AC	9-16 years	PedsQL 4.0
2014 Van Riel *et al.* Holanda Enfermagem	Self-perception and quality of life in adolescents during treatment for a primary malignant bone tumour	To assess the self-perception and QoL of adolescents during or up to three months after adjuvant treatment of a primary malignant bone tumor.	10 teenagers	15 years	KIDSCREEN-52
2014 Rhee *et al.* Coréia do Sul Psicologia	Impact of psychological and cancer-related factors on HRQoL for Korean childhood cancer survivors	To compare HRQoL between Korean childhood AK survivors and healthy controls, and to examine the impact of demographic, diagnostic/treatment, and psychological variables on physical and psychosocial health in survivors.	110 survivors of childhood AC	8-12 years	PedsQL 4.0
2014 Canning *et al.* Reino Unido Psicologia	Psychological, demographic, illness and treatment risk factors for emotional distress amongst paediatric oncology patients prior to reaching 5-year survivorship status	To determine psychological, demographic, disease, and treatment risk factors for emotional distress among pediatric cancer patients.	74 children and adolescents	12-18 years	PedsQL 4.0 e PedsQL 3.0
2015 Batalha *et al.* Portugal Enfermagem	Quality of life in children with cancer: agreement between children and parents	Describe the HRQoL of children with AC; to evaluate the agreement between self-report and hetero-report; and to identify factors influencing divergences in self-	75 children	8-17 years	PedsQL 3.0

		report and hetero-reporting.			
2016 Baytan *et al.* Turquia Medicina	Health-Related Quality of Life, Depression, Anxiety, and Self-Image in Acute Lymphocytic Leukemia Survivors	To investigate health-related quality of life, depression, anxiety, and self-image among all survivors of acute lymphocytic leukemia.	50 teenagers	13-18 years	PedsQL 4.0
2016 Al-Gamal *et al.* Jordânia Enfermagem	Health-related quality of life and its association with self-esteem and fatigue among children diagnosed with cancer	To identify the links between self-esteem, fatigue and HRQoL for children and young people during and after AC treatment.	70 children	5-16 years	PedsQL 4.0 and PedsQL Multidimensional Fatigue Scale
2017 Cipolletta *et al.* Itália Psicologia	Psychosocial functioning, self-image, and quality of life in children and adolescents with neurofibromatosis type 1	To assess the QoL of children and adolescents with neurofibromatosis type 1, as well as to assess the mental state of this group and their parents, and to compare it with healthy children of the same age.	60 children and adolescents	6-17 years	PedsQL 4.0
2018 Sodergren *et al.* Inglaterra Multiprofissional	Does age matter? A comparison of health-related quality of life issues of adolescents and young adults with cancer	To compare the HRQoL of adolescents and young adults aged 14 to 25 years with those of older adults (26 to 60 years) with WC.	33 young people and 25 old people	14-60 years	EORTC QLQ-C30 e EORTC QLQ-ELD15
2018 Vaarwerk *et al.* Reino Unido Medicina	Psychosocial well-being of long-term survivors of pediatric head–neck rhabdomyosarcoma	To assess the psychosocial well-being of head and neck rhabdomyosarcoma survivors and to examine whether psychosocial outcomes were associated with the burden of therapy.	75 survivors of childhood AC	0-18 years	PedsQL 4.0 e KIDSCREEN-52

Five instruments were identified for the assessment of the HRQoL of children and adolescents, of which three are generic and two are specific. Chart 2 presents a summary of the characteristics of the instruments evaluated.

Table 2. General characteristics of instruments to assess quality of life in children and adolescents. Brasília, DF, Brazil, 2020.

Instrument	**Year of creation**	**Target audience**	**Objective**	**Validation for use in Brazil**	**Can it be applied by any researcher?**
PedsQL 3.0	1998	Individuals between 2 and 18 years of age. Available in versions for children and adolescents and guardians.	To evaluate the impact of the disease and treatment on the QoL of individuals affected by childhood neoplasms.	Scarpelli *et al.* 2007	YES
PedsQL 4.0	1998	Individuals between 2 and 18 years of age. Available in versions for children and adolescents and guardians.	To assess the QoL of healthy individuals or those affected by chronic diseases.	Klatchoian *et al.* 2008	YES
KIDSCREEN-52	2001	Individuals between 8 and 18 years old. Available in versions for children and adolescents and guardians.	Assess and monitor the QoL of children and adolescents.	Guedes *et al.* 2011	YES
EORTC QLQ-C30	1987	Individuals of all age groups.	To assess the QoL of cancer patients.	Pais *et al.* 2008	YES
CHQ	1996	Individuals between 5 and 18 years old. Available in versions for children and adolescents and guardians.	To evaluate the health-related QoL of healthy children and adolescents or those affected by diseases.	Machado *et al.* 2001	YES

