

Quality of life of children and adolescents with cancer: revision of studies literature that used the Pediatric Quality of Life Inventory™

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Quality of life of children and adolescents with cancer: revision of studies literature that used the pediatric quality of life inventory™

Objective. To assess the quality of life of children and adolescents with cancer of studies that applied the Pediatric Quality of Life Inventory 3.0 Cancer Module. **Methodology.** The study was carried out on the basis of data Scopus Web of Science, BIREME, EBSCO host and Psycinfo of articles in Spanish, English and Portuguese, and published from 1998 to 2013 that used the Pediatric Quality of life Inventory 3.0 Cancer Module. **Results.** 21 articles were selected, of which 47.6% were carried out in America, and 61.9% of editions comprehended from 2011 to 2013. The scores variation by dimensions and in general was probably related for the selection of comparison groups, as the diversity of inclusion criteria and variants may be observed for the analysis in each study. The existence of a standard dimension could not be verified either for children's /adolescents reports or for parents. **Conclusion.** It is concluded that the scores averages by dimensions in general have not achieved values below 30 and the largest scores by dimension are above 80. It is suggested that the treatment anxiety dimension in children's and adolescents's reports may have obtained the largest scores within each study, that is lesser than the difficulty of the children and adolescents in face of the treatment and cancer. Nursing becomes a constant presence in the life of children and adolescents with cancer and it may provide a better quality of life for developing nursing activities and the team may demistify, clarify and help in all phases of the illness and treatment.

Key words: quality of life; child; adolescent; questionnaire; review.

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Calidad de vida de los niños y adolescentes con cáncer: revisión de literatura de estudios que utilizaron el Pediatric Quality of Life Inventory™

Objetivo. Evaluar la calidad de vida de los niños y adolescentes a quienes se aplicó la escala Pediatric Quality of Life Inventory 3.0 Cancer Module. **Metodología.** Se hizo búsqueda en las bases de datos Scopus, Web of Science, BIREME, EBSCO host y PsycInfo de los artículos en español, inglés o portugués publicados entre 1998 a 2013 que utilizaron la escala. **Resultados.** Se seleccionaron 21 artículos, de los cuales el 47.6% se realizó en América y un 61.9% se publicó en el período 2011-2013. El rango de puntuaciones para las dimensiones, en general, fue probablemente relacionado con la selección de los grupos de comparación porque se pueden observar la diversidad de los criterios de inclusión y variables para el análisis en cada estudio. No se puede comprobar la existencia de un patrón de una dimensión presente en las puntuaciones más pequeñas o más grandes en relación a otras dimensiones en la información de los niños / adolescentes o en la de los familiares. **Conclusión.** De lo anterior se desprende que las puntuaciones medias de las dimensiones globales no llegaron a valores por debajo de 30, y mayores puntuaciones por dimensiones están por encima de 80. La enfermera, quien se convierte en presencia constante en la vida de niños y adolescentes con cáncer, puede proporcionar una mejor calidad de vida. Por lo tanto, el desarrollo de las actividades de enfermería y del equipo puede llevar a desmitificar, clarificar y ayudar a abordar todas las fases del proceso de la enfermedad y del tratamiento

Palabras clave: calidad de vida; niño; adolescente; cuestionarios; revisión.

Qualidade de vida de crianças e adolescentes com câncer: revisão de literatura de estudos que utilizaram o Pediatric Quality of Life Inventory™

Objetivo. Avaliar a qualidade de vida de crianças e adolescentes com câncer de estudos que aplicaram o Pediatric Quality of Life Inventory 3.0 Cancer Module. **Metodologia.** Realizou-se a busca nas bases de dados Scopus, Web of Science, BIREME, EBSCO host y PsycInfo de artigos em espanhol, inglês e português e publicados entre 1998 a 2013 que utilizararam Pediatric Quality of Life Inventory 3.0 Cancer Module. **Resultados.** Selecionou-se 21 artigos, dos quais 47,6% foram realizados na América e 61,9% das publicações estavam compreendidas entre os anos de 2011 a 2013. A variação dos escores por dimensões e o geral provavelmente esteve relacionada com a seleção dos grupos de comparação pois, pode-se perceber a diversidade dos critérios de inclusão e das variáveis para a análise em cada estudo. Não se pode verificar a existência de um padrão de uma dimensão apresentar sempre a menor ou o maior escore em relação as outras dimensões nem para o relato das crianças/adolescentes nem o relato dos parentes. **Conclusão.** Conclui-se que as médias dos escores por dimensões e o geral não alcançaram valores abaixo de 30 e os maiores escores por dimensões estão acima de 80. A enfermagem que se torna presença constante na vida das crianças e adolescentes com câncer pode proporcionar uma melhor qualidade de vida; pois, ao desenvolver as atividades de enfermagem, a equipe pode desmistificar, esclarecer e auxiliar no enfrentamento de todas as fases do processo do adoecimento e do tratamento.

Palavras chave: qualidade de vida; criança; adolescente; questionário; revisão.

