DOI: 10.1590/1413-81232022278.22132021EN

Predominant approaches in studies on health-related quality of life of young survivors of childhood or adolescent cancer: an integrative literature review

María Pía Majdalani (https://orcid.org/0000-0002-6168-8932) [1]
Marcio Alazraqui (https://orcid.org/0000-0002-6507-0208) [2]

Abstract *Survivors of childhood cancer constitute a growing population. The disease experienced, its treatment or the occurrence of late complications may affect survivors' health-related quality of life (HRQOL). Understanding HRQOL is a challenge due to its conceptual complexity and the mode in which it is studied. Objective: To identify the predominant lines of research in the study of HRQOL in this population. Methods: An integrative literature review was carried out, involving a systematic search of primary articles indexed in the Scopus and PubMed databases. Results: In the 48 publications selected, four main lines of research were identified: HRQOL in survivors in general; HRQOL in long-term survivors; the study of determinants of HRQOL; and the study of methodological aspects of HRQOL measurement. A quantitative approach using generic measurement instruments predominates, and the conceptual model of HRQOL based on function emphasizes the importance of physical, psychological, and social functionality and the impact of the disease and treatment on these aspects. Conclusions: incorporating a qualitative, meaning-based approach to the understanding of lived experiences from a subjective and holistic perspective is indispensable.*

Key words *Quality of life, Survivors, Cancer, Review*

[1] División de Medicina Interna General, Hospital de Clínicas "José de San Martín", Universidad de Buenos Aires. Buenos Aires Argentina. piamajdalani@yahoo.com.ar
[2] Instituto de Salud Colectiva, Universidad Nacional de Lanús. Buenos Aires Argentina.

Introduction

Multimodal oncological therapy for the treatment of patients with cancer in childhood or adolescence has brought about, since the 1980s, a marked and progressive increase in survival. The World Health Organization (WHO) reports that, in high-income countries, approximately 80% of children with cancer survive five years or more after their diagnosis[1]. In Argentina, the estimated overall survival rate five years after diagnosis for the period 2005-2014 was 67.6%[2]. According to reports from the Surveillance, Epidemiology and End Results (SEER) program of the National Cancer Institute of the US, the five-year survival rate in children under 15 years of age for the period 1980-1984 was 67.9% and for the period 2008-2014 it was 83.4%. These percentages reflect positive aspects of treatment, although the success rate differs among high-, middle- and low-income countries[3]. Based on improvements achieved in therapies, there is a growing population of long-term survivors of cancers in childhood or adolescence who continue to need health care. In the last decades, observational studies carried out in different populations of survivors of cancer in childhood and adolescence showed an increase in the proportion of late effects of treatment and chronic mid- to long-term health conditions, as compared to people of the same age who did not experience oncological diseases[4-6]. The most frequent effects include: respiratory, cardiac or endocrine diseases of varying severity, and the compromising of sexual and reproductive health; survivors also have a higher risk of experiencing other neoplasms and therefore a higher risk of early death. Other effects that have been described include: compromising of psychosocial wellbeing and difficulties in accessing social security benefits and in school and labor force insertion[3,6], in both females and males affected by different neoplasms and receiving different treatments[7].

Nevertheless, studies looking at quality of life (QOL) and health-related quality of life (HRQOL) in this population are relatively new and complex. The studies on HRQOL in childhood cancer survivors differ in their findings, in which not all experiences of cancer are related to a lower health-related quality of life[8]. The factors most frequently related to a lower quality of life include difficulties in social and labor force insertion, problems within the context of the family, lower levels of education and income, and obstacles in accessing health care, in addition to sequelae and developmental disorders[9]. Although its individuals have in common the positive results achieved in the treatment of an oncological disease, the population is heterogenous with respect to the social support available and the possibilities of dealing with eventual post-treatment sequelae and satisfying health care needs[10].

Although the measurement of HRQOL emerges as necessary for overcoming and complementing the evaluations centered on the disease and the therapeutic interventions and for incorporating the perception of the subject that experiences them[11], its implementation is not simple. Since 2003 different initiatives have incorporated, as a strategy for improving health care for childhood cancer survivors, the measurement of HRQOL as an essential element in the assessment of treatment. Nevertheless, the multiplicity of aspects involved in the concept and the diversity of instruments utilized to explore HRQOL make its study difficult[10].

Given the complexity of the issue, we consider it relevant to explore the predominant approaches to the study of HRQOL in this population in original published research, identifying the primary lines of research, the aspects highlighted as mediators in the perception of HRQOL, and the evaluation methodologies employed in its study. The purpose of this integrative review is to contribute to the comprehension of the contributions and limitations of the predominant approaches in the study of HRQOL in young adults who survived cancer in their childhood or adolescence.

Objective

To identify and describe the predominant lines of research in indexed publications regarding the study of the health-related quality of life (HRQOL) of survivors of cancer in childhood and adolescence.

Methods

An integrative literature review was carried out with the aim of identifying, obtaining, analyzing and synthesizing the selected publications and contributing knowledge regarding the topic[12], following the stages suggested for the development of this type of research[13]: 1) identification of the topic and research question to carry out the review; 2) establishing the inclusion and ex-

Ciência & Saúde Coletiva, 27(8):3063-3077, 2022

clusion criteria and specification of the literature search strategy; 3) categorization of the selected studies; 4) detailed evaluation of the studies included; 5) interpretation of the results; 6) presentation of the revision or knowledge synthesis.

The reflections brought about by the first stage led to the establishment of a study purpose and aim for this review. In order to move to the second stage, a search in the multidisciplinary electronic database Scopus and in the PubMed database was carried out. Assuming that the term "health-related quality of life" could be expressed in the search fields as "quality of life" and in order to better capture publications that could use the term "quality of life" to refer to "health-related quality of life," two search strategies were applied simultaneously. For each of these the terms used were: 1) "childhood cancer survivors" AND "quality of life" AND (hasabstract[text] AND Humans[Mesh] AND adult[MeSH]=; and 2) "childhood cancer survivors" [Title/Abstract] AND "health related quality of life"[Title/Abstract]) AND (hasabstract[text] AND Humans[Mesh] AND adult[MeSH]). The search fields chosen were Title and Abstract. No limits were placed regarding the type of publication nor the year of publication in order to discover what type of publications exist regarding this topic and their time of production (until March 2019). The limits applied included: 1) the availability of the abstract text and 2) regarding the population, humans and 19 years of age or over, since the population of interest was adult. It should be considered that this work was carried out in the framework of a care center for adult survivors of childhood cancer. After reading the title and abstract of the articles obtained, only original research articles whose primary outcome was the measurement of HRQOL in adult women and men who had received and completed treatment for an oncological disease in their childhood or adolescence (as the definition chosen for survivors of cancer in childhood or adolescence) were included.

