J Pediatr Res 2024;11(1):66-74
DOI: 10.4274/jpr.galenos.2024.92053

Original Article

An Evaluation of Quality of Life in Children and Adolescents in an Inpatient Oncology Unit: A 6-month Follow-up Study

Birsen Şentürk Pilan[1], İpek İnal Kaleli[1], Serpil Erermiş[1], Mehmet Kantar[2], Eda Ataseven[2], Burcu Özbaran[1], Tezan Bildik[1]

[1]Ege University Faculty of Medicine, Department of Child and Adolescent Psychiatry, İzmir, Turkey
[2]Ege University Faculty of Medicine, Department of Pediatrics, Pediatric Hematology and Oncology, İzmir, Turkey

ABSTRACT

Aim: Childhood cancers are life-threatening diseases which are universally distressing and potentially traumatic for children and their families at the time of diagnosis, during treatment, and beyond.

Materials and Methods: Thirty-nine child patients between the ages of 0-18 years receiving treatment in a pediatric oncology hospital for various pediatric cancers who consented to participate in this study were recruited. The participants were assessed via Kiddie-Schedule for Affective Disorders and Schizophrenia-Present and Lifetime Version-Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition/K-SADS-PL-DSM-5 for ages 6-18 by a trained and certified child and adolescent psychiatrist. The clinical assessments of patients aged 0-5 years were completed by a trained child and adolescent psychiatrist in agreement with the DSM-5 and the standard principles of psychiatric interview for the pediatric population. The previous and current psychiatric diagnoses of the participants were recorded. The Quality-of-Life Scale for Children was administered to the participants and their caregivers at the first interview and at the 6th month of follow-up.

Results: While no significant differences were observed in the quality of life of children with a novel pediatric cancer diagnosis and children with cancer recurrence/ongoing treatment per their own reports, the parents reported significant improvement in the quality of life of those children who had a novel cancer diagnosis after six months.

Conclusion: The parents' and their children's reports were highly correlated, and this association remained significant in multiple linear regression analyses for both the initial interviews and the follow-ups. The parents' reports on their children's quality of life appear to be reliable in accurately predicting their children's quality of life in the clinical setting.

Keywords: Pediatric oncology, quality of life, child and adolescent mental health, psycho-oncology

Introduction

Childhood cancers are life-threatening diseases which are universally distressing and potentially traumatic for children and their families at the time of diagnosis, during treatment, and beyond. A population-based registry study conducted between 2001 and 2010 revealed age-standardized incidence rates for childhood cancers to be 140.6 per million person-years in the 0-14 year-old

Address for Correspondence
İpek İnal Kaleli, Ege University Faculty of Medicine, Department of Child and Adolescent Psychiatry, İzmir, Turkey
Phone: +90 536 856 07 96 **E-mail:** ipekinal93@gmail.com **ORCID:** orcid.org/0000-0003-2148-2363
Received: 22.12.2023 **Accepted:** 29.02.2024

demographic. Leukemia, central nervous system (CNS) tumors, and lymphomas were the most commonly reported cancers in the pediatric population respectively (1). Similarly, with a relatively younger population, a registry-based study conducted in Turkey reported 2,000 new cases of pediatric cancer each year. In contrast to the world statistics, the most common childhood cancers reported in Turkey were leukemias (31%), lymphomas (19%), CNS neoplasms (13%), and neuroblastomas (7%), which is in line with the reported frequencies in developing countries for lymphomas and CNS tumors; ranking as the second and third most common pediatric cancers, respectively (2). Dramatic improvements in survival rates have occurred as a result of increased aggressive multimodal therapies with 5-year survival rates reaching 74.4% in Turkey (3), but still 10-15% lower than the 5-year survival rates reported in developed countries (4).

Pediatric cancers remain among the leading causes of death in children (2,5), and despite developments in treatment methods and a global increase in survival rates, treatment process and complications negatively affect quality of life (QoL), especially in the pediatric population (6,7). The social and psychological distress experienced and expressed by the child and their caregivers vary depending on the type of cancer, the social environment, and the medical care provided, with all playing a role in the perceived distress. Thus, the health-related QoL, defined by the perceptions of the effects of a disease and its treatment on a patient over time, may worsen in children diagnosed with cancer and their families during and after treatment (8,9). While a multitude of studies have assessed the QoL after treatment, it is equally important to appraise the QoL during the treatment process in vulnerable populations, such as the pediatric population.

