

Health-related quality of life of Brazilian children and adolescents with benign and malignant solid tumours: A prospective cohort study during the first year after hospital admission

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Abstract

Introduction: This study aims to assess the impact of paediatric benign and malignant solid tumours and its treatment on the health-related quality of life of children and adolescents who were followed up in a Reference Center in Pediatric Oncology in Rio de Janeiro.

Methods: It is a prospective cohort study. Quality of life assessment was performed using the PedsQL™ 4.0 Generic Core Scales and PedsQL™ 3.0 Cancer Module protocols three times: during hospital admission (T1), 6 months after admission (T2) and 1 year after admission (T3).

Results: We evaluated 132 patients, 59 men and 73 women, aged 2–17 years. In PedsQL™4.0, the Emotional Functioning scale was the one with the worst scores, while the scores on the Social Functioning scale was the best. In PedsQL™ 3.0, the worst domains were Procedural Anxiety and Worry. Patients with malignant bone tumours had the worst health-related quality of life. The group who received only surgery had better results. Total scores of PedsQL™4.0 and PedsQL™ 3.0 improved between T1 and T3.

Conclusion: Children and adolescents with malignant and benign neoplasms undergo changes in quality of life as a result of the disease and treatment, but an improvement has been observed over time.

KEYWORDS

adolescents, cancer, children, health-related quality of life

1 | INTRODUCTION

Paediatric tumours correspond to a group of several diseases which have in common the uncontrolled proliferation of abnormal cells and can occur in any part of the organism (NCI, 2016). The impact related to these tumours goes beyond the physical damages caused by the disease and its treatment; it has a negative impact on the patients'

quality of life (QOL) (Eiser & Jenney, 2007; Klassen, Anthony, Khan, Sung, & Klaassen, 2011). Progress in the treatment of paediatric tumours in the last years and the higher probability of cure for childhood cancer motivated an interest in monitoring the QOL of those patients during and after treatment (Klassen et al., 2011; Scarpelli et al., 2008; Varni, Katz, Seid, Quiggins, & Friedman-Bender, 1998) The assessment of health-related quality of life (HRQOL) has received

growing appreciation as an important health measure in clinical trials and health services evaluation (Eiser & Jenney, 2007; Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002).

The HRQOL has a subjective and multidimensional nature. Therefore, according to the World Health Organization (WHO) outlines, assessment instruments must approach physical, psychological and social domain (The WHOQOL Group, 1995; Varni, Limbers, & Burwinkle, 2007). The application of HRQOL measurements in health care allows to establish a better communication among patients, family and health team, to identify disease and treatment-related morbidities that were previously neglected and to facilitate decision-making (Eiser & Jenney, 2007; Hinds et al., 2009; Varni, Burwinkle, & Lane, 2005).

The HRQOL of oncologic paediatric patients has been the focus of many studies and is seen to be lower in patients under treatment and who have survived cancer as compared to the healthy population (Pogorzala et al., 2010; Ribi et al., 2005; Speechley, Barrera, Shaw, Morrison, & Mounse, 2016). The measurement of HRQOL in clinical practice represents a tendency to consider the health of patients in their entirety. In this context, our study aims to assess the impact of malignant and benign neoplasms and its treatment in HRQOL of children and adolescents followed up in a Reference Center in Pediatric Oncology in Rio de Janeiro. To our knowledge, this is the first Brazilian study to evaluate the QOL of a heterogeneous group of children and adolescents with various types of benign and malignant solid tumours in a prospective analysis of one year.

2 | METHODS

We developed a prospective cohort study including children aged 2 years and more, and adolescents admitted in the Pediatric Oncology Service of the Instituto Nacional de Câncer (INCA), from March 2014 to April 2015. Our research was approved by the Committee on Ethics in Research (number 492.325/2013), and we obtained the consent form from parents and assent form from the patients.

We assessed 213 patients at the moment of their admission to the hospital. All paediatric patients admitted at the time of the study were invited to participate in the survey by the main researcher, and there was no refusal by the patients and caregivers. The inclusion criteria were children and adolescents admitted to the Pediatric Oncology Service of the Institute. We excluded 48 patients who did not confirm the neoplasm diagnosis after investigation (absence of neoplasm) and five patients who did not remain in follow-up at INCA. During the study, 26 patients were lost due to their decease and two patients did not conclude the assessment process. Therefore, 132 patients with solid malignant and benign tumours were included in our study and were followed up for one year.

For the HRQOL assessment, we used the Brazilian versions of the PedsQL™4.0 *Generic Core Scales* and PedsQL™3.0 *Cancer Module* during three moments: at hospital admission (T1), 6 months after admission (T2) and one year after admission (T3). The questionnaires

were administrated by the main researcher, who applied the protocols for patients and their parents/caregivers separately. All evaluations, in the three moments, were carried out in person.

The generic PedsQL™ 4.0 questionnaire is a measure of 23 items for paediatric patients with chronic health disorders and for healthy school and community population, validated to be applied in Brazil (Klatchoian et al., 2008; Varni et al., 2002). It is characterised by multidimensionality and comprises the assessment of four scales: Physical Health, Emotional Functioning, Social Functioning and School Functioning. The protocol includes a self-assessment for children and teenagers in the age group of 5–18 years (divided into groups of 5–7, 8–12 and 13–18), and parent-proxy questionnaires for children and teenagers in the age group of 2–18 years (classified as 2–4, 5–7, 8–12 and 13–18) (Varni, Burwinkle, & Seid, 2006; Varni, Seid, & Kurtin, 2001).