Introduction

Pediatric Quality of Life Inventory (PedsQL™) is an instrument prepared by James W. Varni and the authors to assess the quality of life of children/adolescents with serious and chronic

illnesses including cancer (CA).¹ There is a general questionnaire that is PedsQL Generic Core scales (PedsLQ™ 4.0) and more of 30 specific modules. The PedsQL™ 3.0 Cancer

Module has the purpose to assess the impact of the illness and the treatment in the quality of life in children and adolescents with neoplasia. It's a matter of an instrument already validated and adapted across cultures, and it also verifies the psychometric proprieties in several languages.²⁻¹¹ It is a multidimensional instrument comprised by 27 items distributed in eight dimensions: pain and hurt (2 items), nausea (5 items), treatment anxiety (3 items) procedure anxiety (3 items), worry (3 items), cognitive problem (5 items), perception physical appearance (3 items), and communication (3 items). It presents two versions, one for the child or the adolescent reports divided by age group 5-7, 8-12, and 13-18 years old and an other for the parent reports from 2-4, 5-7, 8-12, and 13-18 years old. The scale consists of five options of answer, type of likert, corresponding to 0 never, 1 almost never, 2 sometimes, 3 many times, and 4 almost always. In the version of the five-seven-year-old children, there's an adaptation for three answers (0 never, 2 sometimes, and 3 almost always) and the face scale is used too. The score comprises the response values inversely transformed into a scale 0 to 100; namely 0 = 100, 1 = 50, 3 = 25 and 4 = 0 and for the reporting of children 5-7 years, 0 = 100, 2 = 50 and 4 = 0. The higher the score, the lower the difficulties related diseases will and/or treatment.¹¹

For the use of this instrument in researches, or even in institutions, it is necessary the author's authorization that is requested by Mapi Research Trust Company based in France. After sending the necessary documents to the company, respecting the use conditions, it supplies the questionnaires and the procedures to calculate the requested scores of PedsQL. The instructions guide the calculum and the way of interpretation, however there are no values of the requested scores found in the research. In order to supply evidences of reports of pediatric oncology patients, a review was carried out;¹² but it brings the scores found in just one reasearch that used the PedsQL™ 3.0 Cancer Module and valous the other PedsQL™ inventories.

Besides bringing values of other used questionnaires of PedsQL™, the nursing is responsible for caring the children and adolescents both in hospital and in the oncology outpatient department. In most cases of cancer, the admission takes part in the treatment and the nursing team is a fundamental instrument of this indicated process, and may contribute to improve the quality of life of people who are under their responsibility, as the nursing manages the indicated therapies by means of their technical competences and abilities being present from the moment of diagnosis until the discharge or death of the patient. Assessing the QoL in the illness process of cancer may guide clinical actions that reward nursing in the context. In face of the exposed, the objective of this revision is to describe the averages of general scores or by dimensions in studies that used the Pediatric Quality of Life Inventory 3.0 Cancer Module to evaluate the quality of life of children and adolescent with cancer.

Methodology

It is a matter of literature revision of medicine carried out in the period of January 15th to December 21st. 2013 (BIREME), of articles published from 1998 to 2013 in which were used the basis Scopus, Web of Science, Regional Library of Medicine (BIREME), Psycinfo and EBSCO host that integrate a Medical Literature Analysis, and Retrieval System Online (MEDLINE), and cumulative INDEX to Nursing and Allied Health Literature (CINAHL) accessed in the Federal Academic Community (CAFE) linked to the Federate University of Espírito Santo (UFES) through the portal site periodics of the Coordination Improvement of Senior Staff (CAPES). The search strategy was applied "PedsQL and cancer and module" on the basis and the article filter was used excluding thus the selection of books chapters, thesis and other academic editions. As inclusion criteria, the article to be published was adopted, having used the questionnaire PedsQL™ 3.0 Cancer Module, of children and adolescents's age group, comprehending the ages from 2 to 18

years old in Portuguese, English and Spanish languages. As exclusion criteria, the article was defined as a revision article not containing averages of general score dimensions.

The country of study was considered as the place in which it was carried out. The time reference was used to characterize the type of study as transverse when the data collection took place in just one moment, and in longitudinal when they had two or more collections.¹³ To characterize the validity of the study, the criteria of having this purpose expressed or described in the objective was considered, testing its psychometric proprieties, its feasibility and reliability. When the questionnaire was applied for one of the 12 groups of cancer, it was classified as specific diagnosis according to the International Classification of Cancer in Childhood (ICCC) 3rd. Edition,¹⁴ and several types when applied to several groups. The values of averages of studies scores were transcribed to the tables, in case of longitudinal studies when the general scores of the sample was not described, a general score of the baseline was used. Moreover in articles where just values by groups were found, it was opted not to put them in the table for the values could not be chosen.