For the third and fourth stage, a detailed reading was carried out of each text to categorize the selected publications based on the presence of common patterns among them, considering the existence of two primary (and perhaps complementary) conceptual models underlying the methodologies for exploring HRQOL in survivors of cancer in childhood or adolescence: a model based on function, oriented at evaluating the functional capacities of the individual, and another directed at exploring the meaning of lived experiences[14].

During the fourth stage, based on a detailed evaluation of the objectives and aspects examined in each study as possible modulators of the perception of HRQOL, four primary research lines were identified, and the articles were grouped by approach:

. Those focused on biomedical aspects that affect the perception of HRQOL.

. Those focused on the relationship between survival time and HRQOL.

. Those focused on psycho-social, cultural or behavioral aspects that influence HRQOL.

. Those focused on the evaluation of instruments for measuring HRQOL.

Based on the previous stages and in order to respond to this review's proposed objective, in the fifth stage an analysis of the corpus of selected articles was carried out, the development of which is presented in the results section. In the sixth stage, a synthesis is made of the primary aspects that allow for the identification of the predominant approaches of HRQOL in childhood cancer survivors as well as the contributions and limitations of those approaches (expressed in the results, discussion and conclusions).

Results

In the initial search, 221 publications were obtained from Scopus and 119 from PubMed. After eliminating the articles duplicated in each database and among the two databases, 165 articles remained that went on to the stage of evaluation of eligibility based on title and abstract. In this stage, 91 articles were eliminated for not meeting the inclusion criteria and another 11 were eliminated because they were reviews and not original research studies. The reasons for elimination centered on not having as a primary objective the study of HRQOL in adult survivors of childhood cancer, such as studies carried out in oncological patients during their treatment or in survivors under 18 years of age, studies directed at the HRQOL of families or caretakers, evaluations of strategies or interventions to improve quality of life, or reviews. Of the 63 publications remaining, 48 were included for analysis. After a full-text reading, 15 articles were excluded for not fulfilling the inclusion criteria (Figure 1). Of the 48 articles selected, 37 had the objective of evaluating HRQOL in survivors of childhood cancer and 11 aimed to study aspects related to the mediation of HRQOL in this population. The majority of the articles were published between

2001-2019. Cuadro 1 details all of the articles included in this review, according to their classification for analysis, first author and publication year. Among the first group of 37, 10 were carried out in survivors of a specific cancer (three in survivors of leukemia survivors[15-17], two in lymphoma survivors[18,19], one in bone tumor survivors[20], one in rhabdomyosarcoma survivors[21], one in Wilms tumor survivors[22], one in head and neck tumor survivors[23], one in survivors of tumors of the central nervous system[24], and 27 in populations of survivors of different types of cancer[25-51]. Among the 11 works with the objective of studying specific aspects mediating HRQOL, 8 looked at the development, validation, comparison or evaluation of different instruments to measure health-related quality of life[52-59] and in only three questions of clinical significance, response bias or possible missing content in the study of HRQOL were examined[60-62].

Following a detailed reading, and responding to the stated objective, all the texts were organized according to two primary topics. The first sought to highlight the primary lines of research identified in the study of HRQOL in this population, based on an analysis of the primary objective of each publication, and the second the considerations regarding the instruments for measuring HRQOL applied in the studies and the dimensions explored by these instruments.

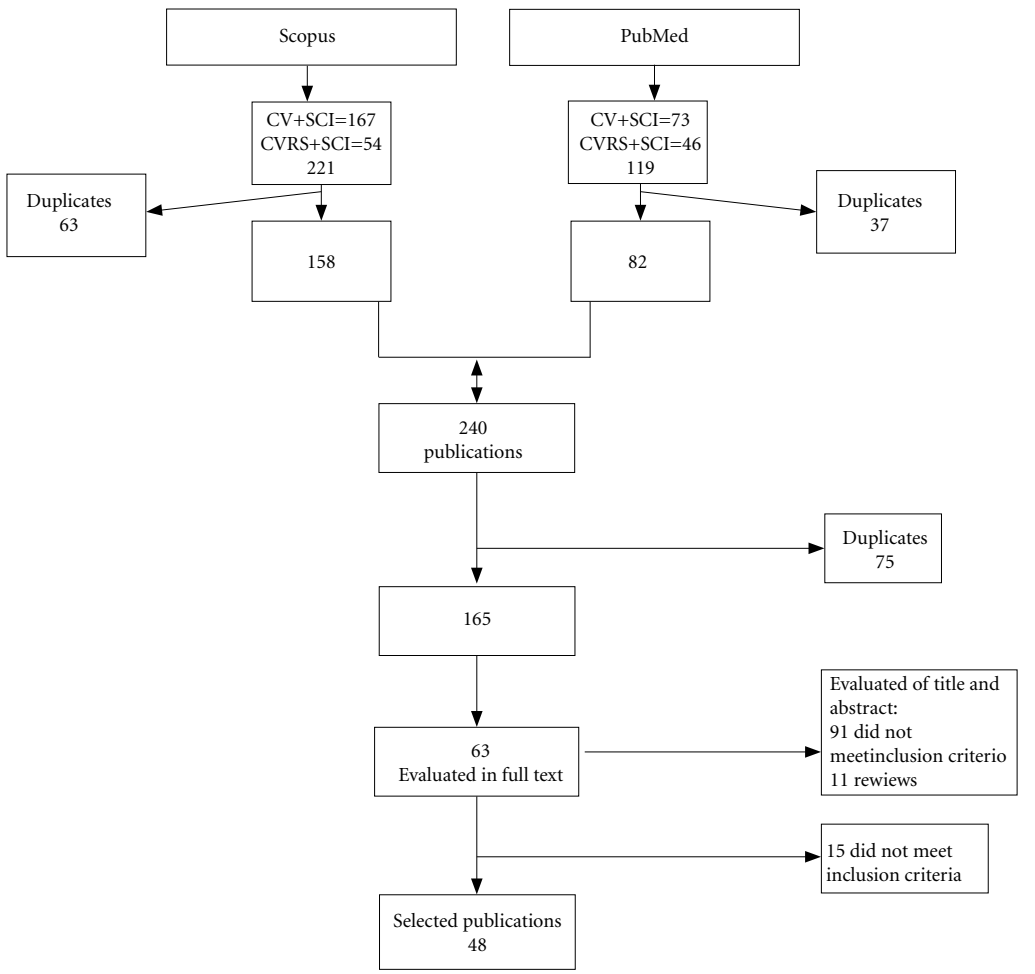

Figure 1. Flow chart of article selection for the literature review.

QOL: quality of life; HRQOL: health-related quality of life; CCS: childhood cancer survivors.

Source: Authors.

Ciência & Saúde Coletiva, 27(8):3063-3077, 2022

Based on these overarching topics, we can highlight the following:

1) *Primary lines of research identified and relevant aspects of each* (Cuadro 2).

a) Research focused on biomedical aspects that can affect the perception of HRQOL: studies the primary objective of which was to measure HRQOL in survivors of cancer in childhood or

Chart 1. Original articles included in the review, in each line of research.