The present study aimed (1) to identify differences in QoL of children with a novel cancer diagnosis and those with recurrence or ongoing treatment, (2) to examine changes in QoL over time for both groups of children, and (3) to evaluate the level of agreement between parental reports on QoL of their children with the children's own reports to assess if the parent reports could be used in the place of the children's in situations where children may not be able to express their needs effectively.

Materials and Methods

Study Design

Forty-one child patients and their parents were recruited into this study. The patients were between the ages of 0-18 years receiving treatment in a pediatric oncology hospital for various pediatric cancers and all consented to participate in this study. The participants were assessed via Kiddie-Schedule for Affective Disorders and Schizophrenia (K-SADS)-Present and Lifetime Version-Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition/K-SADS-PL-DSM-5 for ages 6-18 years by a trained and certified child and adolescent psychiatrist. A trained child and adolescent psychiatrist completed the clinical assessments of those patients aged 0-5 years in agreement with DSM-5 and the standard principles of psychiatric interview for the pediatric population. The previous and current psychiatric diagnoses of the participants were recorded. The Quality-of-Life Scale for Children (PedsQL) was administered to the patients and their parents at their first and their 6th-month follow-up interviews.

Of the 41 patients recruited initially, two were unable to complete the second interview or the QoL assessment performed at six months and were excluded. Thus, a total of 39 patients and their parents were included in this study. Sixteen participants had been recently admitted to the hospital with a novel oncologic diagnosis (diagnosis made less than 6 months prior to the initial interview) and formed the novel diagnosis group, and 23 patients had been diagnosed more than 6 months prior with a history of either readmission for ongoing treatment or recurrence and formed the recurrence group.

This study was conducted at Ege University Faculty of Medicine and Ege University Faculty of Medicine Medical Research Ethics Committee approved the study regarding ethical principles (approval no.: 19-3.1T/45, date: 20.03.2019). Children and their parents were verbally informed about the study's design and verbal assent or written informed consent forms were obtained from the children and their parents, where appropriate.

Measures

K-SADS

K-SADS is a widely utilized semi-structured psychiatric interview for the diagnosis of various pediatric mental disorders (10). K-SADS is an internationally valid and reliable tool for diagnosing psychiatric disorders of childhood including for the Turkish youth (11).

The PedsQL

PedsQL is a brief measure assessing five subdomains: physical functioning, emotional functioning, psychosocial functioning, social functioning, and school functioning to create a composite assessment of health-related QoL (12).

This measure can be completed by either the children and adolescents aged 2-18 years as a self-report questionnaire or by their caregivers (13). In the current study, even though 25.6% of the pediatric population (n=10) were unable to complete the scale due to their age, 74.4% were deemed to be at a capable level and the PedsQL was completed by both the caregivers and the children and both were included in the analysis.

Statistical Analysis

IBM SPSS Statistics v25.0 was used for the statistical analyses. The distribution of the PedsQL scores were assessed by Shapiro-Wilk. The differences between the children's and their parents' PedsQL scores were assessed with Student's t-test for normally distributed variables and the Mann-Whitney U test for variables with a non-normal distribution. Changes in PedsQL scores during the initial interview and follow-up as paired samples were assessed with the Paired Samples t-test and Wilcoxon Rank-Sum test for normal and non-normal distributions, respectively. Pearson's and Spearman's correlation was utilized to determine the level of agreement between the parents' and children's PedsQL reports. Multiple Linear Regression Analyses were conducted in order to predict the children's PedsQL scores in the initial and the follow-up interviews by using the parents' PedsQL scores as the predictors in the respective interviews, while accounting for group and psychiatric diagnoses. All parametric and non-parametric tests were two-tailed, and p values <0.05 were considered statistically significant for all analyses.

Results

A total of 39 pediatric patients and their caregivers were included in this study. The mean age of the population was 9.71 (±4.66) years, 38.5% (n=15) were male and 61.5% (n=24) were female. The highest frequencies among the pediatric neoplasms were rhabdomyosarcoma (n=7, 17.9%), osteosarcoma (n=7, 17.9%), medulloblastoma (n=4, 10.3%), and acute lymphoblastic leukemia (n=4, 10.3%) in the study population. The most common psychiatric diagnosis was depression (n=20, 51.3%), followed by adjustment disorder (n=7, 17.9%), anxiety disorder (n=3, 7.7%), and intellectual disability (n=1, 2.6%). Eight participants did not meet any criteria for any psychiatric disorder (20.5%). The sociodemographic data with pediatric oncologic and psychiatric disorders are summarized in Table I.