Results

During this period of study of study, according to the flow chart (Figure 1) 210 summaries and titles were identified for duplicate with the search strategy proposed by a reviewer. On the basis of EBSCO host, 16 duplicate summaries were excluded automatic. The reading of 194 summaries and titles, were excluded 163 duplicate and for not attending the exclusion criteria. 31 full articles were analysed, ten articles were discharged for attending the exclusion criteria and also presenting the averages values and standard diversion overtaking the value of 100 (one hundred) which is the limit of the questionnaire scale. For this study were elected 21 articles.

General Characteristics

All the articles of revision were found in the English language. The years of the edition varied from 2002 to 2013, and 13 articles (61.9%) dated from 2011 to 2013, being the largest frequency in the year of 2011, with 8 (38.1%). Most studies (47.6%) were concentrated in America, and one of these was in Brazil. Asia comes in second place as it has one less article than America. Europe is in the last place with 2 (9.5%). As to the type of study, 9 (42.9%) of the articles, they are transverse studies; 8 (38.3%) of validity and 4 (19.0%) longitudinal (Table 1).

The study¹⁵ carried out in USA had the purpose to assess the QoL in different weeks after the use of chemotherapy (CHT); in spite of being described as longitudinal, it was classified in this revision as transverse, because in the article content, the QoL is assessed in one moment of the collection, in one of the moments of the collection, and the moment of one week after the use of CHT.

The total sample varied from 26 to 420 people, 13 (61.4%) articles applied the questionnaires both in children and parents and others only for parents (Table 1).

In most cases, 15 (71.4%) articles are different samples of CA diagnosis and 6 (28.6%) have chosen a specific group (Table 1). The specific illnesses, the most studied ones were leukemia^{7,16-18} and cerebral tumors.^{19,20} It is pointed out that a study²¹ carried out in USA compared the QoL in patients with cerebral tumors and acute lymphoid Leukemia.

Characteristics of Scores

Concerning the children and adolescents' report, observing the Table 2, it is verified that 17 articles have used the PedsQL 3.0 Cancer Module, and reports of children and adolescents have been collected; of these just 6 articles^{2,3,5,7,9,19} described the general score of QL of the sample varying from 46.11 ± 13.15 to 83.9 ± 12.6 . One article¹⁵ showed the values of general score in a graphic of the article. For this factor it is not possible to extract the numeric figures of the general score, and totals described in the studies are divided by age groups of the groups.