HRQOL in survivors of cancer in childhood or adolescence with a focus on biomedical aspects.					
First author, year	**Total n, age (years)**	**Type of cancer**	**Outcomes**	**Instrument**	**Comparisons**
Pemberger S, 2004	78, 22.6 ± 3.8	Various	HRQOL and chronic health conditions	SF36	------
Punyko J, 2007	417 vs 2685, >18	Rhabdomyosarcoma	Physical deterioration and social adaptation	Designed for the study	Siblings
Nathan P, 2007	654 y 432, 18-34	Wilms y Neuroblastoma	HRQOL	SF-36	Between the two types of cancer
Ness K, 2008	7.147, > 18	Various	HRQOL, functional limitations	SF36	General population
Zeltzer L, 2008	7.147 vs 308, 32 (18-54)	Various	HRQOL, Life satisfaction, chronic health conditions	SF36	Siblings
Nagarajam R, 2009	629, > 21 years	Lower extremity bone tumors	QOL, Physical function	QOL-CS	------
Zebrack B, 2010	599, 27 ± 5.5	Various	HRQOL, sexual function, and emotional distress	SF36 MO Sexual Function	------
Ishida Y, 2010	185 vs 1.000, 23.2 ± 4.9	Various	HRQOL	SF36	General population and QOL without bone marrow transplant
Ishida Y, 2010	185 vs 1.000, 24 ± 5	Various	Disfigurement, HRQOL and emotional distress	SF 36	General population and QOL without radiotherapy
Ishida Y, 2011	184 vs 72, 23.1 ± 4.9	Various	HRQOL, chronic health conditions	SF36	Siblings
Kinahan K, 2012	14.358 vs 4.023	Various	HRQOLand psychological distress	SF36	Siblings
Rueegg C, 2013	1.593 vs 695, 25 ± 6.9	Various	HRQOL	SF36	Siblings
Chan C, 2014	614 vs 208, 21.9 ± 5.6	Various	QOL and chronic conditions	SF36	Siblings
Rhee M, 2014	110, 8-18	Various	HRQOL and symptoms of emotional distress	PedsQL	Healthy controls
Corella Aznar E, 2019	54, > 18	Acute leukemia	HRQOL and symptoms of emotional distress	SF36 and interview	---

it continues

Chart 1. Original articles included in the review, in each line of research.

First author, year	Total n, age (years)	Type of cancer	Outcomes	Instrument	Comparisons
Tremolada M, 2018	32 vs 28, 19.4 ± 3.8	Various	HRQOL and comorbidities after radiotherapy with proton beam	SF36	Healthy controls
Fukushima H, 2017	17	Head or neck tumors	HRQOL and comorbidities after radiotherapy with proton beam	PedsQL	----
Halvorsen J, 2018	91 vs 223, 24,7 ± 2,77	Various	HRQOL, late effects, distress, received treatment	PedsQL for young adults	Healthy controls

HRQOL in survivors of cancer in childhood or adolescence focused on long-term survival

First author, year	N, age (years)	Type of cancer	Outcomes	Instrument	Comparisons
Blaauwbroek R, 2007	123, 19-50 years	Various	HRQOLand long-term late effects	RAND-36	Controls
Blaauwbroek R., 2007	333, 20-60 years	Various	HRQOLand long-term late effects	RAND-36	Controls
Alessi D, 2007	691 de 1005, > 18 years	Various	HRQOLand long-term late effects	HUI	----------
Kenney L, 2010	55 de 88, 51-71 years	Various	Health statusandHRQOL	SF-36	Controls
Harila M, 2010	74, 17-37 years	Acute L Leukemia	HRQOL	RAND-36	Controls
Essig S, 2012	457, > 16 years	Acute L Leukemia	HRQOL	SF-36	Controls
Calaminus G, 2013	1202, M 26.7 years	Hodgkin's Lymphoma	HRQOL	EORTC-QLQ-C30	Controls

HRQOL in survivors of cancer in childhood or adolescence focused on psychosocial or behavioral aspects

First author, year	N, age (years)	Type of cancer	Outcomes	Instrument	Comparisons
Casillas J, 2006	27 Latinos 18-32 years and 30 non -latinos, 18-37	Various	HRQOL	SF-12 Qualitative: focus group and telephone interview	Latinos vs non-latinos
Servitzoglou M, 2008	103, 19.8	Various	HRQOLand psychosocial functioning	SF-36	Control
Cantrell MA, 2008	35, 22-28	Various	HRQOLand determinants (self-esteem, social and affective support)	MMIQL	----------
Mört S, 2011	271, ND	Various	HRQOLand factors associated with the disease	SF-36 y 15D	Control
Badr H, 2013	170, ND	Various	HRQOL, lifestyles, medical variables	PEDQ	----------
Hocking M, 2015	34 child/mother dyads	CNS Tumor	HRQOLand cognitive function, mediated by the family	POQOLS	----------
Huang I-Chan, 2017	7103, average 31.8±7.5	Various	HRQOLand emotional stress	SF-36	Control

it continues

Chart 1. Original articles included in the review, in each line of research.

First author, year	N, age (years)	Type of cancer	Outcomes	Instrument	Comparisons
Cantrell MA, 2017	95 women, 22.5±2.5	Various	HRQOLpre- and post-intervention regarding care of self-esteem and hope	MMIQL	----------
Zhang F, 2018	2480, ND	Various	HRQOLand modifiable lifestyle factors	SF-36	----------
Wogksch M, 2018	336, 19.1-60.6	Various	HRQOL, chronic diseases and physical exercise	SF-36	Control
Ritt-Olson A, 2018	194, 20.75	Various	HRQOL, depression, gender and culture	PedsQL	Latinos vs no latinos
Dixon S, 2019	white/non-Hispanic 600 black/non-Hispanic 821 Hispanic	Various	Racial and ethnic disparities in neurocognitive, emotional and HRQOL outcomes	SF-36	Hermanos

Studies for the development, validation or adaptation of instruments for measuring HRQOL in survivors of cancer in childhood or adolescence	
Author, year	**Objective**
Zebrack B, 2001	Psychometric evaluation of Quality of Life-Cancer Survivors (QOL-CS)
O'Leary T, 2007	Effects of response bias on self-reported quality of life among childhood cancer survivors
Zebrack B, 2010	Psychometric evaluation of the Impact of Cancer (IOC-CS) scale for young adult survivors of childhood cancer
Huang I-Chang, 2012	Comparison of two instruments for measuring HRQOL in young adult survivors of cancer (QOL-CS y YASCC)
Huang I-Chang, 2012	Development of an instrument for measuring HRQOL (YASCC) in survivors of childhood cancer based on three legacy measures
Jervaeus A, 2013	Psychometric properties of KIDSCREEN-27 among childhood cancer survivors
Quinn G, 2013	Missing content in the evaluation of HRQOL
Jervaeus A, 2014	Clinical significance in self-rated HRQOL using KIDSCREEN-27 demonstrated by qualitative anchor-based thresholds
Koike M, 2014	Development of the Japanese version of the MMQL-Adolescent Form and evaluation of its reliability and validity
Bosworth A, 2018	Evaluation of the reliability and validity of the MMQLI in adult survivors of childhood cancer