Description of the instruments

The PedsQL 3.0 is a multidimensional instrument developed in 1998 to assess the impact of disease and treatment on the health-related quality of life (HRQoL) of pediatric patients with AC. The questionnaire is available in versions for children and adolescents aged 5-7, 8-12 and 13-18 years, as well as versions for guardians of children and adolescents aged 2-4, 5-7, 8-12 and 13-18 years. Children aged 2-4 years do not have a self-report version. The instrument consists of 27 items distributed in 8 subscales: pain and injuries (2 items), nausea (5 items), anxiety about the procedure (3 items), anxiety about the treatment (3 items), worries (3 items), cognitive difficulties (5 items), perception of physical appearance (3 items) and communication (3 items). The application is quick, taking about five min. The final interpretation is based on the score, where a higher score indicates fewer difficulties related to the disease or treatment and, therefore, better QoL.[19]

The PedsQL 4.0 is a generic instrument developed in 1998 to assess HRQoL in children and adolescents with chronic disorders and in healthy children and adolescents. PedsQL 4.0 includes versions for children and adolescents aged 5 to 18 years and for guardians of children and adolescents aged 2 to 18 years. The questionnaire consists of 23 items that cover the physical (8 items), emotional (5 items), social (5 items) and school (5 items) dimensions. The language of the items is adapted to the child's developmental level and to the use of the first and third person. The application is quick, taking about five min. Interpretation is based on the final score, where a higher score indicates better QoL. The scores are calculated by the sum of the items divided by the number of questions answered in each dimension. The instrument was translated and validated for Brazilian culture.[20]

The KIDSCREEN-52 is a generic questionnaire developed in Europe in 2001 to assess and monitor the QoL of children and adolescents, both healthy and with chronic diseases. It includes two versions: one for children and teenagers aged 8-18 and one for parents and guardians (proxy version). The instrument has 52 questions distributed in ten dimensions of HRQoL: health and physical activity, feelings, emotional state, self-perception, autonomy and free time, family/family environment, financial aspect, friends and social support, school environment and teasing/bullying. Both versions evaluate the same components, allowing comparisons between the groups. The interpretation is based on the scores obtained in each dimension, which are recoded on a scale from 0 to 100, where zero indicates the lowest HRQoL and one hundred indicates the highest. The instrument is self-administering, takes about 30 min to complete, and has cross-cultural adaptation for the Brazilian population.[20,21]

The EORTC QLQ-C30 is a multidimensional instrument developed in 1987 by the European Organization for Research and Treatment of Cancer to assess the QoL of patients with AC. The questionnaire is self-administered and independent of the patient's level of education, consisting of 30 items distributed in 16 domains. It is divided into four scales: global health status and quality of life (1 domain and 2 items), functional (5 domains and 15 items), symptoms (9 domains and 12 items), and financial difficulties (1 domain and 1 item).[22,23]

The interpretation of the scales is different: in the Global Measure of Quality of Life and Functional Scales, a high score indicates better QoL, while in the Symptom and Financial Difficulties Scales, a high score indicates greater impairment and, therefore, lower QoL. In all scales, the scores range from 0 to 100. The average application time is 11 min, and the instrument has been translated and validated for use in Brazil.[22,23]

The Child Health Questionnaire (CHQ) is a generic instrument to assess the HRQoL of children and adolescents, both healthy and with chronic diseases. There are four versions of the questionnaire: two for parents (Child Health Questionnaire Parent Form 50 (CHQ-PF50) with 50 items and Child Health Questionnaire Parent Form 28 (CHQ-PF28) with 28 items) and two for children and adolescents (Child Health Questionnaire Child Form 87 (CHQ-CF87) with 87 items and Child Health Questionnaire Child Form 45 (CHQ-CF45) with 45 items). The parent and child/teen versions allow for cross-group comparisons.[20-24]