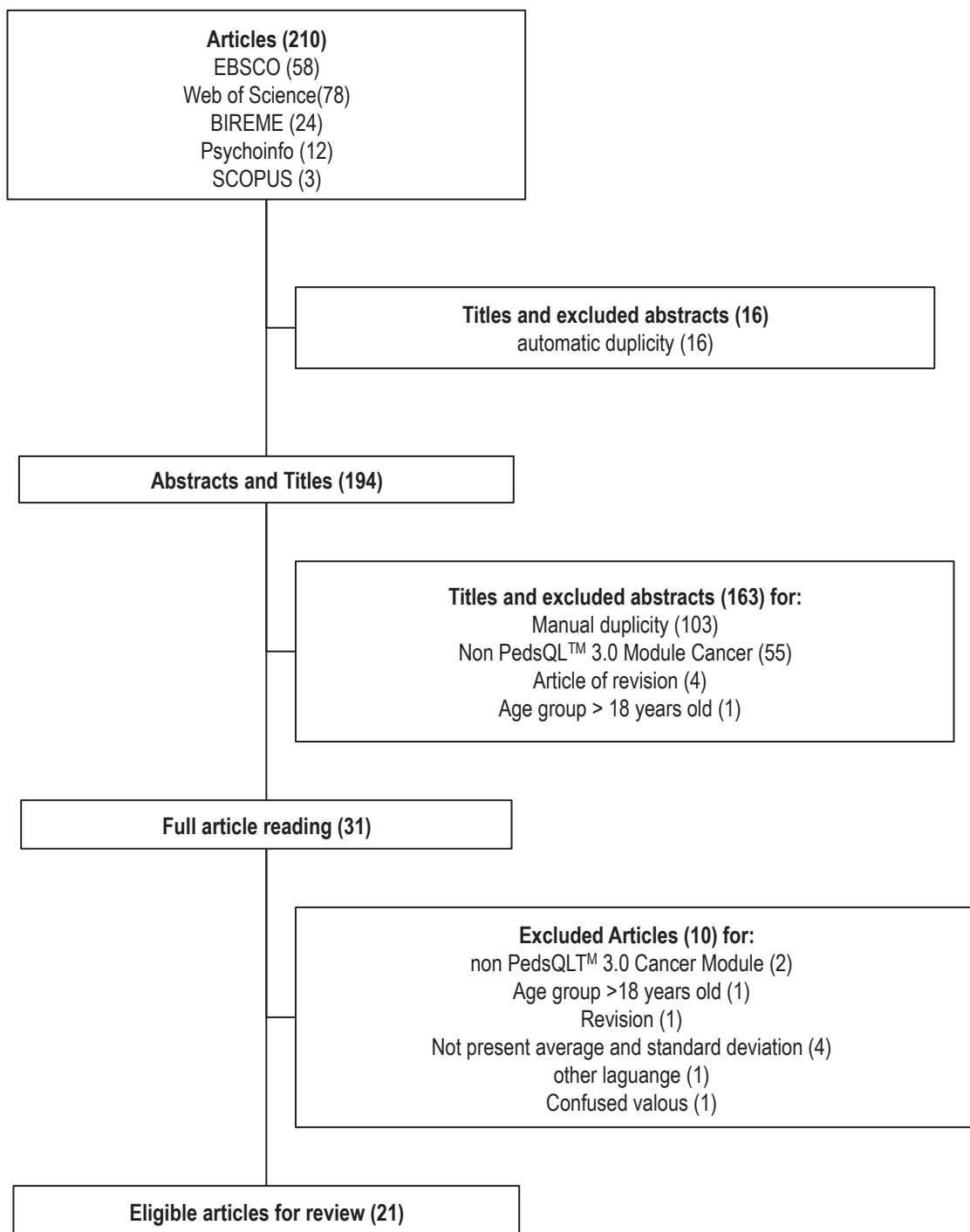


Figure 1. Selection chart flow of articles for revision

Table 1. Country characterization, type of study, age group, sample, CA diagnosis, reports of children/adolescentes and parent

Authors/year	Country	Study type	Age group	Total n	CA Diagnosis	ch//ado reports	Parent reports
Abu-Saad Huijjer, Sagherian, Tamim (2013) ²²	Lebanon	Transverse	7 a 18	85	Several types	X	n.a
Baggott <i>et al.</i> (2011) ¹⁵	USA	Transverse	10 a 18	61	Several types	X	n.a
Barrera, Schulte (2009) ¹⁹	Canada	Longitudinal	8 a 18	32	Specific	X	X
Chaudhry, Siddiqui (2012) ²	Pakistan	Validity	8 a 18	26	Several types	X	X
Felder-Puig <i>et al.</i> (2004) ³	Austria	Validity	2 a 18	126	Several types	X	X
Hansson <i>et al.</i> (2013) ²³	Denmark	Longitudinal	0 a 18	110	Several types	X	X
Ji <i>et al.</i> (2011) ⁴	China	Validity	2 a 18	266	Several types	X	X
Kuhlthau <i>et al.</i> (2012) ²⁰	USA	Longitudinal	2 a 17	142	Specific	X	X
Lau <i>et al.</i> (2010) ⁵	China	Validity	2 a 18	420	Several types	X	X
Meeske <i>et al.</i> (2004) ²¹	USA	Transverse	2 a 18	256	Several types	n.a	X
Pek <i>et al.</i> (2010) ²⁴	Singapore	Transverse	7 a 17	31	Several types	X	n.a
Pound <i>et al.</i> (2012) ¹⁶	Canada	Longitudinal	3 a 18	43	Specific	X	X
Scarpelli <i>et al.</i> (2008) ⁶	Brazil	Validity	2 a 18	190	Several types	X	X
Sitairesmi <i>et al.</i> (2008) ⁷	Indonésia	Transverse	2 a 16	98	Specific	X	X
Sung <i>et al.</i> (2011) ¹⁷	Canada	Transverse	2 a 18	206	Specific	n.a	X
Syahrlul Bariah <i>et al.</i> (2011) ¹⁸	Malaysia	Transverse	5 a 15	34	Specific	X	n.a
Tanir, Kuguoglu (2011) ⁸	Turkey	Validity	8 a 12	146	Several types	X	X
Tomlinson <i>et al.</i> (2011) ²⁵	Canada	Transverse	2 a 18	73	Several types	n.a	X
Tomlinson <i>et al.</i> (2011) ²⁶	Canada	Transverse	3.4 to 6.7*	26	Several types	n.a	X
Tsuji <i>et al.</i> (2011) ⁹	Japan	Validity	2 to 18	245	Several types	X	X
Varni <i>et al.</i> (2002) ¹¹	USA	Validity	2 a to 18	337	Several types	X	X

Note: USA – United States of America, CA – Cancer, ch//ado – child/adolescent, USA – United States of America, n.a – non assessed. CA Diagnosis – Specific (application of questionnaires for just one of the groups of ICC 3rd edition) and Several types (application for 2 or more ICC groups 3rd edition). * Tomlinson *et al.* describe the age group average.

Table 2. Values of averages and standard deviation of the total sample of children/adolescents' reports by dimension and general scores