Source: Authors.

adolescence. There were 18 in total, 11 of which could be said to stem from the premise that oncological disease could affect HRQOL, especially in survivors with late effects, that is, with chronic health conditions secondary to the disease or treatment received. Among these studies, nine were carried out in survivors of primary oncological disease in general[25-27,31,33-35,37,53] and two in populations with specific diseases, leukemia in one of the studies (15) and Wilms tumor or neuroblastoma in the other[22]. In these articles, possible statistical associations were explored among values of HRQOL, the sociodemographic variables included (age, sex, educational level, occupation, relationship status) and the chronic health conditions found (physical, psychical, or social). In the majority, the information was collected from secondary sources, databases from previous surveys or from health care centers or medical records. In these studies, associations between health aspects considered of particular interest for the study of HRQOL were also examined, using other questionnaires specific to each topic, for example, in the assessment of: depres-

sion, post-traumatic stress, anxiety, somatization, sexual dysfunction or limitations in certain areas of functionality considered relevant for the HRQOL of the studied population.

In all cases, HRQOL was evaluated using a quantitative approach, through generic instruments for the measurement of HRQOL, validated for the studied populations. The research designs were cross-sectional. No successive measurements over time were reported to have been carried out, even in cohorts of survivors. Some studies made comparisons with control groups.

The remaining seven articles had the objective of studying HRQOL in childhood cancer survivors in which a particular reduction in HRQOL was suspected, due to the type of cancer, the type of treatment received or sequelae considered especially negative. This group of articles particularly studied survivors with secondary effects associated with radiotherapy[23,30], bone marrow transplants[29,36], treatment of bone tumors in lower limbs (amputations) (63), physical deterioration after treatment of rhabdomyosarcoma and scarring or permanent disfiguration[21,32]. In these articles the approach was also quantitative, with generic instruments for measuring HRQOL applied for a single measurement. Some studies incorporated the instruments into longer questionnaires in order to explore psychosocial factors considered relevant. This strategy implied in some cases responding to over 200 questions.

b) Research focused on the relationship between survival time and HRQOL: this line of research brings together seven articles[16-18,38-41] that seek to evaluate HRQOL in long-term survivors. The methodology utilized in these works was similar to that of the previous group: quantitative measurements with generic instruments and comparison with control groups. In no case were successive measurements taken over time, nor were results compared with previous measurements in the same population. That is to say that the survival time was a characteristic that defined the eligible population for the study at the start, but was not constructed as a variable associated with possible changes over time in HRQOL, although on occasion comparisons were made with other survivors who had finished treatment more recently.

c) Research focused on psycho-social or behavioral aspects that influence HRQOL: this line included 12 articles with the objective of studying some factors proposed by the researchers as possible determinants of HRQOL in survivors of cancer in childhood or adolescence. The factors explored included aspects related to healthy

Chart 2. Primary lines of research identified and relevant aspects of each.

Lines of research	Publications (n 48)	Methodology	Instrumentof measurement
HRQOL in survivors of cancer in childhood or adolescence	11 (survivors in general) 7 (survivors with greater associated comorbidities)	Quantitative Cross-Sectional	SF 36 (9) PedQoL (2) SF 36 (2) PedQoL (1) Questionnaire designed for the study (4)
HRQOL in long-term survivors	7	Quantitative Cross-Sectional	SF36 (3) RAND 36 (2) HUI (1) EORTC-QL-C30 (1)
HRQOL in relation to possible determinants	12 (1)	Quantitative Cross-Sectional (Quali-quantitative)	SF36 (6) SF12 (1) PedQol (2) MMQLI (2) POQOL (1)
Instruments for evaluation of HRQOL	11	Development, psychometric analysis, validation and/or comparison of questionnaires	QOL MMQLI KIDSCREEN 27 IOC-CS

Source: Authors.

lifestyles (three articles)[19,46,59]; belonging or not belonging to Latino culture or having depressive symptoms (one article)[50] or belonging to Latino culture (one article)[42]; disparities in neurocognitive or emotional aspects according to ethnicity (one article)[51]; aspects related to the type of cancer (one article)[45]; characteristics related to self-esteem and psychosocial aspects (four articles)[43,44,47,48] and family functioning as a mediator of neurocognitive function in survivors of brain tumors (one article)[24]. Similar to what was previously observed in the majority of works, the methodology was quantitative, despite the limitations that such an approach implies. The only exception was found in one of the works carried out with the Latino population in which qualitative techniques were applied through focus groups.

d) Research focused on the evaluation of instruments for measuring HRQOL in this population: this line of research included 11 publications[52-62] with aims involving the development, psychometric analysis, validations studies and/or comparison studies of questionnaires for the evaluation of HRQOL in cancer survivors. Some of these studies were targeted particularly at young adults. One study explored as a variable of interest that the evaluation of HRQOL be carried out in the health care facility[58]. Three studies sought to explore potential limitations in the measurement, such as the effect of response bias in self-reported HRQOL in cancer survivors[60], the clinical significance of HRQOL as self-reported in a questionnaire[61] and the possible missing content in HRQOL measurement instruments in young adult survivors of cancer[62]. In the latter two, interviews with adult survivors of childhood cancer were are also carried out.

2) *Primary instruments for measuring the HRQOL identified and the dimensions explored* (Cuadro 3)

The different instruments used to measure HRQOL in the evaluated publications were those known as "patient-reported outcome instruments," that is, the information they collect is not mediated by any member of the health team.

At the same time, within this type of instruments, the great majority of the published research used generic instruments such as the SF-36, SF-12 (the short form of the Medical Outcome Survey), RAND-SF26 or PedsQL (Pediatric Quality of Life). In conjunction, these types of instruments were used in 28 articles. With less frequency, the articles made use of what are known as specific instruments, designed to research certain diseases or situations (they include lists of symptoms and affections generated specifically by a disease or treatment) such as MMQL-I (Minneapolis-Manchester Quality of Life Instrument), EORTC QL (European Organisation for Research and Treatment of Cancer), and the POQOL (Pediatric Oncology Quality of Life). These instruments were employed, in addition to four instruments designed specifically for the studies, in 8 studies, and one article used the HUI (Health Utilities Index), a questionnaire to evaluate state of health and HRQOL. These questionnaires explore the following dimensions: physical functioning, physical role functioning, bodily pain, general health, vitality, social role functioning, emotional role functioning and mental health. The SF-36 additionally includes a transition item that explores changes in the person's overall state of health in relation to the previous year. This item is not used in the calculation of any of the scales, but it offers information regarding perceived changes in one's state of health in the year prior to the administration of the SF-36. Additionally, the MMQ-I includes a domain to evaluate cognitive function. Although the majority of the articles do not offer explicit definitions of the theoretical models underlying the measurement of HRQOL, in the stated objectives, in the study methodology and in the instruments utilized, an implicit model can be perceived, referenced in the relation between function and HRQOL and not based in the meaning to the subject, who holistically incorporates lived experience in their HRQOL[64,65].