The CHQ assesses the physical and psychosocial well-being of children and adolescents. It is self-administered, based on the experiences of the last four weeks, except for the global health scale, which must consider the previous year. The time to complete the CHQ varies according to the environment, context, age, and cognitive functioning. CHQ-PF28 takes about 10 min to complete, while CHQ-PF50, with more questions, takes 10-15 min. The instrument is culturally adapted to the Brazilian population.[20-24]

Discussion

The instruments to assess HRQoL are classified as generic and specific. Generics assess the HRQoL of healthy and sick individuals, allowing general comparisons and the identification of specific impacts of different health conditions. Specific areas, on the other hand, measure areas particularly affected by specific diseases. In the last 20 years, there has been low use of new instruments and a lack of publications on new questionnaires, although there has been an increase in cultural adaptations of existing instruments. PedsQL was widely used in studies, possibly due to its translation and validation in several languages.

In one study, the pilot version of PEDQOL was used to assess the quality of life of healthy children and children with childhood neoplasms. The sample included 62 healthy children and 49 children with AC (51% with leukemia and 49% with solid tumors), aged 8 to 17 years. The questionnaire was well accepted, and the children answered independently, with guidance to highlight problematic issues. Nine participants reported difficulties. Quality of life was considered good in both groups, with a slight difference between healthy children and those with AC. Children with AC had greater impairment in physical function. Among children with leukemia or lymphoma, impairment was more pronounced in autonomy, emotional functioning, cognition, and family interactions, while solid tumor survivors reported less impairment, especially regarding physical functioning and body image.[25]

In another study, the HRQoL of retinoblastoma survivors was assessed using KIDSCREEN-52. The research involved 65 participants, including children aged 8 to 11 years, adolescents aged 12 to 18 years, and their parents. The questionnaires were sent by mail, with instructions for independent completion, and help for visual impairments was offered through an adapted computerized version. Parents were contacted to verify the completeness of the questionnaires and ensure that they were filled out correctly. Parents generally rated their children's HRQoL as lower than their own children. Survivors with normal visual acuity had better scores on "physical well-being" compared to those with visual impairment. Participants' age was negatively associated with "psychological well-being" and "self-perception," and visual acuity was also negatively associated with "self-perception." The perceptions of survivors and parents had a low correlation in all dimensions of HRQoL.

In relation to PODCI, a study evaluated the QoL of children undergoing surgical treatment for primary bone sarcoma using this instrument. Three versions of the questionnaire were used: for parents of children under 10 years of age, for parents of adolescents and for adolescents between 11 and 18 years of age. The sample included 19 girls and 24 boys, with a median follow-up of 3 years. The results showed good, but variable, scores in five of the six domains of the PODCI. The "Sports/Physical Function" domain had lower scores in the first 12 months postoperatively, with improvement observed up to 24 months. Factors such as tumor size above 8 cm and location in the lower limbs were negative predictors for "Sports/Physical Function". Gender also influenced the scores, with girls reporting lower scores in "Sports/Physical Function," "Pain/Comfort," and "Global Function." The type of surgery did not significantly affect the perception of QoL. Children with bone sarcoma had lower scores on "Basic Transfer/Mobility" and "Sports/Physical Function" compared to children without an orthopedic or tumor diagnosis.[27]

Unlike the previous ones, a study evaluated the HRQoL of children with AC and their parents during hospitalization and at home, comparing the perceptions of the two groups. The sample included 28 children, aged 9 to 18 years, treated in a hospital, and used two versions of the CHQ: one for parents and one for children. The questionnaires were completed separately at the beginning and end of hospitalization. Agreement between parents and children varied according to location: during hospitalization, agreement was higher for domains such as mental health and self-esteem, while at home, it was higher for physical function and family activities. Scores were lower during hospitalization than at home.[28]

A study conducted in Hong Kong evaluated the psychosocial well-being and quality of life of 137 Chinese child survivors of childhood AC, aged between 9 and 16 years. The sample was equally distributed between boys and girls, with 56.9% of the participants having leukemia and 21.9% having lymphoma. Using PedsQL 4.0, the children filled out the questionnaire autonomously. After data collection, they received material on mental health, including exercises for depression and relaxation. The study found that many survivors had low self-esteem and high levels of depression due to the adverse effects of the treatment. Symptoms of depression were associated with greater anxiety, low self-esteem, and lower quality of life.[29]