Authors	Dimensions (Mean ± Standard Deviation)								General Score
	1	2	3	4	5	6	7	8	
Abu-Saad Huijjer, Sagherian, Tamim ²²	75.1±8.2	64.8±25.7	91.3±17.1	88.6±14.9	68.1±30.8	85.3±15.9	89.41±15.2	85.3±20.3	n.d
Baggott <i>et al.</i> ¹⁵	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g
Barrera, Schulte ¹⁹	n.d	n.d	n.d	n.d	n.d	n.d	n.d	n.d	67.6±16.6
Chaudhry, Siddiqui ²	n.d	n.d	n.d	n.d	n.d	n.d	n.d	n.d	46.1±13.1
Felder-Puig <i>et al.</i> ³	86.8±20.6	81.8±16.2	75.3±30.7	87.1±25.2	77.9±24.4	81.2±19.0	84.9±21.1	79.5±24.4	81.6±15.4
Hansson <i>et al.</i> ²³	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	n.d
Ji <i>et al.</i> ⁴	74.24±21.8	75.73±20.5	68.2±27.34	71.68±24.2	68.14±25.2	71.72±29.3	76.3±20.5	72.19±20.19	n.d
Kulthau <i>et al.</i> ²⁰	n.d	n.d	n.d	83.3±21.4	n.d	n.d	81.4±22.1	73.3±26.9	n.d
Lau <i>et al.</i> ⁵	89.0±16.4	90.2±19.2	77.4±27.1	93.5±15.7	82.7±17.3*	75.4±18.3	n.d	79.3±24.0	83.9±12.6
Meeske <i>et al.</i> ²¹	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a
Pek <i>et al.</i> ²⁴	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	n.d
Pound <i>et al.</i> ¹⁶	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	n.d
Scarpelli <i>et al.</i> ⁶	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	n.d
Sitairesmi <i>et al.</i> ⁷	80.1±27.4	82.6±21.4	69.9±32.3	88.2±22.5	75.5±27.7	76.9±23.2	76.4±27.2	68.3±37.0	77.1±16.8
Sung <i>et al.</i> ¹⁷	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a
Syahrul Bariah <i>et al.</i> ¹⁸	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	n.d
Tanir, Kuguoglu ⁸	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	n.d
Tomlinson <i>et al.</i> ²⁵	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a
Tomlinson <i>et al.</i> ²⁶	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a
Tsuji <i>et al.</i> ⁹	84.72±19.6	82.96±23.9	72.90±30.9	93.14±17.0	76.61±25.9	72.39±22.1	70.34±28.5	67.03±27.01	77.89±15.3
Varni <i>et al.</i> ¹¹	76.20±25.2	75.81±22.6	68.26±30.6	82.19±24.8	70.08±26.9	70.46±22.0	70.33±23.9	74.36±24.76	n.d

Note: Dimensions: 1 - Pain and Hurt, 2 - Nausea, 3 - Procedure Anxiety, 4 - Treatment Anxiety, 5 - Worry, 6 - Cognitive Problem, - 7 - Perception physical appearance, 8 - Communication. n.d. - non described, n.a. - non assessed, d.g - described by groups. *Barrera, Schulte, 2009 considered baseline

Total sample scores by dimensions were described in 8 articles,^{3-5,9,20,22} and the authors study of the QoL of children and adolescents with cerebral tumors treated with radiotherapy (RDT)²⁰, displayed the results of 3 dimensions (Table 2). In these articles, there were no values of dimensions scores less than 68 and superior to 94. It is interesting to highlight that 6 articles had the highest values of average in dimension treatment anxiety.^{3,5,7,11,20}

Concerning the parents' reports, it is observed in Table 3 the general score of QoL described in 6 articles,^{2,3,5,7,19} with variants among 42.01 ± 13.17 to 80.4 ± 13.7 . The score by dimensions is displayed in 7 articles,^{3-5,7,9,11,20} the least average value was found in dimensions treatment anxiety 60.1 in the assessment of QoL of 95 children and adolescents in the age group from 2 to 16 years old, diagnosed with acute lymphoid leukemia⁷ and the largest one 90.9 in validity study of PedsQLTM with 413 parents of children and adolescents in the Chinese version with 413 parents of children and adolescents in the age group from 1 to 18 years old.⁵

As to the groups description, 11 articles^{6,8,15,16,18,21,23} described the values by dimensions, however they just displayed values according to groups (Tables 2, 3); it was noted that 3 articles^{6,16,23} described by group both for the reports of parents, children and adolescents. And the other ones were not described as they applied the questionnaires depending on the study for parents, children and adolescents.

The comparison group by type of report was used by 11 articles,^{2-7,9,19,23,26} but they have used for gender/sex,^{8,15,18} being or not receiving treatment,^{5,6,11,21} the age group^{9,15,21,22} and other groups, according to Table 4.

Analysing all averages independent from being total sample or of a determined group, it is noted that the least scores by dimension and general had variable averages between 31.8 and 55.3, the largest ones varied from 83.9 to 100. It is highlighted that the least score values in 05 dimensions: pain and hurt (44.3), nausea (47.7), procedure anxiety (31.8), treatment anxiety (55.3), cognitive problem (52.1) belong to the study carried out in Canada that compared the quality of life (QoL) of children with no possibility of

a cure from Cancer,²⁶ this datum may be justified by the fact of the sample being composed of parents of children under palliative care. In the dimensions of worry, and perception physical appearance, that got the score 100, the groups are composed of children and adolescents with low risk, and in the maintenance phase within the study,¹⁷ they described the physical, emotional and social signs of QoL of 206 Canadian children and adolescents in age group of 10 to 18 years old.