Cuadro 3 describes the domains explored in the most frequently utilized questionnaires.

Discussion

In the last 20 years, there has been significant academic production regarding the study of HRQOL and its possible determinants in adults who are survivors of cancer in childhood and adolescence. These studies can offer important knowledge regarding the health of this population from the perspective of the subject.

The importance of these studies lies in the identification of factors that are consistently associated with HRQOL, which could orient the development of care strategies for improving or maintaining health. Nevertheless, the type of study predominantly utilized presents important limitations to a full comprehension of the topic.

In 1994, the WHO defined quality of life as "an individual's perception of their position in

Chart 3. Primary instruments for the measurement of HRQOL identified and dimensions explored.

Generic HRQOL Instruments	Dimensions Explored
SF-36 RAND-36	Functioning and limitation in the physical, social, and emotional spheres; energy/fatigue; pain; and general well-being
PedsQL	Physical, emotional and social functioning, school performance
Specific HRQOL Instruments	**Dimensions Explored**
MMQL-I Specific to childhood cancer survivors	Physical, cognitive, psychological, and social functioning, body image,relationships, and general outlook on life
EORTC QL	Physical, social and emotional functioning; symptoms scale; financial impact; and general well-being

Source: Authors.

life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (66); based on this conceptual definition and with the goal of estimating the extent to which different aspects of health affect *quality of life*, in 1995 the WHOQOL group established points of consensus regarding the measurement of *health related quality of life*, highlighting that the variables measured should be subjective, in the sense of collecting the perception of the person involved, and multidimensional, for which it is necessary to survey different aspects of the individual's life at least in the physical, emotional, social and interpersonal levels; include positive and negative sentiments; and register variability in time, whether in different life stages, moments of the disease experienced, or treatments[67]. From this point of view, the predominant use of "patient-reported outcome instruments" emerges to an extent as a positive strategy, and the generic instruments for measuring HRQOL, administered in person, by mail or via internet, can facilitate the study of HRQOL and offer measurements of general aspects of health perception comparable among different study populations, be they survivors of different types of cancer, survivors with different post-treatment survival times or the general population. Nevertheless, the measurements carried out in a single point in time are insufficient to provide a thorough understanding of HRQOL, as they do not allow temporal variations to be evaluated. This aspect constitutes a limitation in carrying out comparisons, whether they be in relation to different life stages, the time passed since diagnosis and treatment or in reference to relevant milestones in the lives of those evaluated that may or may not be related to the disease, its treatment and the sequelae. In this way, it is not possible to perceive the occurrence of possible internal adjustments through the resources of confrontation and variation of expectations[68,69]. It is important to consider that, although the evaluations of HRQOL in the analyzed publications were carried out in adults, the experience of an oncological disease that occurred in childhood or adolescence and was without a doubt unique and significant for each individual and social context. In this sense, the aspects that mediated HRQOL during the disease and treatment could influence the perception of HRQOL evaluated without being reflected in the domains explored by the utilized instruments[70,71]. Hinds describes the HRQOL of pediatric patients in treatment as a construct expressed as"a general feeling of well-being based on the ability to participate in everyday activities; to interact with other and feel taken care of; to find meaning in the experience of illness"[72,73]. Along with the previous considerations, it is important to highlight that *function-based models*, which underly the operationalization of HRQOL from the biomedical model, emphasize the importance of physical function and the impact of the disease and treatment on this dimension[74], as opposed to *meaning-based models* that emphasize patterns and experiences of disease and treatment from a subjective and holistic perspective[75]. This latter approach could contemplate, for example, that a child not attending an activity could be reflective not of a functional limitation but rather of the choice to stay at home with his or her family[68]. In the area of pediatric oncology, academic developments regarding the conceptualization of HRQOL recognize the difficulty of defining the concept given that it is considered a dynamic phenomenon in which the different lived experiences interact with psychological and cognitive

Ciência & Saúde Coletiva, 27(8):3063-3077, 2022

processes that allow one to redefine one's world and adjust one's expectations[73]. In relation to pediatric cancer survivors in particular, the relevance of other aspects that modify the perception of HRQOL have also been studied, including: personality traits, beyond whether an oncological illness has been experienced; affection in the perception of body image; the possibilities for the development of autonomy; affection of sexuality; and above all, changes these perceptions might face in an individual over time[69]. We can therefore consider that, notwithstanding the effort placed on studying HRQOL in this population, there are extremely relevant, constitutive aspects of HRQOL that are not incorporated into the approach in the majority of studies. In this sense, it is clear that it is not possible to access the subjectivity sought after in HRQOL solely through the implementation of structured self-responses, in which subjects generally respond to proposed functional domains. It would appear to be indispensable to complement these questionnaires in this population with qualitative approaches that explore meanings immersed in life stories and experiences that allow us to understand the sense of the perception that each subject has regarding their quality of life in relation to their health and in their personal situation within their social world.

It is crucial to develop lines of research that incorporate aspects complementary to those presently carried out. Making explicit underlying definitions and conceptual models in each study can contribute to comprehension of the nuances of this topic and enrich the production of knowledge in this area, with the subsequent benefit in the health care of survivors of cancer in childhood or adolescence, considering their health from a comprehensive perspective.

Among the primary limitations that this study presents, it should be mentioned that, given difficulties in accessing other sources, the literature search was carried out in only two electronic databases of indexed publications. Nevertheless, they are those most frequently utilized in clinical practice.

Conclusions

The primary lines of research on HRQOL in survivors of cancer in childhood or adolescence are focused on: biomedical aspects that affect the perception of HRQOL; the relationship between HRQOL and post-treatment survival time; in social, cultural or behavior aspects; and in the study of methodological aspects regarding the measurement of HRQOL in these populations. In the first three, generic measurement instruments were predominantly utilized, applied on a single occasion.

The majority of the publications evaluate whether the HRQOL of survivors is or is not affected and the possible relationship with sociodemographic aspects, the type of oncological disease experienced, the treatment received, the presence of sequelae or long-term complications with different degrees of severity or with the limitations that these bring. To a lesser extent, associations with depression, anxiety and self-esteem were explored in studies limited to the application of self-administered questionnaires. Often the results obtained were compared with measurements in populations without a history of cancer. In some cases, results of survivors of different oncological diseases or of differing severity were compared. Despite the important amount of published scientific production, the predominant approach adopted for the study of HRQOL does not provide us with knowledge of subjective aspects, nor the assessment of modifications produced throughout the subject's life.