Another study using the same instrument assessed the HRQoL of Korean childhood AK survivors compared to healthy controls and examined the impact of demographic, diagnostic/treatment, and psychological variables. Survivors reported significantly lower scores on the physical and psychosocial dimensions of HRQoL compared to controls. Variables such as self-concept, time since treatment completion, history of stem cell transplantation, multiple treatment modalities, and severe late effects explained more than 50% of the variation in survivors' physical and psychosocial HRQoL.[30]

Regarding adolescents, one study evaluated the self-perception and QoL of 10 adolescents with primary malignant bone tumor during treatment and up to three months after, comparing them with two healthy pairs. Using the KIDSCREEN-52 questionnaire, the results showed that adolescents with bone tumor reported consistently lower scores in physical well-being, autonomy, social support, and school environment, both during treatment and after three months. Self-perception scores were similar between the study and control groups.

Also with adolescents, another study used versions 3.0 of the cancer module and 4.0 of the generic module of PedsQL to evaluate 74 pediatric cancer patients aged between 12 and 18 years. Both questionnaires were applied independently, without the presence of parents. The results revealed that pain, hurt, concerns about the disease, communication difficulties, negative self-image regarding mathematical skills, and relationships with parents and peers of the opposite sex were risk factors for emotional distress. The study highlighted modifiable psychological factors and provided guidelines for future interventions.[32]

Unlike the others, one study evaluated the HRQoL of 75 children with AC and compared the children's self-reports with the parents' heteroreports using PedsQL 3.0. Both questionnaires were completed separately and simultaneously at the hospital. The results showed that children reported a more positive HRQoL than their parents, possibly due to parents' projection of their own concerns about their children's lives. In the self-report, the highest scores were in the subscales "perception of physical appearance" and "anxiety in treatments", while in the hetero-report, they were in the subscales "communication" and "perception of physical appearance". The worst-scoring subscale was "concern" in both reports, reflecting concerns about the effects of treatment, its efficacy, and disease recurrence.[33]

In the case of AC remission, a study investigated the HRQoL of 50 survivors of childhood Lymphoblastic Leukemia (ALL) in remission, aged between 13 and 18 years, compared to healthy siblings. PedsQL 4.0 was used, applied independently in both groups. The results showed that the children who survived ALL had more intense symptoms of depression and anxiety, a negative self-image, and lower HRQoL than their siblings. Physical, psychological, and total life qualities were significantly lower among ALL survivors.[34]

With a slightly larger sample, another study investigated the relationship between self-esteem, fatigue and HRQoL in 70 children and young people during and after cancer treatment. Using the PedsQL 4.0 and the Pediatric Quality of Life Inventory Multidimensional Fatigue Scale, a significant positive correlation was found: lower fatigue symptoms were associated with higher HRQoL scores. Children with high levels of fatigue had a lower quality of life. Thus, other researchers examined the QoL of children with Neurofibromatosis type 1 (NF1) compared to a control group. The sample included 60 children with NF1, 60 parents of these children, and 60 healthy children and parents, aged 6 to 17 years. Using PedsQL 4.0, the study revealed that children with NF1 had a lower quality of life compared to their healthy peers. Parents of children with NF1 expressed greater concerns about their children's sociability and school performance.[35,36]

One study compared HRQoL among adolescents (14-25 years) and adults (26-60 years) with AC, using the EORTC QLQ-C30 for adolescents and the Elderly 15 version for adults. The results showed that the emotional impact was relevant in both groups, with equally low scores and no significant differences between ages. Quality of life was better evaluated by adolescents, who reported that their concerns were more related to the interruption of daily activities.[37]

Finally, the latest study in this review assessed the long-term psychosocial well-being of 65 paediatric head and neck rhabdomyosarcoma survivors, with a median follow-up of 11 1/2 years. Using the PedsQL questionnaires and the KIDSCREEN-52 self-perception domain, survivors reported significantly lower scores in the school and professional domains.

Although there was no significant difference in self-perception scores compared to reference values, participants had a negative self-image and reported disease-specific consequences. The low quality of life and self-perception scores were attributed to the disease, not to the adverse effects of the treatment.[38]

All 14 studies analyzed used the same methodology for applying the questionnaires, that is, independently, without the interference of third parties. Among the questionnaires studied, four have versions for children or adolescents and for parents or guardians: PedsQL 3.0, PedsQL 4.0, KIDSCREEN-52 and CHQ. The EORTC QLQ-C30 has a single version for all ages, which can make it difficult for children to interpret. Having different versions allows researchers to choose the most appropriate instrument for the study and makes it possible to compare different groups.[39,40]

In terms of application time, the questionnaires vary significantly. KIDSCREEN-52, with 30 min of application and a high number of questions, is the longest. The EORTC QLQ-C30 takes about 11 min, while the CHQ takes about 10 min, with variation depending on the version. Both versions of PedsQL have the shortest application time, about 5 min. All questionnaires are self-administered, but the PedsQL can be administered by the interviewer.