Nine children were unable to complete the PedsQL. The child and adolescent reported PedsQL scores were not found to be statistically different between the novel diagnosis (n=10) or the recurrence (n=20) groups in either the initial or follow-up interviews (all p>0.05). Only the parents' PedsQL School Functioning sub-scores in the initial interview were higher than the recurrence/ongoing treatment group (p=0.035). No differences in the parents' PedsQL total or subscale scores were found among the groups in the initial interview (all p>0.05). In contrast, the parents' PedsQL total scores (p=0.022) and Emotional Functioning (p=0.022), School Functioning (p=0.041), and Psychosocial Functioning (p=0.002) scores were found to be higher in the novel diagnosis group compared to the recurrence group at the 6-month follow-up interview. The differences in PedsQL scale scores between the novel diagnosis and recurrence groups in the initial and follow-up interviews are summarized in Table II.

The PedsQL scores according to the children did not significantly change between the initial and the follow-up interviews, for either the novel diagnosis or the recurrence groups (all p>0.05). However, the parents' PedsQL scores in the novel diagnosis group were found to be different between the initial and follow-up interviews for all domains except for the School Functioning domain (all p<0.05). The Physical Functioning (p=0.013), Emotional Functioning (p=0.020), Social Functioning (SFS) (p<0.001), Psychosocial Health Total Score (p=0.005) and scale total scores (p=0.002) were significantly higher in the sixth-month interview in comparison to the initial interview for the novel diagnosis group. However, a significant change was not observed for the parents' PedsQL scores of the readmission/ ongoing treatment group with a history of oncologic disease greater than 6 months during their initial and follow-up assessments (Table III).

The parents' scores for PedsQL were found to be highly correlated with the children's PedsQL scores in all subdomains for both interviews (all p<0.05). The correlation between the total scores and the subscale scores in the initial and the follow-up interview of the patients and their caregivers for the PedsQL are summarized in Table IV.

Multiple linear regression analyses were conducted to test whether the parents' PedsQL scores could be used to reliably predict the children's PedsQL scores, while also accounting for group (novel diagnosis vs. recurrence)

and psychiatric diagnosis for both the initial and follow-up interviews. The multiple linear regression model [F (3,26)=5.075, p=0.007, R^2=0.369, adjusted R^2=0.297] while accounting for group and psychiatric diagnosis and the parents' PedsQL scores as the predictor was significant, and the parents' PedsQL scores were found to be a significant predictor of the children's PedsQL scores at the initial interview (β=0.616, p=0.001).

The multiple linear regression model for the follow-up interview [F (3,25)=42.720, p<0.001, R^2=0.837, adjusted R^2=0.817] was also significant, and the parents' PedsQL scores were found to be a significant predictor of the children's PedsQL scores (β=0.950, p<0.001), when the group and psychiatric diagnosis variables were accounted for. The results of the multiple linear regression analyses can be found in Table V.

Table I. Socio-demographic data with oncologic and psychiatric diagnoses of the participants

	Novel diagnosis (n=16)	**Recurrence/ongoing treatment (n=23)**	**Total (n=39)**	**Z/χ^2**	**p value**
	M (SD)/n (%)	**M (SD)/n (%)**	**M (SD)/n (%)**		
Age	7.31±3.94	11.39±4.45	9.71±4.66	-2.788	0.004[a]*
Gender				0.011	0.918[b]
Male	6 (37.5)	9 (39.1)	15 (38.5)		
Female	10 (62.5)	14 (60.9)	24 (61.5)		
Age at diagnosis	7.31±3.94	9.19±4.49	8.42±4.32	-1.274	0.207[a]
Oncologic diagnosis					
Rhabdomyosarcoma	1 (2.6)	6 (15.4)	7 (17.9)		
Osteosarcoma	3 (7.7)	4 (10.3)	7 (17.9)		
Acute lymphoblastic leukemia	2 (5.1)	2 (5.1)	4 (10.3)		
Medulloblastoma	2 (5.1)	2 (5.1)	4 (10.3)		
Lymphoma	2 (5.1)	1 (2.6)	3 (7.7)		
Wilms tumor	1 (2.6)	1 (2.6)	2 (5.1)		
Neuroblastoma	2 (5.1)	0 (0)	2 (5.1)		
Hepatocellular carcinoma	0 (0)	2 (5.1)	2 (5.1)		
Myeloid sarcoma	1 (2.6)	0 (0)	1 (2.6)		
Acute myeloblastic leukemia	0 (0)	1 (2.6)	1 (2.6)		
Rhabdoid/Teratoid sarcoma	1 (2.6)	0 (0)	1 (2.6)		
Pilocytic astrocytoma	0 (0)	1 (2.6)	1 (2.6)		
Anaplastic astrocytoma	0 (0)	1 (2.6)	1 (2.6)		
Ovarian tumors	1 (2.6)	0 (0)	1 (2.6)		
PNET	0 (0)	1 (2.6)	1 (2.6)		
Ewing sarcoma	0 (0)	1 (2.6)	1 (2.6)		
Psychiatric diagnoses, n (%)	10 (25.6)	21 (53.8)	31 (79.5)		
No psychiatric diagnosis	6 (15.4)	2 (5.1)	8 (20.5)		0.045*
Major depressive disorder	6 (15.4)	14 (35.9)	20 (51.3)		0.133[c]
Generalized anxiety disorder	0 (0)	3 (7.7)	3 (7.7)		0.255[c]
Adjustment disorder	3 (7.7)	4 (10.3)	7 (17.9)		1.000[c]
Intellectual disability	1 (2.6)	0 (0)	1 (2.6)		0.410[c]