Collaborations

As first author I have worked on the conception, design and implementation of the integrative review presented, and on the writing of the submitted manuscript. Dr. Marcio Alazraqui, as director of the thesis project, has worked significantly in the conception and design of the review, as well as in the discussion of the results and critical review of the writing of the manuscript.

Acknowledgements

Our thanks to Dr. José Ricardo de C.M. Ayres and Dr. Damián Herkovits for their valuable contributions in the development of the doctoral dissertation project from which this article emerges. We also thank Dr. Jorge Arakaki for his special dedication in a stylistic review of the manuscript.

References

1. Steliarova-Foucher E, Ullrich A. Preguntas frecuentes sobre el cáncer infantil: Organización Mundial de Salud. 2019. [consultado 2019 dez 2]. Disponible en: https://www.who.int/cancer/media/news/Childhood_cancer_day/es/
2. Moreno F. *Registro oncopediátrico hospitalario argentino*. Buenos Aires: Instituto Nacional del Cáncer; 2021. [consultado 2021 jun 7]. Disponible en: https://bancos.salud.gob.ar/sites/default/files/2021-06/2021-06-07-Registro-oncopediatrico-argentino.pdf
3. National Cancer Institute. *Childhood cancer survivor study: an overview*. Washington, DC: National Institutes of health; 2018. [cited 2022 mar 20]. [Available from: https://www.cancer.gov/types/childhood-cancers/ccss.
4. Green DM. Late effects of treatment for cancer during childhood and adolescence. *Curr Probl Cancer* 2003; 27(3):127-142.
5. Hudson MM, Mertens AC, Yasui Y, Hobbie W, Chen H, Gurney JG, Yeazel M, Recklitis CJ, Marina N, Robison LR, Oeffinger KC, Childhood Cancer Survivor Study Investigators. Health status of adult long-term survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *JAMA* 2003; 290(12):1583-1592.
6. Oeffinger KC. Longitudinal risk-based health care for adult survivors of childhood cancer. *Curr Probl Cancer* 2003; 27(3):143-167.
7. Oeffinger KC, Mertens AC, Sklar CA, Kawashima T, Hudson MM, Meadows AT, Friedman DL, Marina N, Hobbie W, Kadan Lottick N, Schwartz C, Leisenring W. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med* 2006; 355(15):1572-1582.
8. Silva G, Salazar C. Impacto psicosocial y calidad de vida en sobrevivientes de cáncer infantil. *Horiz Enfer* 2011; 22(1):65-71.
9. Ness KK, Mertens AC, Hudson MM, Wall MM, Leisenring WM, Oeffinger KC, Sklar Ch, Robison L, Gurney J. Limitations on physical performance and daily activities among long-term survivors of childhood cancer. *Ann Intern Med* 2005; 143(9):639-647.
10. Cantrell MA. A narrative review summarizing the state of the evidence on the health-related quality of life among childhood cancer survivors. *J Pediatr Oncol Nurs* 2011; 28(2):75-82.
11. Schawrtzmann L. Calidad de vida relacionada con la salud: aspectos conceptuales. *Ciencia y Enfermeria* 2003; 9(2):9-21.
12. Botelho LL CdAC, Macedo M. O método da revisão integrativa nos estudos organizacionais. *Gestão e Sociedade* 2011; 5(11):121-36.
13. Mendes KDS SR, Galvao CM. Revisao integrativa: método de pesquisa para a incorporacion de evidencias na saúde é na enfermagem. *Texto Contexto Enferm* 2008; 17(4):758-764.
14. Cantrell MA. Health-related quality of life in childhood cancer: state of the science. *Oncology Nursing Forum* 2007; 34(1):103-11.
15. Corella Aznar EG, Ayerza Casas A, Carbone Baneres A, Calvo Escribano MAC, Labarta Aizpun JI, Samper Villagrasa P. Quality of life and chronic health conditions in childhood acute leukaemia survivors. *Med Clin (Barc)* 2019; 152(5):167-173.
16. Harila MJ, Salo J, Lanning M, Vilkkumaa I, Harila-Saari AH. High health-related quality of life among long-term survivors of childhood acute lymphoblastic leukemia. *Pediatr Blood Cancer* 2010; 55(2):331-336.
17. Essig S, von der Weid NX, Strippoli MPF, Rebholz CE, Michel G, Rueegg CS, Niggli F, Kuehni C. Health-related quality of life in long-term survivors of relapsed Childhood acute lymphoblastic leukemia. *PLoS ONE* 2012; 7(5):e38015.
18. Calaminus G, Dorffel W, Baust K, Teske C, Riepenhausen M, Bramswig J, Flechtner HH, Singer S, Hinz A, Schellong G. Quality of life in long-term survivors following treatment for Hodgkin's disease during childhood and adolescence in the German multicentre studies between 1978 and 2002. *Support Care Cancer* 2014; 22(6):1519-1529.
19. Wogksch MD, Howell CR, Wilson CL, Partin RE, Ehrhardt MJ, Krull KR, Brinkman T, Mulrooney D, Hudson M, Robison L, Ness K. Physical fitness in survivors of childhood Hodgkin lymphoma: A report from the St. Jude Lifetime Cohort. *Pediatr Blood Cancer* 2019; 66(3):e27506.
20. Nagarajan R, Mogil R, Neglia JP, Robison LL, Ness KK. Self-reported global function among adult survivors of childhood lower-extremity bone tumors: a report from the Childhood Cancer Survivor Study (CCSS). *J Cancer Surviv* 2009; 3(1):59-65.
21. Punyko JA, Gurney JG, Scott Baker K, Hayashi RJ, Hudson MM, Liu Y, Robison L, Mertens A. Physical impairment and social adaptation in adult survivors of childhood and adolescent rhabdomyosarcoma: a report from the Childhood Cancer Survivors Study. *Psychooncology* 2007; 16(1):26-37.
22. Nathan PC, Ness KK, Greenberg ML, Hudson M, Wolden S, Davidoff A, Laverdiere C, Mertens A, Whitton J, Robison L, Zeltzer L, Gurney J. Health-related quality of life in adult survivors of childhood wilms tumor or neuroblastoma: a report from the childhood cancer survivor study. *Pediatr Blood Cancer* 2007; 49(5):704-715.
23. Fukushima H, Fukushima T, Suzuki R, Iwabuchi A, Hidaka K, Shinkai T, Masumoto K, Muroi A, Yamamoto T, Nakao T, Oshiro Y, Mizumoto M, Sakurai H, Sumazaki R. Comorbidity and quality of life in childhood cancer survivors treated with proton beam therapy. *Pediatr Int* 2017; 59(10):1039-1045.
24. Hocking MC, Hobbie WL, Deatrick JA, Hardie TL, Barakat LP. Family functioning mediates the association between neurocognitive functioning and health-related quality of life in young adult survivors of childhood brain tumors. *J Adolesc Young Adult Oncol* 2015; 4(1):18-25.
25. Pemberger S, Jagsch R, Frey E, Felder-Puig R, Gadner H, Kryspin-Exner I, Topf R. Quality of life in long-term childhood cancer survivors and the relation of late effects and subjective well-being. *Support Care Cancer* 2005; 13(1):49-56.
26. Ness KK, Gurney JG, Zeltzer LK, Leisenring W, Mulrooney DA, Nathan PC, Robison L, mertens A. The impact of limitations in physical, executive, and emotional function on health-related quality of life among adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Arch Phys Med Rehabil* 2008; 89(1):128-136.