The instruments evaluated measure quality of life based on the child's perception, but the KIDSCREEN-52 does not cover all age groups in childhood, which may limit the expression of children's opinions. The review highlights the importance of using these instruments to monitor and improve patients' quality of life, which is fundamental for care and planning in pediatric nursing.

Final Considerations

In view of the above, and after deepening the content of the scientific production found, it was observed that there is a reasonable number of questionnaires to assess the Health-Related Quality of Life (HRQoL) of children and adolescents diagnosed with cancer. Among them, PedsQL and KIDSCREEN-52 stand out, which are self-applicable and validated for use in Brazil.

This study shows the scarcity of national instruments, which reflects the difficulty of the scientific community in developing tools to assess quality of life, given that it is a subjective construct. It is known that, in order to create questionnaires to assess HRQoL, the stage of the child's cognitive development should be considered, as well as the sociocultural diversity of the country. There is a gap in the production of studies on this theme in the Brazilian context.

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References

1. World Health Organization. WHO | WHOQOL: Measuring quality of life. Whoint [Internet]. 2014 Mar 11; Available from: https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/

2. Rocha RS, Pinheiro LP, Oriá MOB, Ximenes LB, Pinheiro AKB, Aquino P de S. Determinantes sociais da saúde e qualidade de vida de cuidadores de crianças com câncer. Rev Gaúcha Enferm [Internet]. 2016;37(3):e57954. Available from: https://doi.org/10.1590/1983-1447.2016.03.57954

3. Pereira ÉF, Teixeira CS, Santos A dos. Qualidade de vida: abordagens, conceitos e avaliação. Rev bras educ fís esporte [Internet]. 2012Apr;26(2):241–50. Available from: https://doi.org/10.1590/S1807-55092012000200007

4. Brasil. Estimativa 2023: incidência de câncer no Brasil [Internet]. INCA - Instituto Nacional de Câncer. 2023. Available from: https://www.inca.gov.br/publicacoes/livros/estimativa-2023-incidencia-de-cancer-no-brasil.

5. Brasil. O que é câncer? [Internet]. INCA - Instituto Nacional de Câncer. 2018. Available from: https://www.inca.gov.br/o-que-e-cancer

6. Garófolo A, Avesani CM, Camargo KG, Barros ME, Silva SRJ, Taddei JA de AC, *et al.*. Dieta e câncer: um enfoque epidemiológico. Rev Nutr [Internet]. 2004Oct;17(4):491–505. Available from: https://doi.org/10.1590/S1415-52732004000400009

7. Brasil. Câncer infantojuvenil [Internet]. INCA - Instituto Nacional de Câncer. 2018. Available from: https://www.inca.gov.br/tipos-de-cancer/cancer-infantojuvenil

8. Reis RS, Santos MO, Thuler LCS. Incidência de tumores pediátricos no Brasil. Rev. Brasileira de Cancerologia, 2007; 53(1): 5-15.

9. Stenmarker E, Mellgren K, Matus M, Schroder Hakansson A, Stenmarker M. Qualidade de vida, cultura e comunicação relacionadas à saúde: um estudo comparativo em crianças com câncer na Argentina e na Suécia. J Resultados do representante do paciente. Dezembro de 2018; 2 (1): 49.

10. Nunes MDR, Nascimento LC, Fernandes AM, Batalha L, de Campos C, Gonçalves A, *et al.* Dor, padrões de sono e qualidade de vida relacionada à saúde em pacientes pediátricos com câncer. Eur J Cancer Care [Internet]. Julho de 2019 [citado 1º de outubro de 2020]; 28 (4). Disponível em: https://onlinelibrary.wiley.com/doi/abs/10.1111/ecc.13029

11. Aguilar BA. A eficácia da arteterapia em pacientes pediátricos oncológicos: uma revisão integrativa da literatura. Revista de Enfermagem Pediátrica. Setembro de 2017; 36: 173-8.