The PedsQL™ 3.0 Cancer Module studies the same range of ages and measures the disease and treatment impact on QOL of children with cancer through eight subscales: Pain and Hurt, Nausea, Procedural Anxiety, Treatment Anxiety, Worry, Cognitive Problems, Physical Appearance Perception and Communication (Varni et al., 2002). The cultural adaptation and the evaluation of psychometric properties of the test were conducted by Scarpelli et al. in 2008, and the Brazilian version proved to have proper replicability and validity with regard to the assessment of neoplasm impact on QOL of children and adolescents with cancer (Scarpelli et al., 2008).

The items measured by PedsQL™ 4.0 and PedsQL™ 3.0 were scored on a 5-point scale, where 0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; and 4 = almost always a problem. These points were transformed into a 0–100 scale (0 = 100; 1 = 75; 2 = 50; 3 = 25; 4 = 0), wherein the higher scores indicate a better HRQOL (Chaudhry & Siddiqui, 2012).

Due to the lack of specific protocols for HRQOL assessment of patients with benign neoplasm, the PedsQL™ 3.0 was also applied for this group since these patients were treated at the same paediatric oncology service of the cancer patients and we considered the issues addressed in the subscales of this protocol suitable for the group of benign tumours.

Data from socio-demographic and clinical characteristics of patients were registered in a specific form based on the information provided by caregivers at the moment of the assessment and during the consultation of medical records.

Malignant neoplasms were classified based on the third edition of the International Classification of Childhood Cancer (ICCC-3) that divides tumours into 12 main groups: I—leukaemias, myeloproliferative and myeloid diseases; II—lymphomas and reticuloendothelial neoplasms; central nervous system (CNS) and miscellaneous intracranial and intraspinal neoplasm; IV—neuroblastoma and other peripheral nervous cell tumours; V—retinoblastoma; VI—renal tumours; VII—hepatic tumours; VIII—malignant bone tumours; IX—soft tissue sarcomas; X—germ cell tumours, trophoblastic tumours, and neoplasms of gonads; XI—other malignant epithelial neoplasms and malignant melanomas; and XII—other and unspecified malignant neoplasms (Steliarova-Foucher, Stiller, Lacour, & Kaatsch, 2005). This classification includes some tumours with uncertain behaviour

whether malignant or benign (borderline tumours), considering the modifications in ICD-O-3 (Percy, Van Holter, & Muir, 2000).

In the analysis of the relation between the type of tumour and the HRQOL, patients with malignant and borderline tumours classified in ICC-3 were separated into three groups: tumours of CNS (category III in ICC-3), bone tumours (category VIII) and other solid tumours, including neuroblastoma, retinoblastomas, renal tumours, hepatic tumours, soft tissue tumours, germ cells and other malignant epithelial neoplasms (category IV, V, VI, VII, IX, X and XI respectively).

With regard to the treatment influence developed in HRQOL, we considered only results obtained in T2 and T3 moments, as, in T1, most of the patients did not receive any treatment. In this analysis, patients were categorised into four groups: surgery, surgery associated with chemotherapy, surgery associated with chemotherapy and radiotherapy and other plans which correspond to patients undergoing chemotherapy, isolated chemotherapy and isolated radiotherapy.

For the descriptive analysis of the quantitative variables, we analysed the median and the standard deviation, and for the qualitative ones, the absolute and relative frequencies. For the evaluation of the differences between HRQOL and the independent variables, we applied Student's *t* test and Wilcoxon test, considering 5% of significance. We evaluated the concordance between HRQOL scores from answers provided by parents and children, using the Spearman correlation coefficient, classifying as very weak (0.00–0.19), moderate (0.40–0.69), strong (0.70–0.89) and very strong (0.90–1.00).

3 | RESULTS

We analysed 132 children and adolescents, most of them women (55.3%), and in the age range of 2–17 years (mean age = 9.10 ± 4.84). Out of the total participants, 115 (87.1%) had malignant or borderline tumours, and 17 (12.9%) had benign tumours (Table 1).

The most frequent solid tumours in the group assessed were the CNS types (category III in ICC-3), which were present in 29 patients (22.0%), followed by bone tumours (category VIII in ICC-3) that were present in 22 patients (16.7%; Table 1).

The results obtained from child self-report and parent-proxy report from PedsQL™ 4.0 are described in Table 2. In the questionnaire, the Emotional Functioning scale had the worst scores observed, both in the patient report and parent-proxy report, in moments T1, T2 and T3. The Social Functioning scale had the best results in both reports.

Considering the child self-report from PedsQL™ 3.0 (Table 2), the worst scores were in Procedural Anxiety and Worry in T1, T2 and T3. According to child self-report, the Pain and Hurt subscale had inferior scores in T1 compared to the scores in T2 and T3. The Nausea subscale had the worst scores in T2 (a moment when a great number of patients were under chemotherapy treatment).

Table 3 describes the associations between the total scores in questionnaires PedsQL™ 4.0 and PedsQL™ 3.0 and between socio-demographic and clinical variables.