27. Zeltzer LK, Lu Q, Leisenring W, Tsao JCI, Recklitis C, Armstrong G, mertens A, Robison L, Ness K. Psychosocial outcomes and health-related quality of life in adult childhood cancer survivors: a report from the Childhood Cancer Survivor Study. *Cancer Epidemiol Biomarkers Prev* 2008; 17(2):435-446.
28. Zebrack BJ, Foley S, Wittmann D, Leonard M. Sexual functioning in young adult survivors of childhood cancer. *Psychooncology* 2010; 19(8):814-822.
29. Ishida Y, Honda M, Ozono S, Okamura J, Asami K, Maeda N, Sakamoto N, Inada H, Iwai T, Kamibeppu K, Kakee N, Horibe K. Late effects and quality of life of childhood cancer survivors: part 1. Impact of stem cell transplantation. *Int J Hematol* 2010; 91(5):865-876.
30. Ishida Y, Sakamoto N, Kamibeppu K, Kakee N, Iwai T, Ozono S, Maeda N, Okamura J, Asami K, Inada H, Honda M, Horibe K. Late effects and quality of life of childhood cancer survivors: Part 2. Impact of radiotherapy. *Int J Hematol* 2010; 92(1):95-104.
31. Ishida Y, Honda M, Kamibeppu K, Ozono S, Okamura J, Asami K, Maeda N, sakamoto N, Inada H, Iwai T, Kakee N, Horibe K. Social outcomes and quality of life of childhood cancer survivors in Japan: a cross-sectional study on marriage, education, employment and health-related QOL (SF-36). *Int J Hematol* 2011; 93(5):633-644.
32. Kinahan KE, Sharp LK, Seidel K, Leisenring W, Didwania A, Lacouture ME, Stovall M, Haryani A, Robison L, Krull K. Scarring, disfigurement, and quality of life in long-term survivors of childhood cancer: a report from the childhood cancer survivor study. *J Clin Oncol* 2012; 30(20):2466-2474.
33. Rueegg CS, Gianinazzi ME, Rischewski J, Beck Popovic M, von der Weid NX, Michel G, Kuehni C. Health-related quality of life in survivors of childhood cancer: the role of chronic health problems. *J Cancer Surviv* 2013; 7(4):511-522.
34. Rhee MA, Chung KM, Lee Y, Choi HK, Han JW, Kim HS, Kim SH, Shin YJ, Lyu ChJ. Impact of psychological and cancer-related factors on HRQoL for Korean childhood cancer survivors. *Qual Life Res* 2014; 23(9):2603-2612.
35. Chan CW, Choi KC, Chien WT, Cheng KK, Goggins W, So WK, Karis K F Cheng, Chi Kong Li, Hui Leung Yuen, Chi Keung Li. Health-related quality-of-life and psychological distress of young adult survivors of childhood cancer in Hong Kong. *Psychooncology* 2014; 23(2):229-236.
36. Tremolada M, Bonichini S, Taverna L, Basso G, Pillon M. Health-related quality of life in AYA cancer survivors who underwent HSCT compared with healthy peers. *Eur J Cancer Care (Engl)* 2018; 27(6):e12878.
37. Halvorsen JF, Sund AM, Zeltzer L, Ådnanes M, Jensberg H, Eikemo TA, Lund B, Hjemdal O, Reinfjell T. Health-related quality of life and psychological distress in young adult survivors of childhood cancer and their association with treatment, education, and demographic factors. *Qual Life Res* 2018; 27(2):529-537.
38. Blaauwbroek R, Groenier KH, Kamps WA, Meyboom-de Jong B, Postma A. Late effects in adult survivors of childhood cancer: the need for life-long follow-up. *Ann Oncol* 2007; 18(11):1898-1902.
39. Blaauwbroek R, Stant AD, Groenier KH, Kamps WA, Meyboom B, Postma A. Health-related quality of life and adverse late effects in adult (very) long-term childhood cancer survivors. *Euro J Cancer* 2007; 43(1):122-130.
40. Alessi D, Dama E, Barr R, Mosso ML, Maule M, Magnani C, Pastore G, Merletti F. Health-related quality of life of long-term childhood cancer survivors: a population-based study from the Childhood Cancer Registry of Piedmont, Italy. *Euro J Cancer* 2007; 43(17):2545-2552.
41. Kenney LB, Nancarrow CM, Najita J, Vrooman LM, Rothwell M, Recklitis C, Li FP, Diller L. Health status of the oldest adult survivors of cancer during childhood. *Cancer* 2010; 116(2):497-505.
42. Casillas JN, Zebrack BJ, Zeltzer LK. Health-related quality of life for Latino survivors of childhood cancer. *J Psychosoc Oncol* 2006; 24(3):125-145.
43. Servitzoglou M, Papadatou D, Tsiantis I, Vasilatou-Kosmidis H. Psychosocial functioning of young adolescent and adult survivors of childhood cancer. *Support Care Cancer* 2008; 16(1):29-36.
44. Cantrell MA, Lupinacci P. Investigating the determinants of health-related quality of life among childhood cancer survivors. *J Adv Nurs* 2008; 64(1):73-83.
45. Mört S, Salanterä S, Matomäki J, Salmi TT, Lähteenmäki PM. Cancer related factors do not explain the quality of life scores for childhood cancer survivors analysed with two different generic HRQL instruments. *Cancer Epidemiol* 2011; 35(2):202-210.
46. Badr H, Chandra J, Paxton RJ, Ater JL, Urbauer D, Cruz CS, Demark-Wahnefried W. Health-related quality of life, lifestyle behaviors, and intervention preferences of survivors of childhood cancer. *J Cancer Surviv* 2013; 7(4):523-534.
47. Huang IC, Brinkman TM, Armstrong GT, Leisenring W, Robison LL, Krull KR. Emotional distress impacts quality of life evaluation: a report from the Childhood Cancer Survivor Study. *J Cancer Surviv* 2017; 11(3):309-319.
48. Cantrell MA, Conte TM, Hudson MM, Ruble K, Herth K, Shad A, Canino A. Developing the evidence base in pediatric oncology nursing practice for promoting health-related quality of life in pediatric oncology patients. *J Pediatr Oncol Nurs* 2017; 34(2):90-97.
49. Zhang FF, Hudson MM, Huang IC, Bhakta N, Ness KK, Brinkman TM, Klosky J, Lu L, Chan F, Ojha R, Lanctot J, Robison L, Krull K. Lifestyle factors and health-related quality of life in adult survivors of childhood cancer: a report from the St. Jude Lifetime Cohort Study. *Cancer* 2018; 124(19):3918-3923.
50. Ritt-Olson A, Miller K, Baezconde-Garbanati L, Freyer D, Ramirez C, Hamilton A, Milam J. Depressive symptoms and quality of life among adolescent and young adult cancer survivors: impact of gender and Latino culture. *J Adolesc Young Adult Oncol* 2018; 7(3):384-388.
51. Dixon SB, Li N, Yasui Y, Bhatia S, Casillas JN, Gibson TM, Ness K, Porter J, Howell RM, Leisenring W, Robison L L, Hudson MM, Krull K, Armstrong GT. Racial and ethnic disparities in neurocognitive, emotional, and quality-of-life outcomes in survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Cancer* 2019; 125(20):3666-3677.