Discussion

It is interesting to highlight that in spite of the PedsQLTM 3.0 cancer Module is indicated for the age group of 2 years old. The study was applied in the age group below 2 years old²³ and the other one is a study that excluded in its sample 2 patients over 18 years old, even having used the questionnaires for the age group of maximum limit for 18 years old.³ The least number of total sample was 26 people and this number is equivalent to 13 pairs, that is 13 questions were answered by children and adolescents, and 13 were answered by parents.²⁶ The reduced number of samples occurs for the rarity condition of this pathology that also justifies the high frequency of studies of transverse type. The fatal rates contribute for the losses of samples in the type of longitudinal studies.

The small size of sample may limit the power of statistic analysis^{2,16,18,19,22} might justify not find significant differences between different application times,¹⁹ age, race,¹⁵ sex,^{5,8,9,15,16,24} and in with or without treatment¹¹, and in home cares and standard treatment in reports of children.²³ Nevertheless, the QoL had statistically meaningful differences in the variants, age of the child diagnosis,^{9,11} guardian age⁹, child and adolescent without treatment. ≤ 12 months and > 12 months,^{4-6,21} cancer diagnosis and epilepsy,³ for nutrition condition,¹⁸ death in less than six months and over six months after interview.²⁵ The studies that collected the reports of children and adolescents reinforce the importance of giving voice to children and adolescents, and knowing what they think of the illness and the treatment²⁶ and it is suggested as a limitation having used just the parents' reports.¹⁷

Table 3. Averages values ± standard diversion of total sample of parents reports for dimensions and general score

Authors	Dimensions (Mean ± Standard Deviation)								General Score	
	1	2	3	4	5	6	7	8		
Abu-Saad Huijer; Sagherian; Tamim ²²	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a
Baggott et al. ¹⁵	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a
Barrera; Schulte ¹⁹	n.d	n.d	n.d	n.d	n.d	n.d	n.d	n.d	n.d	59.6±10.8
Chaudhry; Siddiqui ²	n.d	n.d	n.d	n.d	n.d	n.d	n.d	n.d	n.d	42.1±13.1
Felder-Puig et al. ³	87.3±18.0	81.5±17.1	63.0±33.5	84.2±26.1	81.5±22.6	74.5±22.5	84.5±22.1	71.9±28.6	79.1±14.0	
Hansson et al. ²³	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	n.d
Ji et al. ⁴	77.4±20.7	73.2±19.4	64.1±24.7	67.1±23.9	362.9±24.3	73.9±26.6	77.9±17.2	71.6±23.6	n.d	
Kuhlthau et al. ²⁰	n.d	n.d	n.d	70.8±26.9	n.d	n.d	75.9±24.4	75.2±26.1	n.d	
Lau et al. ⁵	88.1±18.0	90.9±17.7	74.7±27.9	88.0±19.5	79.4±24.6	68.4±21.1	80.7±21.2	73.8±28.0	80.4±13.7	
Meeske et al. ²¹	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g
Pek et al. ²⁴	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a
Pound et al. ¹⁶	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	n.d
Scarpelli et al. ⁶	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	n.d
Sitairesmi et al. ⁷	71.0±29.8	78.8±19.5	60.1±36.9	74.4±33.2	74.6±25.8	77.6±23.9	82.5±22.6	60.2±36.9	72.2±18.3	
Sung et al. ¹⁷	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	n.d
Syahrul Bariah et al. ¹⁸	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a
Tanir; Kuguoglu ⁸	n.d	n.d	n.d	n.d	n.d	n.d	n.d	n.d	n.d	n.d
Tomlinson et al. ²⁵	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	n.d
Tomlinson et al. ²⁶	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	d.g	
Tsuji et al. ⁹	82.8±22.0	80.4±25.7	63.1±31.7	84.8±25.7	81.3±21.9	68.7±21.6	73.7±27.9	62.2±25.4	74.9±15.2	
Varni et al. ¹¹	74.7±25.7	77.7±23.7	60.2±32.8	71.5±27.6	75.9±28.3	74.0±22.1	76.2±25.0	78.3±23.5	n.d	

Note: Dimensions: 1 - Pain and Hurt, 2 – Nausea, 3 –Procedure Anxiety, 4 –Treatment Anxiety, 5 – Worry, 6 – Cognitive Problem, - 7 – Perception physical appearance, 8 – Communication. n.d. - non described, n.a. - non assessed, d.g – described by groups. *Barrera; Schulte, 2009 considered baseline

Table 4. Distribution by articles, by authors, by several types of variants and analysis groups