12. Abdulah DM, Abdulla BMO. Eficácia da terapia de arte em grupo na qualidade de vida em pacientes pediátricos com câncer: um ensaio clínico randomizado. Terapias Complementares em Medicina. Dezembro de 2018; 41: 180-5.

13. BRASIL. Ministério da Saúde. Instituto Nacional de Cancer Jose Alencar Gomes da Silva (INCA). Diagnóstico precoce do câncer na criança e no adolescente. 2. ed. Rio de Janeiro, 2014. p. 81.

14. Guyatt GH, Cook DJ. Estado de saúde, qualidade de vida e indivíduo. JAMA. 24 de agosto de 1994; 272 (8): 630-1.

15. Roncada C, Mattiello R, Pitrez PM, Sarria EE. Instrumentos específicos para avaliar a qualidade de vida em crianças e adolescentes com asma. J Pediatr (Rio J) [Internet]. 2013May;89(3):217–25. Available from: https://doi.org/10.1016/j.jped.2012.11.010

16. Mendes KDS, Silveira RC de CP, Galvão CM. Revisão integrativa: método de pesquisa para a incorporação de evidências na saúde e na enfermagem. Texto contexto - Enferm [Internet]. 2008Oct;17(4):758–64. Available from: https://doi.org/10.1590/S0104-07072008000400018

17. Santos CM da C, Pimenta CA de M, Nobre MRC. A estratégia PICO para a construção da questão de pesquisa e busca de evidências. Rev Latino-Am Enfermagem. junho de 2007; 15 (3): 508–11.

18. PORTAL DE PERIÓDICOS CAPES/MEC. Disponível em: www.periodicos.capes.gov.br. Acesso em 21 maio 2020.

19. Scarpelli AC, Paiva SM, Pordeus IA, Ramos-Jorge ML, Varni JW, Allison PJ. Measurement properties of the Brazilian version of the Pediatric Quality of Life Inventory (PedsQLTM) cancer module scale. Health and Quality of Life Outcomes. 2008;6(1):7. https://doi.org/10.1186/1477-7525-6-7

20. Souza JGS, Pamponet MA, Souza TCS, Pereira AR, Souza AGS, Martins AME de BL. Tools used for evaluation of Brazilian children's quality of life. Rev paul pediatr [Internet]. 2014Jun;32(2):272–8. Available from: https://doi.org/10.1590/0103-0582201432214313

21. Guedes DP, Guedes JERP. Tradução, adaptação transcultural e propriedades psicométricas do KIDSCREEN-52 para a população brasileira. Rev paul pediatr [Internet]. 2011Sep;29(3):364–71. Available from: https://doi.org/10.1590/S0103-05822011000300010

22. Campos JADB, Spexoto MCB, Silva WR da, Serrano SV, Marôco J. European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30: factorial models to Brazilian cancer patients. Einstein (São Paulo) [Internet]. 2018;16(1):eAO4132. Available from: https://doi.org/10.1590/S1679-45082018AO4132

23. Vendrusculo, LM. Capacidade funcional e qualidade de vida de mulheres com câncer de mama após o tratamento oncológico [dissertação]. Ribeirão Preto: Universidade de São Paulo, Escola de Enfermagem de Ribeirão Preto; 2011 [citado 2020-10-10]. Doi:10.11606/D.22.2011.tde-15082012-135511.

24. Morales, NMO. Avaliação transversal da qualidade de vida em crianças e adolescentes com paralisia cerebral por meio de um instrumento genérico (CHQ-PF50). Repositorioufubr [Internet]. 2013; Available from: https://repositorio.ufu.br/handle/123456789/

25. Calaminus G, Weinspach S, Teske C, Gobel U. Qualidade de vida em crianças e adolescentes com câncer – Primeiros resultados de uma avaliação de 49 pacientes com o questionário PEDQOL® -. Klin Padiatr. Agosto de 2000; 212 (4): 211-5.

26. Van Dijk J, Huisman J, Moll AC, Schouten-van Meeteren AY, Bezemer PD, Ringens PJ, *et al.* Qualidade de vida relacionada à saúde de crianças e adolescentes sobreviventes de retinoblastoma na Holanda. Resultados de Saúde Qual Life. Dezembro de 2007; 5 (1): 65.