There was no statistically significant difference between PedsQL™ 4.0 and PedsQL™ 3.0 scores according to gender. With

TABLE 1 Socio-demographic and clinical characteristics

Variable	N	%
Age		
Median	9.10	
Standard deviation	4.84	
Age group		
2–4	39	29.5
5–7	19	14.4
8–12	37	28.0
13–18	37	28.0
Gender		
Male	59	44.7
Female	73	55.3
Diagnosis		
Malignant or borderline tumours	115	87.1
Benign tumours ^a	17	12.9
Type of tumour (ICCC-3)		
III: CNS and miscellaneous intracranial and intraspinal neoplasms	29	22.0
IV: Neuroblastoma and other peripheral nervous cell tumours	6	4.5
V: Retinoblastoma	6	4.5
VI: Renal tumours and VII: Hepatic tumours	11	8.3
VIII: Malignant bone tumours	22	16.7
IX: Soft tissue and other extraosseous sarcomas	17	12.9
X: Germ cell tumours, trophoblastic tumours, and neoplasms of gonads	8	6.1
XI: Other malignant epithelial neoplasms and malignant melanomas	12	9.1
Non-classified by ICC-3 ^b	21	15.9
Treatment developed		
No treatment	6	4.5
Surgery	40	30.3
Radiotherapy	5	3.8
Chemotherapy	5	3.8
Surgery + Radiotherapy	4	3.0
Surgery + Chemotherapy	38	28.8
Radiotherapy + Chemotherapy	8	6.1
Surgery + Radiotherapy + Chemotherapy	26	19.7

^aCystoadenofibroma, osteoblastoma, lipoblastoma, ganglioneuroma, mature teratoma, paraganglioma, pheochromocytoma, meningioma, hemangioma, schwannoma, pleomorphic adenoma.

^bPatients with benign neoplasms and those with uncertain biologic behaviour that is not described in ICC-3.

respect to age, in the parent-proxy report, the PedsQL™ 4.0 scores for children in the age group of 2–4 years were better in relation to the other ages.

In the comparison between malignant and borderline tumours and benign tumours, patients with malignant and borderline

TABLE 2 Scale comparisons for the PesdQL™ 4.0 Generic Core Scales and PesdQL™ 3.0 Cancer Module child self-report and parent-proxy report at moments T1, T2 and T3

HRQOL	Moments of evaluation					
	T1		T2		T3	
	Child [*] Mean (±SD)	Parent Mean (±SD)	Child ^{**} Mean (±SD)	Parent Mean (±SD)	Child ^{***} Mean (±SD)	Parent Mean (±SD)
PesdQL™4.0						
Physical health	65.84 (±26.46)	66.45 (±29.92)	70.89 (±23.45)	71.75 (±26.97)	71.34 (±22.79)	74.17(±25.82)
Emotional Functioning	63.86 (±20.58)	60.89 (±20.63)	69.58 (±19.39)	68.30 (±20.67)	70.26 (±21.38)	69.51 (±18.41)
Social Functioning	85.49 (±16.10)	86.03 (±19.45)	86.09 (±16.95)	85.42 (±18.77)	86.85 (±16.04)	85.83 (±20.58)
School functioning	66.09 (±17.59)	72.86 (±18.13)	70.24 (±15.29)	76.98 (±17.96)	71.11 (±16.28)	75.91 (±18.51)
Total score	69.37 (±16.29)	70.52 (±19.07)	73.34 (±15.39)	74.64 (±18.51)	73.94 (±15.28)	75.46 (±17.81)
HRQOL	Moments of evaluation					
	T1		T2		T3	
	Child [*] Mean (±SD)	Parents Mean (±SD)	Child ^{**} Mean (±SD)	Parents Mean (±SD)	Child ^{***} Mean (±SD)	Parents Mean (±SD)
PedsQL™3.0						
Pain and Hurt	79.12 (±25.27)	79.51 (±30.19)	88.93 (±19.69)	92.14 (±16.66)	91.25 (±15.84)	89.58 (±19.61)
Nausea	90.25 (±15.66)	93.43 (±13.50)	78.23 (±22.19)	81.53 (±21.40)	84.75 (±21.10)	85.72 (±22.10)
Procedural Anxiety	64.22 (±34.09)	40.40 (±38.30)	68.49 (±33.90)	53.22 (±38.04)	71.08 (±34.21)	59.72 (±38.04)
Treatment Anxiety	84.33 (±24.17)	64.20 (±36.93)	91.84 (±17.39)	75.63 (±30.45)	91.85 (±16.23)	80.18 (±30.12)
Worry	52.72 (±31.40)	72.12 (±30.56)	54.39 (±30.21)	75.45 (±30.96)	59.50 (±31.18)	76.26 (±29.97)
Cognitive Problems	77.69 (±19.12)	83.72 (±20.64)	80.42 (±18.60)	81.93 (±19.62)	79.54 (±19.94)	81.63 (±20.47)
Physical Appearance	80.41 (±23.99)	82.76 (±25.16)	81.86 (±22.49)	82.95 (±25.70)	80.32 (±23.58)	83.78 (±23.24)
Communication	70.29 (±28.85)	67.04 (±29.15)	74.83 (±24.21)	70.87 (±30.26)	78.20 (±23.82)	72.74 (±30.31)
Total score	76.51 (±13.87)	74.86 (±12.79)	77.19 (±11.66)	76.66 (±13.11)	79.49 (±12.46)	79.04 (±13.04)

Abbreviation: HRQOL, Health-related quality of life.