Authors	Variants	Analysis groups
Abu-Saad Huijjer, Sagherian, Tamim ²²	Age group	7 to12 and 13 a 18 years old
Baggott <i>et al.</i> ¹⁵	Age group Sex Race/colour	<13 years old and ≥13 years old Male and female White and other colours
Barrera, Schulte ¹⁹	Type of report Collection moment	Surviving children, adolescents and parents Baseline, pré-intervention, pos-intervention and six months after intervention.
Chaudhry, Siddiqui ²	Type of report <u>Illness status</u>	Children, adolescents and parents with and without cancer
Felder-Puig <i>et al.</i> ³	Type of report	Children, adolescents and parents
Hansson <i>et al.</i> ²³	Type of report Service place Collection moment	Children, adolescents and parents Standard and home service T1 (1st. collection) e T2 (3 months after the 1st. collection)
Ji <i>et al.</i> ⁴	Type of report	Children, adolescents and parents
Kuhlthau <i>et al.</i> ²⁰	Type of report Treatment status	Children, adolescents and parents During, and after three months t
Lau <i>et al.</i> ⁵	Type of report Age group Treatment status	Children, adolescents and parents 2-4; 5-7; 8-12 and 13-18 years old with and without treatmet.
Meeske <i>et al.</i> ²¹	Group age Typed ofcancer Treatment status	2-4; 5-7; 8-12 and 13-18 years old Leukemia and Cerebral Tumor Receiving treatmet, out of treatmet ≤12 months and out of the treatmet <12 months
Pek <i>et al.</i> ²⁴	Type of Cancer	Solid and hematologic tumors
Pound <i>et al.</i> ¹⁶	Use of steroides	With and without steroids
Scarpelli <i>et al.</i> ⁶	Type of report Status of Treatment	Children, adolescents and parents Receiving treatmet,out of treatmet ≤ 12 months and out of treatmet >12 months
Sitairesmi <i>et al.</i> ⁷	Type of report Age group Intensity of treatment	Children, adolescents and parents 2-4 and 5-16 years old Intensive and non intensive treatment
Sung <i>et al.</i> ¹⁷	LLA Maintenance Protocol stay	Before and in maintenance Low risk and high risk
Syahrul Bariah <i>et al.</i> ¹⁸	Sex	Male and female
Tanir, Kuguoglu ⁸	Sex	Male and female
Tomlinson <i>et al.</i> ²⁵	Type of report	Reports of fathers and mothers
Tomlinson <i>et al.</i> ²⁶	Time between interview and death	Death with ≤ 6 and death > 6 months
Tsuji <i>et al.</i> ⁹	Type of report Age group	Children, adolescents and parents p 2-4; 5-7; 8-12 and 13-18 years old
Varni <i>et al.</i> ¹¹	Type of report Status of Treatment	Children, adolescents and parents Receiving treatm., and out of treatmet ≤ 12 months and out of treatmet >12 months

Note: ch//ado – ch//adolescent, LLA – Acute Linfoid Leukemia, treatm. – treatment, RDT radiotherapy

The variation of dimensions and general scores is probably related to the selection of comparison groups for the criteria of inclusion and the variants may be realized in the studies analysis. The possibility of comparison is reduced in most articles due to the shortage of studies in the comparison groups^{2,6,15,25} or the largest existence of researches aiming at adults². In this revision the following limitations were found: having just one reviser; the difficulty of establishing standards of comparison variants of articles due to the analysis diversity and objective groups adopted by authors but not in description of general and dimension scores of total sample in most part of the articles. It is concluded that the averages of scores by dimension and general scores have not achieved values below 30 and the largest scores by dimension are over 80. The existence of a standard of dimension could not be verified, always presenting the least or the largest score in relation to the other dimensions either for the children's / adolescents' or the parents' reports. However, it is suggested that the dimensions treatment anxiety in children's / adolescents' reports may have gotten the largest scores within each study; that is, it represents a least difficulty in face of the treatment and the illness in the dimensions treatment anxiety.

The nursing becomes a constant presence in children/adolescents' life with cancer, and may provide them with a better quality of life developing nursing activities as the team demistifies, clarify and help in the confrontation and all phases of the process of falling ill and the treatment.

References

- Varni J, Seid M, Rode C. The PEDSQL: measurement model for the pediatric quality of life inventory. *Med Care*. 1999; 37(2):126–39.
- Chaudhry Z, Siddiqui S. Health related quality of life assessment in Pakistani pediatric cancer patients using PedsQLTM 4.0 generic core scale and PedsQL(TM) cancer module. *Health Qual Life Outcomes*. 2012; 10:52.
- Felder-Puig R, Frey E, Proksch K, Varni JW, Gardner H, Topf R. Validation of the German version of the Pediatric Quality of Life Inventory (PedsQL) in childhood cancer patients off treatment and children with epilepsy. *Qual Life Res*. 2004; 13(1):223–34.
- Ji Y, Chen S, Li K, Xiao N, Yang X, Zheng S, et al. Measuring health-related quality of life in children with cancer living in Mainland China: feasibility, reliability and validity of the Chinese Mandarin version of PedsQL 4.0 Generic Core Scales and 3.0 Cancer Module. *Health Qual Life Outcomes*. 2011; 23 (9):103.
- Lau JTF, Yu X -n, Chu Y, Shing MMK, Wong EMC, Leung TF, et al. Validation of the Chinese version of the Pediatric Quality of Life Inventory™ (PedsQL™) Cancer Module. *J Pediatr Psychol*. 2009; 35(1):99–109.
- 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 (PedsQL (TM)) cancer module scale. *Health Qual Life Outcomes*. 2008; 22:6-7.
- Sitairesmi MN, Mostert S, Gundy CM, Sutaryo, Veerman AJP. Health-related quality of life assessment in Indonesian childhood acute lymphoblastic leukemia. *Health Qual Life Outcomes*. 2008; 6:96.
- Tanir MK, Kuguoglu S. Turkish validity and reliability of a pediatric quality of life cancer module for children aged 8-12 and parents. *Asian Pac J Cancer Prev*. 2011; 12(1):125–30.
- Tsuji N, Kakee N, Ishida Y, Asami K, Tabuchi K, Nakadate H, et al. Validation of the Japanese version of the Pediatric Quality of Life Inventory (PedsQL) Cancer Module. *Health Qual Life Outcomes*. 2011; 9:22–22.
- Varni JW, Burwinkle TM, Seid M. The PedsQL as a pediatric patient-reported outcome: reliability and validity of the PedsQL Measurement Model in 25,000 children. *Expert Rev Pharmacoecon Outcomes Res*. 2005; 5(6):705–19.
- Varni JW, Burwinkle TM, Katz ER, Meeske K, Dickinson P. The PedsQL in pediatric cancer: reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module. *Cancer*. 2002; 94(7):2090–106.