27. Frances JM, Morris CD, Arkader A, Nikolic ZG, Healey JH. O que é qualidade de vida em crianças com sarcoma ósseo? Ortopedia clínica e pesquisas relacionadas. Junho de 2007; 459: 34-9.

28. Speyer E, Herbinet A, Vuillemin A, Chastagner P, Briançon S. Acordo entre crianças com câncer e seus pais no relato da qualidade de vida relacionada à saúde da criança durante a permanência no hospital e em casa. Criança: Cuidado, Saúde e Desenvolvimento. julho de 2009; 35 (4): 489–95.

29. Li HCW, Chung OKJ, Ho KYE, Chiu SY, Lopez V. Um estudo descritivo do bem-estar psicossocial e da qualidade de vida de sobreviventes de câncer infantil em Hong Kong: Cancer Nursing. 2012; 35 (6): 447–55.

30. Rhee MA, Chung KM, Lee Y, Choi HK, Han JW, Kim HS, *et al.* Impacto de fatores psicológicos e relacionados ao câncer na QVRS para sobreviventes de câncer infantil coreanos. Qual Life Res. Novembro de 2014; 23 (9): 2603-12.

31. Van Riel CA, Meijer-van den Bergh EE, Kemps HL, Feuth T, Schreuder HW, Hoogerbrugge PM, De Groot IJ, Mavinkurve-Groothuis AM. Self-perception and quality of life in adolescents during treatment for a primary malignant bone tumour. Eur J Oncol Nurs. 2014 Jun;18(3):267-72.

32. Canning S, Bunton P, Talbot Robinson L. Fatores de risco psicológicos, demográficos, de doença e de tratamento para estresse emocional entre pacientes oncológicos pediátricos antes de atingir o status de sobrevivência de 5 anos: sofrimento emocional entre pacientes oncológicos pediátricos. Psico-Oncologia. novembro de 2014; 23 (11): 1283–91.

33. Batalha LMC, Fernandes AM, Campos C de. Qualidade de vida em crianças com câncer: concordância entre relatos de crianças e pais. Escola Anna Nery – Revista de Enfermagem [Internet] 2015 [citado em 6 de novembro de 2020]; 19 (2). Disponível em: http://www.gnresearch.org/doi/10.5935/1414- 8145.20150039

34. Baytan B, AşutÇ, Çirpan Kantarcıoğlu A, Sezgin Evim M, Güneş AM. Health-Related Quality of Life, Depression, Anxiety, and Self-Image in Acute Lymphocytic Leukemia Survivors Turk J Haematol. 2016; 33 (4): 326-330.

35. Al-Gamal E, Long T. Qualidade de vida relacionada à saúde e sua associação com autoestima e fadiga em crianças com diagnóstico de câncer. J Clin Nurs. Novembro de 2016; 25 (21-22): 3391-9.

36. Cipolletta S, Spina G, Spoto A. Funcionamento psicossocial, autoimagem e qualidade de vida em crianças e adolescentes com neurofibromatose tipo 1. Puericultura. Março de 2018; 44 (2): 260-8.

37. Sodergren SC, Husson O, Rohde GE, Tomaszewska IM, Griffiths H, Pessing A, *et al.* A idade importa? Uma comparação de questões de qualidade de vida relacionada à saúde de adolescentes e adultos jovens com câncer. Eur J Cancer Care. Novembro de 2018; 27 (6): e12980.

38. Vaarweck B, Schoot RA, Maurice-Stam H, Slater O, Hartley B, Saeed P, *et al.* Bem-estar psicossocial de sobreviventes de longo prazo de rabdomiossarcoma

pediátrico de cabeça-pescoço. Pediatr Blood Cancer. Fevereiro de 2019; 66 (2): e27498.

39. Machado CSM. A versão brasileira do questionário de avaliação de saúde infantil (Chaq) e do questionário de saúde infantil (Chq) [dissertação]; Disponível em: https://repositorio.ufu.br/bitstream/123456789/12702/1/NMOMoralesDISSPRT.pdf

40. Klatchoian DA, Len CA, Terreri MTRA, Silva M, Itamoto C, Ciconelli RM, *et al.*. Qualidade de vida de crianças e adolescentes de São Paulo: confiabilidade e validade da versão brasileira do questionário genérico Pediatric Quality of Life InventoryTM versão 4.0. J Pediatr (Rio J) [Internet]. 2008Jul;84(4):308–15. Available from: https://doi.org/10.1590/S0021-75572008000400005

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