**n* = 92.

***n* = 96.

****n* = 100.

tumours had the QOL scores slightly inferior to patients with benign neoplasms. However, there was a significant difference only in the PedsQL™ 4.0 parent-proxy report in T1 and T2 and in PedsQL™ 3.0 parent-proxy report in T2.

PedsQL™ 4.0 scores varied significantly according to the ICCC-3 category. Patients with bone tumours had HRQOL scores inferior to CNS and other tumours in all moments assessed. However, when the T1 and T3 scores were compared, the scores of patients with bone tumours had improved the most. In PedsQL™ 3.0, we observed a difference in HRQOL between groups with malignant tumours in the parent-proxy report in T1 and T3 (Table 3).

With regard to the treatment influence developed in HRQOL, patients who underwent surgery alone had higher scores in PedsQL4.0™ and PedsQL3.0™. In PedsQL4.0™, T3 scores were worse in relation to T2 results from patients of other plans group, which includes subgroups of isolated chemotherapy, isolated radiotherapy and chemotherapy associated with radiotherapy (Table 4). It was not possible to perform adjusted analysis (multiple linear regression) with the data from Tables 3 and 4 due to insufficient sample size.

During the analysis of the results from child/adolescent and parent-proxy reports, we observed a strong correlation between total scores in PedsQL™ 4.0, and a moderate correlation between scores in PedsQL™ 3.0. The information is presented in Figure 1.

When comparing the total scores during the three moments of assessment (Table 5), there was a statistically significant improvement between the mean of PedsQL™ 4.0 total scores for T1 and T2, for both child and parent-proxy report. Therefore, in PedsQL™ 3.0, the difference in T1 and T2 moments had no statistical significance. In PedsQL™ 3.0, there was a score improvement for children between T2 and T3 moments.

We observed a statistically significant improvement in the total scores of PedsQL™ 4.0 and PedsQL™ 3.0 in child and parent-proxy report, between T1 and T3 moments (Table 5).

4 | DISCUSSION

In our study, we observed an improvement in HRQOL of children and adolescents with solid malignant and benign tumours after

TABLE 3 Association of total scores from socio-demographic and clinical variables

	T1				T2				T3			
	Total score PedsQL™ 4.0 Child*		Total score PedsQL™ 4.0 Parents		Total score PedsQL™ 4.0 Child**		Total score PedsQL™ 4.0 Parents		Total score PedsQL™ 4.0 Child***		Total score PedsQL™ 4.0 Parents	
	Mean (±SD)	p-value	Mean (±SD)	p-value	Mean (±SD)	p-value	Mean (±SD)	p-value	Mean (±SD)	p-value	Mean (±SD)	p-value
Gender												
Male	69.09 (±15.04)	0.886	68.00 (±17.38)	0.173	74.12 (±15.88)	0.671	74.47 (±17.32)	0.923	74.97 (±13.42)	0.550	74.72 (±17.02)	0.668
Female	69.58 (±17.32)		72.56 (±20.22)		72.76 (±15.14)		74.79 (±19.55)		73.12 (±16.67)		76.06 (±18.51)	
Age												
2-4		0.364	79.24 (±13.41)	0.006		0.336	81.95 (±15.49)	0.022		0.872	81.35 (±13.89)	0.047
5-7	74.00 (±14.50)		69.07 (±22.15)		78.24 (±13.65)		74.90 (±15.86)		76.13 (±13.05)		72.46 (±18.61)	
8-12	67.34 (±17.88)		65.11 (±19.88)		73.47 (±14.84)		70.31 (±20.88)		73.03 (±14.53)		70.36 (±20.74)	
13-18	69.14 (±15.38)		67.48 (±19.23)		70.41 (±16.83)		71.15 (±18.52)		74.30 (±17.41)		75.90 (±16.66)	
Diagnosis												
Malignant	68.34 (±16.63)	0.137	69.12 (±19.33)	0.028	72.17 (±15.56)	0.072	72.76 (±18.77)	0.002	73.71 (±15.57)	0.721	74.50 (±18.05)	0.108
Benign	75.60 (±12.85)		79.96 (±14.39)		80.19 (±12.78)		87.40 (±9.97)		75.25 (±13.97)		81.94 (±14.96)	
ICCC-3 ^d												
CNS (III)	71.91 (±13.32)	<0.001	64.13 (±17.12)	<0.001	75.18 (12.92)	<0.001	73.11 (±15.76)	<0.001	71.45 (±13.18)	<0.001	68.09 (±18.47)	<0.001
Bone (VIII)	51.45 (±15.47)		48.96 (±19.45)		58.64 (13.66)		53.75 (±22.04)		63.46 (±16.96)		60.14 (±20.93)	
Others	75.96 (±11.32)		78.42 (±13.69)		78.17 (13.03)		78.98 (±14.21)		80.67 (±12.17)		82.08 (±11.86)	
Gender												
Male	79.17 (±12.19)	0.106	75.16 (±12.66)	0.808	78.16 (±10.02)	0.481	75.70 (±12.57)	0.453	81.36 (±11.93)	0.183	78.58 (±13.70)	0.721
Female	74.46 (±14.83)		74.61 (±12.98)		76.46 (±12.80)		77.43 (±13.56)		78.01 (±12.77)			
Age												
2-4		0.941	76.35 (±9.43)	0.148		0.117	77.23 (±11.61)	0.047		0.388	82.67 (±10.29)	0.077
5-7	77.54 (±13.84)		79.71 (±9.17)		81.30 (±9.74)		83.08 (±10.79)		83.72 (±11.74)		79.56 (±10.44)	
8-12	76.26 (±15.41)		72.15 (±14.64)		78.59 (±11.98)		72.78 (±15.70)		79.17 (±11.94)		74.89 (±15.22)	
13-18	76.25 (±12.56)		73.50 (±14.87)		74.43 (±10.70)		76.64 (±11.86)		78.58 (±13.78)		79.09 (±13.74)	