12. Varni JW, Limbers C, Burwinkle TM. Literature Review: Health-related Quality of Life Measurement in Pediatric Oncology: Hearing the Voices of the Children. *J Pediatr Psychol.* 2007; 32(9):1151–63.
13. Almeida Filho N, Barreto ML. *Epidemiologia e saúde: fundamentos, métodos, aplicações.* Rio de Janeiro: Guanabara Koogan; 2012.
14. Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. *International Classification of Childhood Cancer, third edition.* *Cancer.* 2005; 103(7):1457–67.
15. Baggott CR, Dodd M, Kennedy C, Marina N, Matthay KK, Cooper B, et al. An evaluation of the factors that affect the health-related quality of life of children following myelosuppressive chemotherapy. *Support Care Cancer.* 2011; 19(3):353–61.
16. Pound CM, Clark C, Ni A, Athale U, Lewis V, Halton JM. Corticosteroids, behavior, and quality of life in children treated for acute lymphoblastic leukemia; a multicentered trial. *J Pediatr Hematol Oncol.* 2012; 34(7):517–23.
17. Sung L, Yanofsky R, Klaassen RJ, Dix D, Pritchard S, Winick N, et al. Quality of life during active treatment for pediatric acute lymphoblastic leukemia. *Int J Cancer.* 2011; 128(5):1213–20.
18. Syahrul Bariah AHS, Roslee R, Zahara AM, Norazmir MN. Nutritional Status and Quality of Life (QoL) Studies among Leukemic Children at Pediatric Institute, Hospital Kuala Lumpur, Malaysia. *Asian J of Clin Nutr.* 2011; 3(2):62–70.
19. Barrera M, Schulte F. A Group Social Skills Intervention Program for Survivors of Childhood Brain Tumors. *J Pediatr Psycho.* 2009; 34(10):1108–18.
20. Kuhlthau KA, Pulsifer MB, Yeap BY, Rivera Morales D, Delahaye J, Hill KS, et al. Prospective Study of Health-Related Quality of Life for Children With Brain Tumors Treated With Proton Radiotherapy. *J Clin Oncol.* 2012; 30(17):2079–86.
21. Meeske K, Katz ER, Palmer SN, Burwinkle T, Varni JW. Parent proxy-reported health-related quality of life and fatigue in pediatric patients diagnosed with brain tumors and acute lymphoblastic leukemia. *Cancer.* 2004; 101(9):2116–25.
22. Abu-Saad Huijjer H, Sagherian K, Tamim H. Quality of life and symptom prevalence as reported by children with cancer in Lebanon. *Eur J Oncol Nurs.* 2013; 17(6):704–10
23. Hansson H, Kjaergaard H, Johansen C, Hallström I, Christensen J, Madsen M, et al. Hospital-based home care for children with cancer: feasibility and psychosocial impact on children and their families. *Pediatr Blood Cancer.* 2013; 60(5):865–72.
24. Pek JH, Chan Y-H, Yeoh AEJ, Quah TC, Tan PL, Aung L. Health-related Quality of Life in Children with Cancer Undergoing Treatment: A First Look at the Singapore Experience. *Ann Acad Med Singap.* 2010; 39(1):43–8.
25. Tomlinson D, Hinds P, Bartels U, Hendershot E, Sung L. Parent reports of quality of life for pediatric patients with cancer with no realistic chance of cure. *J Clin Oncol.* 2011; 29(6):639–45.
26. Tomlinson D, Hendershot E, Bartels U, Maloney A-M, Armstrong C, Wrathall G, et al. Concordance Between Couples Reporting Their Child's Quality of Life and Their Decision Making in Pediatric Oncology Palliative Care. *J Pediatr Oncol Nurs.* 2011; 28(6):319–25.