52. Zebrack BJ, Chesler MA. A psychometric analysis of the Quality of Life-Cancer Survivors (QOL-CS) in survivors of childhood cancer. *Qual Life Res* 2001; 10(4):319-329.
53. Zebrack BJ, Donohue JE, Gurney JG, Chesler MA, Bhatia S, Landier W. Psychometric evaluation of the Impact of Cancer (IOC-CS) scale for young adult survivors of childhood cancer. *Qual Life Res*. 2010;19(2):207-18.
54. Huang IC, Quinn GP, Krull K, Eddleton KZ, Murphy DC, Shenkman EA, Shearer P. Head-to-head comparisons of quality of life instruments for young adult survivors of childhood cancer. *Support Care Cancer* 2012; 20(9):2061-2071.
55. Huang IC, Quinn GP, Wen PS, Shenkman EA, Revicki DA, Krull K, Li Z, Shearer P. Using three legacy measures to develop a health-related quality of life tool for young adult survivors of childhood cancer. *Qual Life Res* 2012; 21(8):1437-1450.
56. Jervaeus A, Kottorp A, Wettergren L. Psychometric properties of KIDSCREEN-27 among childhood cancer survivors and age matched peers: a Rasch analysis. *Health Qual Life Outcomes* 2013;11:96.
57. Koike M, Hori H, Rikiishi T, Hayakawa A, Tsuji N, Yonemoto T, Uryu H, Matsushima E. Development of the Japanese version of the Minneapolis-Manchester Quality of Life Survey of Health – Adolescent Form (MMQL-AF) and investigation of its reliability and validity. *Health Quality Life Outcomes* 2014;12:127.
58. Henderson JR, Kiernan E, McNeer JL, Rodday AM, Spencer K, Henderson TO, Parsons S. Patient-reported health-related quality-of-life assessment at the point-of-care with adolescents and young adults with cancer. *J Adolesc Young Adult Oncol* 2018; 7(1):97-102.
59. Bosworth A, Goodman EL, Wu E, Francisco L, Robison LL, Bhatia S. The Minneapolis-Manchester Quality of Life Instrument: reliability and validity of the Adult Form in cancer survivors. *Qual Life Res* 2018; 27(2):321-332.
60. O'Leary TE, Diller L, Recklitis CJ. The effects of response bias on self-reported quality of life among childhood cancer survivors. *Qual Life Res* 2007; 16(7):1211-1220.
61. Jervaeus A, Lampic C, Johansson E, Malmros J, Wettergren L. Clinical significance in self-rated HRQoL among survivors after childhood cancer – demonstrated by anchor-based thresholds. *Acta Oncol* 2014; 53(4):486-492.
62. Quinn GP, Huang IC, Murphy D, Zidonik-Eddelton K, Krull KR. Missing content from health-related quality of life instruments: interviews with young adult survivors of childhood cancer. *Qual Life Res* 2013; 22(1):111-118.
63. Nagarajan R, Neglia JP, Clohisy DR, Robison LL. Limb salvage and amputation in survivors of pediatric lower-extremity bone tumors: what are the long-term implications? *J Clin Oncol* 2002; 20(22):4493-501.
64. McDougall J, Tsonis M. Quality of life in survivors of childhood cancer: a systematic review of the literature (2001-2008). *Support Care Cancer* 2009; 17(10):1231-1246.
65. Vilagut G FM, Rajmil L, Rebollo P, Permanyer-Miralda G, Quintana JM, Santed R, Valderas JM, Ribera A, Domingo-Salvany A, Alonso J. El Cuestionario SF-36 español: una década de experiencia y nuevos desarrollos. *Gaceta Sanitaria* 2005; 19(2):135-150.
66. World Health Organization (WHO). *Quality of Life Assesment: an annotated bibliography*. Geneva: WHO; 1994.
67. WHOQOL Group. The World Health Organiztion Quality of Life Assesment (WHOQOL). Position paper from the WHO. *Soc Sci Med* 1995; 41(10):1403-1409.
68. Cantrell MA, Lupinacci P. Methodological issues in online data collection. *J Adv Nurs* 2007; 60(5):544-549.
69. Eiser C. Assessment of health-related quality of life after bone cancer in young people: easier said than done. *Euro J Cancer* 2009; 45(10):1744-1747.
70. Espada Barón MC, Grau Rubio C. Estrategias de afrontamiento en padres de niños con cáncer. *Psicooncología* 2012; 9(1):25-40.
71. García AAG, Luciio E. Estilo de afrontamiento y calidad de vida en adolescentes con cáncer. *Gacet Mexicana de Oncología* 2016; 15(1):3-9.
72. Hinds PS. The hopes and wishes of adolescents with cancer and the nursing care that helps. *Oncol Nurs Forum* 2004; 31(5):927-934.
73. Hinds PS. Shifting perspectives: adolescent-focused oncology nursing research. *Oncol Nurs Forum* 2004; 31(2):281-287.
74. Gill TM, Feinstein AR. A critical appraisal of the quality of quality-of-life measurements. *JAMA* 1994; 272(8):619-626.
75. Haase JE, Heiney SP, Ruccione KS, Stutzer C. Research triangulation to derive meaning-based quality-of-life theory: adolescent resilience model and instrument development. *Int J Cancer Suppl* 1999; 12:125-131.

Article submitted 18/07/2021
Approved 30/03/2022
Final version submitted 02/04/2022

Chief editors: Romeu Gomes, Antônio Augusto Moura da Silva