(Continues)

TABLE 3 (Continued)

Diagnosis	Total score PedsQL™ 3.0 Child*		Total score PedsQL™ 3.0 Parents		Total score PedsQL™ 3.0 Child**		Total score PedsQL™ 3.0 Parents		Total score PedsQL™ 3.0 Child***		Total score PedsQL™ 3.0 Parents	
	Mean (±SD)	p-value	Mean (±SD)	p-value	Mean (±SD)	p-value	Mean (±SD)	p-value	Mean (±SD)	p-value	Mean (±SD)	p-value
Malignant	76.28 (±14.41)	0.707	74.19 (±12.63)	0.119	76.26 (±11.76)	0.060	75.53 (±13.22)	0.010	79.01 (±12.76)	0.368	78.27 (±13.16)	0.080
Benign	77.86 (±10.41)		79.63 (±13.35)		82.59 (±9.83)		84.28 (±9.56)		82.17 (±10.59)		84.21 (±11.21)	
ICCC-3****												
CNS (III)	78.94 (±14.23)	0.052	75.14 (±12.77)	0.023	79.87 (±11.28)	0.064	76.78 (±12.00)	0.075	81.84 (±11.60)	0.219	75.38 (±14.37)	0.011
Bone (VIII)	69.88 (±17.52)		67.60 (±16.09)		71.70 (±9.71)		69.59 (±16.81)		75.36 (±13.70)		72.84 (±17.76)	
Others	78.75 (±11.62)		76.08 (±10.55)		76.97 (±12.07)		76.73 (±11.94)		79.66 (±12.27)		81.60 (±9.77)	

Abbreviation: CNS, central nervous system.

*n = 92.

**n = 96.

***n = 100.

****It is included in this classification patients with malignant neoplasms and with uncertain biologic behaviour described in ICC-3.

one year of their hospital admission in a public Reference Center in Pediatric Oncology in Rio de Janeiro. As per our knowledge, this study is the first Brazilian prospective cohort study that evaluated the HRQOL of a heterogeneous group of children and adolescents with malignant solid tumours and benign tumours.

The scores observed in our study were inferior to that of the healthy Brazilian individuals studied by Klatchoian et al. (2008). They were also inferior to the scholar samples of healthy American individuals who participated in the Varni et al. (2006) study. This reflects the impact of the disease and its treatment on the HRQOL of individuals.

The scores were higher on the Social Functioning scale as was observed in other studies conducted with paediatric oncologic populations using the same instrument (Ji et al., 2011; Varni et al., 2002). This could be explained, in part, by the fact that in the institution where the study was carried out, humanisation programmes promote social interaction among children and adolescents undergoing treatment that could possibly lead to a reduction in the impact of the disease on the social domain of the evaluated group. Varni et al. (2002) had observed the worst scores in Scholar Functioning scale, while in our study, the Emotional Functioning scale had the lower scores.

In the specific module PedsQL™ 3.0, patients had worse scores in Worry and Procedural Anxiety subscales. These dimensions had lower values in other studies as well (Ji et al., 2011; Scarpelli et al., 2008; Varni et al., 2002).

Some authors described the HRQOL of the female gender to be worse as compared to the men, which was mainly due to body image modifications that would affect girls more (Klassen et al., 2011; Meeske, Katz, Palmer, Burwinkle, & Varni, 2004; Mounir & Abolfotouh, 2007; Shankar et al., 2005; Vlachiotti et al., 2016). In a longitudinal study conducted by Landolt, Vollrath, Niggli, Gnehm, and Sennhauser (2006) using TACQOL, girls had better scores in autonomy domain, whereas boys had better scores in emotional and cognitive domains (Landolt et al., 2006). In our study, we did not observe the relation between gender and QOL of our sample. This may be related to the fact that almost half of the group are children younger than 7 years and these gender issues are less evident for them (Pogorzala et al., 2010; Yaris, Yavuz, Yavuz, & Okten, 2001).

An association between age and HRQOL scores was also observed in the parent-proxy PedsQL™ 4.0 report. Children between 2 to 4 years of age were assessed by caregivers as having a better HRQOL than older children and adolescents. Such results may be related to the parental judgement that children in this age had no notion of the real disease, its gravity and implications, which would affect their interpretation concerning the QOL of these younger children. Other studies showed that older patients had worse HRQOL (Maurice-Stam, Grootenhuis, Brons, Caron, & Last, 2007; Meeske et al., 2004; Pogorzala et al., 2010; Sung et al., 2008; Wu et al., 2007). Despite the small difference in the number of items in the questionnaires for parents of 2- to 4-year olds (21 items) and the other versions (23 items), we do not believe that this could be related to the difference in the observed results.

TABLE 4 Association of the treatments with total scores at the moments T2 and T3

Treatments	T2				T3			
	Total score PedsQL™ 4.0 Child* Mean (±SD)	p-value	Total score PedsQL™ 4.0 Parents Mean (±SD)	p-value	Total score PedsQL™ 4.0 Child** Mean (±SD)	p-value	Total score PedsQL™ 4.0 Parents Mean (±SD)	p-value
Surgery	82.17 (±10.53)	<0.001	83.69 (±10.67)	0.001	78.78 (±12.07)	0.060	82.11 (±12.58)	0.003
Surgery + CT	65.13 (±15.47)		69.01 (±20.42)		73.24 (±11.95)		76.21 (±15.24)	
Surgery + CT + RDT	70.23 (±16.70)		69.62 (±22.60)		71.81 (±22.29)		73.05 (±21.93)	
Other plans	71.27 (±13.80)		71.55 (±16.66)		67.14 (±15.04)		65.11 (±19.73)	

Treatments	T2				T3			
	Total score PedsQL™ 3.0 Child* Mean (±SD)	p-value	Total score PedsQL™ 3.0 Parents Mean (±SD)	p-value	Total score PedsQL™ 3.0 Child** Mean (±SD)	p-value	Total score PedsQL™ 3.0 Parents Mean (±SD)	p-value
Surgery	81.23 (±11.79)	0.010	80.99 (±11.70)	0.057	82.06 (±10.99)	0.434	81.72 (±10.13)	0.286
Surgery + CT	74.38 (±11.56)		76.02 (±14.15)		76.62 (±14.87)		78.74 (±13.63)	
Surgery + CT + RDT	70.72 (±12.11)		72.22 (±14.72)		79.10 (±12.08)		79.42 (±14.48)	
Other plans	79.68 (±8.87)		75.19 (±11.54)		79.56 (±13.10)		75.04 (±14.52)	

Abbreviations: CT, chemotherapy; RDT, radiotherapy.

*n = 96.

**n = 100.

Although patients with malignant and benign tumours are distinct in gravity and treatment intensity manners, there is no significant difference between these groups in the patient report of PedsQL™ 4.0

and PedsQL™ 3.0, except in some parent-proxy report. It is important to discuss that benign neoplasms, similar to malignant neoplasms, can have a physical, emotional and social impact on patients. Considering

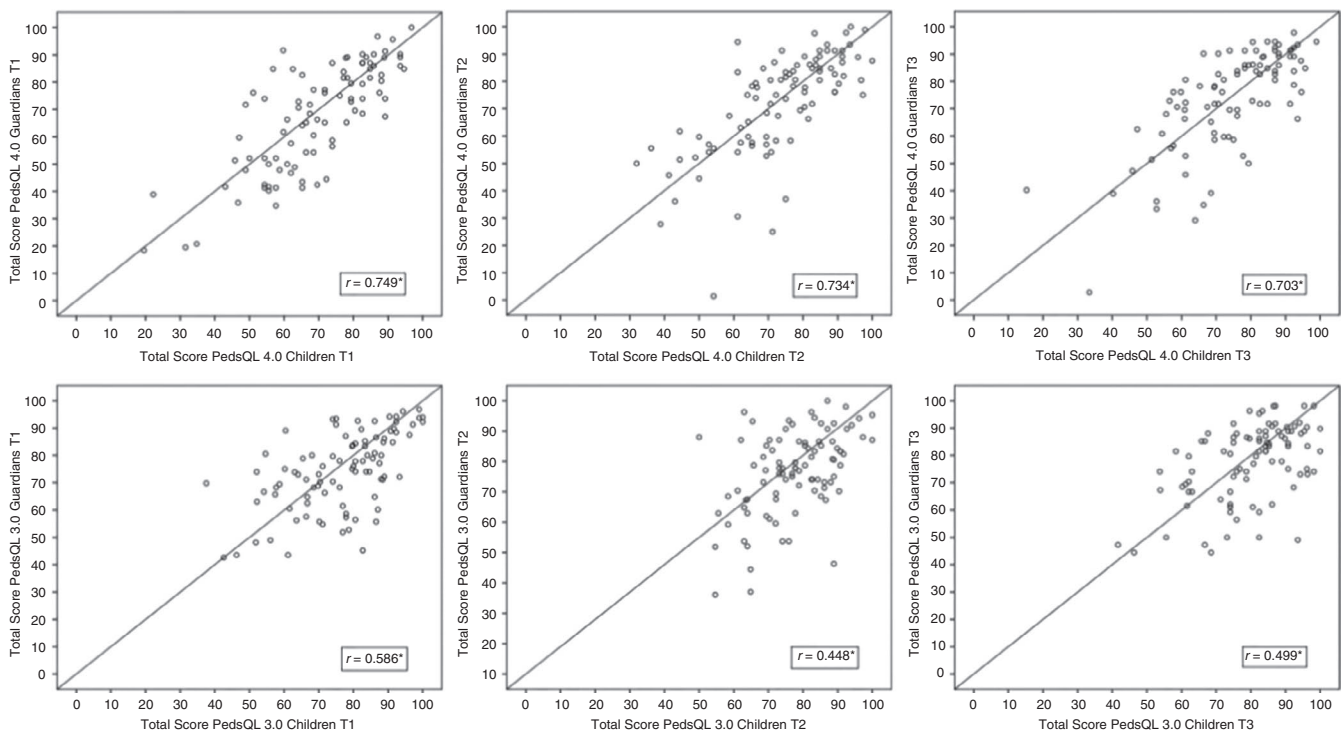


FIGURE 1 Correlation between children/guardians scores

TABLE 5 Comparison between total scores in the PedsQL™ 4.0 and PedsQL™ 3.0 at the moments T1, T2 and T3

PedsQL™ 4.0 total score	T1	T2	Differences (before–after)				Wilcoxon test		
	Mean	Mean	95% CI			p-value	Negative	Positive	Maintained
			Mean	Inferior	Superior				
Pair 1 (T2-T1) Children n = 92	69.37	73.17	3.807	0.829	6.785	0.012	36	55	1
Pair 1 (T2-T1) Parents n = 132	70.52	74.64	4.125	1.521	6.728	0.002	50	77	5
PedsQL™ 4.0 total score	T2	T3	Differences (before–after)				Wilcoxon test		
	Mean	Mean	95% CI			p-value	Negative	Positive	Maintained
			Mean	Inferior	Superior				
Pair 2 (T3-T2) Children n = 96	73.34	74.19	0.844	-1.667	3.356	0.506	35	49	12
Pair 2 (T3-T2) Parents n = 132	74.64	75.46	0.818	-1.772	3.407	0.533	51	65	16
PedsQL™ 4.0 total score	T1	T3	Differences (before–after)				Wilcoxon test		
	Mean	Mean	95% CI			p-value	Negative	Positive	Maintained
			Mean	Inferior	Superior				
Pair 3 (T3-T1) Children n = 92	69.37	74.15	4.780	2.071	7.489	0.001	29	59	4
Pair 3 (T3-T1) Parents n = 132	70.52	75.46	4.942	2.297	7.587	<0.001	45	81	6
PedsQL™ 3.0 total score	T1	T2	Differences (before–after)				Wilcoxon test		
	Mean	Mean	95% CI			p-value	Negative	Positive	Maintained
			Mean	Inferior	Superior				
Pair 1 (T2-T1) Child n = 92	76.51	77.44	0.938	-1.628	3.505	0.470	46	45	1
Pair 1 (T2-T1) Parents n = 132	74.86	76.66	1.802	-0.277	3.881	0.089	55	76	1
PedsQL™ 3.0 total score	T2	T3	Differences (before–after)				Wilcoxon test		
	Mean	Mean	95% CI			p-value	Negative	Positive	Maintained
			Mean	Inferior	Superior				
Pair 2 (T3-T2) Children n = 96	77.19	79.83	2.642	0.350	4.933	0.024	33	55	8
Pair 2 (T3-T2) Parents n = 132	76.66	79.04	2.377	0.341	4.414	0.022	53	63	16
PedsQL™ 3.0 total score	T1	T3	Differences (before–after)				Wilcoxon test		
	Mean	Mean	95% CI			p-value	Negative	Positive	Maintained
			Mean	Inferior	Superior				
Pair 3 (T3-T1) Children n = 92	76.51	79.82	3.315	0.588	6.041	0.018	34	54	4
Pair 3 (T3-T1) Parents n = 132	74.86	79.04	4.179	1.941	6.418	<0.001	52	80	0

the subjective nature of HRQOL, the fact that patients with benign neoplasms are being treated in the same institution of cancer patients and receiving could explain the similarity between groups. Besides, the small statistical difference found can be due to the size of the sample. No other studies comparing HRQOL in individuals with malignant and benign tumours have been found in the literature.

Among cancer patients, those with bone tumours have worse HRQOL at every moment of assessment as compared to that of patients with CNS and other solid tumours. Bone tumour patients often need extensive surgical intervention associated with intense chemotherapy, which can cause problems in mobility, functioning and body image limitations. Compared to the healthy population,

bone tumour patients commonly have the worst HRQOL (Barrera, Teall, Barr, Silva, & Greenberg, 2012; Gerber et al., 2006; Koopman et al., 2005; Nagarajan, Mogil, Neglia, Robison, & Ness, 2009; Stokke, Sung, Gupta, Lindberg, & Rosenberg, 2015). According to the study conducted by Batra, Kumar, Gomber, and Bhatia (2014), patients with CNS tumours had worse HRQOL than patients with haematologic tumours and other solid tumours; however, the sample included only two patients with bone tumours (Batra et al., 2014). In a study comparing adolescents with osteosarcoma and leukaemia at diagnosis, the osteosarcoma patients presented significantly inferior values of HRQOL as compared to the leukaemia patients (Hinds et al., 2009).

In our study, even though the worse scores of HRQOL were observed in bone tumour patients, they presented better improvement between T1 and T3 moments, which can be related to symptom control during treatment, adaptations and coping strategies (Stokke et al., 2015). Prospective studies on bone tumour patients show an improvement in the HRQOL over time. As in the study by Koopman et al. (2005), which reported that paediatric patients after eight years of treating bone tumours had HRQOL similar to healthy individuals, suggesting they had gradually adapted to their difficulties. On the contrary, many studies on CNS tumour survivors revealed altered HRQOL in these patients, even after a long term period (Bhat et al., 2005; Eiser, Vance, Horne, Glaser, & Galvin, 2003; Meeske, Patel, Palmer, Nelson, & Parow, 2007; Palmer, Meeske, Katz, Burwinkle, & Varni, 2007; Pogorzala et al., 2010).

Our results revealed that the HRQOL of patients with CNS tumours was worse than that of patients with other solid tumours, although better than patients with bone tumours during the first year. A longer follow-up could reveal how these groups develop in the long term, depending on the sequelae and treatment. Brain tumour survivors have a higher risk of having a worse psychosocial HRQOL, considering the chances of undergoing neurocognitive, social and behavioural impairments due to neurological damages (Anderson et al., 2001; Meeske et al., 2004, 2007; Ribí et al., 2005; Vannata, Garstein, Short, & Noll, 1998).

With regard to oncologic treatments, we observed that patients who had to undergo only surgery had better HRQOL at 6 months and after one year following admission at the institution. Similar results were also found by Mounir and Abolfotouh (2007) and Bhat et al. (2005). For patients who received chemotherapy and radiotherapy associated with surgery, their HRQOL was greatly impacted due to toxicity and adverse effects of these treatments (Melaragno & De Camargo, 2013; Pogorzala et al., 2010; Sung et al., 2008).

The group of patients classified into other plans, which included isolated chemotherapy, isolated radiotherapy or chemotherapy associated with radiotherapy, had worse HRQOL at the end of the first year. This group included patients with brain stem tumours and advanced tumours without a possibility of a surgical resection and considered as bad prognosis patients, which reflected in the worse quality of their life at the end of one year. Vlachiotti et al. (2016) observed that children and adolescents with neurological tumours treated with exclusive radiotherapy had lower levels of

HRQOL in comparison to those who received other types of therapy. Frequently, children who do not present a good response to conventional therapies, who have relapse or disease progression or who do not have a perspective of cure of the disease have worse QOL (Tomlinson et al., 2011). Particularly, children with incurable brain tumours are a distinct set owing to their progressive neurological deteriorations that invariably affect their psychological status (Cataudella & Zelcer, 2012).

With regard to the concordance between the results from patients and parent-proxy reports, we observed a strong correlation between the results of PedsQL™ 4.0 and moderate correlation between the PedsQL™ 3.0 scores, which is congruent to the results presented in the studies by Klatchoian et al. (2008) and Scarpelli et al. (2008) respectively. The variation in the concordance ranges can be related to how subjective and objective are the symptoms investigated (Tomlinson et al., 2011).

There was an improvement in HRQOL scores in PedsQL™ 4.0 between the initial moment and after 6 months, which may indicate that disease-related symptom control due to initiation of treatment had a positive impact on the general HRQOL. On the other hand, there was no difference between the same moments in the PedsQL™ 3.0 that is more sensitive to treatment effects. As an example, Nausea scale had the worse average in T2, the moment where many patients were undergoing chemotherapy.

In the comparison between the initial and final moments, the average of the scores for both instruments improved, which means that most of the patients had better HRQOL at the end of 1-year treatment. This result refers to the 132 patients evaluated at the three moments during a year. It is noteworthy that the information on the QOL of the 26 patients who died during the development of the study was not considered in the analysis. Other studies also revealed poor HRQOL during the diagnosis and an improvement after treatment and at the end of it (Batra et al., 2014; Landolt et al., 2006; Meeske et al., 2004; Varni et al., 2007). Nevertheless, Vlachiotti et al. (2016) did not observe significant variations in the QOL of children and adolescents with cancer throughout the treatment and disclosed that these patients may have good results in the QOL despite the physical and psychosocial impairment. It was not possible to analyse the informations related to the treatments comparing different time points, considering the size of the sample, the diversity of diagnoses and different treatment schemes.

The main limitation of our study was the size of the sample, which prevented the development of a predictor pattern of risk associated with worsening of HRQOL. However, cancer in a paediatric population is a rare condition and our study encloses an important number of patients followed up in one reference centre for oncologic treatment. Another important aspect to be considered is that many HRQOL studies present cross-sectional characteristics (Pogorzala et al., 2010). Our study has the advantage of being a longitudinal prospective study that allows a better understanding of the QOL modifications through a period of time and at different moments of the treatment.

5 | CONCLUSION

We found that children and adolescents with malignant and benign neoplasms undergo changes in their QOL due to the disease and its treatment, but an improvement in HRQOL has been observed over time. Individuals with bone tumours had worse HRQOL. The group of patients who received only surgery had better HRQOL over the course of one year.

The use of HRQOL measures as a health outcome on patients with paediatric tumours is relevant and aims to allow the implementation of strategies to improve global care for this population.

CONFLICT OF INTEREST

The authors have no conflict of interest to report.

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