[a]Mann-Whitney U test, [b]Chi-square test, [c]Fisher's Exact test
*p<0.05
SD: Standard deviation

Table II. Children and their parents' PedsQL total and subscores comparison between novel diagnosis and recurrence/ongoing treatment groups for each interview

Childrens' PedsQL scores	**Novel diagnosis (n=10)**	**Recurrence/Ongoing treatment (n=20)**	**Z/t**	**p value**
	Mean ± SD	**Mean ± SD**		
Initial interview				
Physical functioning	40.31±26.90	42.97±35.25	-0.110	0.914[b]
Emotional functioning	61.50±28.68	56.25±24.0	0.530	0.601[a]
Social functioning	85.0±18.86	83.75±13.08	-0.671	0.530[b]
School functioning	67.22±22.38	53.16±24.62	-1.559	0.129[b]
Total scale score	60.11±19.37	56.72±21.43	0.421	0.677[a]
Psychosocial score	71.67±20.20	64.50±16.66	-1.343	0.183[b]
Follow-up interview				
Physical functioning	55.90±34.64	50.0±33.43	0.741	0.667[a]
Emotional functioning	73.33±22.36	64.75±28.07	0.807	0.427[a]
Social functioning	87.22±15.83	83.0±17.04	-0.528	0.627[b]
School functioning	67.22±18.89	45.53±30.04	0.085	0.59[a]
Total scale score	68.96±15.91	59.47±24.15	0.086	0.293[a]
Psychosocial score	77.04±15.16	62.79±19.13	0.169	0.060[a]
Parents' PedsQL scores	**Novel diagnosis (n=16)**	**Recurrence/Ongoing treatment (n=23)**	**Z/t**	**p value**
	Mean ± SD	**Mean ± SD**		
Initial interview				
Physical functioning	37.89±27.07	43.20±30.38	0.404	0.578[a]
Emotional functioning	52.96±27.88	50.43±22.45	0.330	0.755[a]
Social functioning	75.0±15.91	75.65±16.11	0.875	0.901[a]
School functioning	62.0±24.28	42.14±22.99	0.965	0.035[a]*
Total scale score	52.33±19.39	52.31±18.62	0.764	0.998[a]
Psychosocial score	62.78±19.19	57.10±34.61	0.146	0.255[a]
Follow-up interview				
Physical functioning	61.04±20.07	52.41±34.61	0.957	0.345[a]
Emotional functioning	78.0±18.30	60.22±25.47	-2.282	0.022[b]*
Social functioning	88.0±12.50	79.54±18.05	-1.190	0.249[b]
School functioning	70.5±24.20	47.0±30.10	2.141	0.041[a]*
Total scale score	73.64±11.43	59.02±24.79	2.415	0.022[a]*
Psychosocial score	80.77±12.79	62.42±21.14	23.284	0.002[a]*

[a]Student's t-test, [b]Mann-Whitney U test, *p<0.05
SD: Standard deviation, PedsQL: Quality-of-Life Scale for Children

Table III. Children and their parents' PedsQL total and sub-scores changes in time

Children's PedsQL scores	Novel diagnosis group (n=10)			Recurrence/Ongoing treatment group (n=20)		
	Initial assessment	6-month follow-up	p value	Initial assessment	6-month follow-up	p value
	Mean ± SD	Mean ± SD		Mean ± SD	Mean ± SD	
Physical functioning	40.31±26.90	55.90±34.64	0.291[a]	42.97±35.25	50.0±33.43	0.381[b]
Emotional functioning	61.50±28.68	73.33±22.36	0.264[a]	56.25±24.0	64.75±28.07	0.289[a]
Social functioning	85.0±18.86	87.22±15.83	0.416[b]	83.75±13.08	83.0±17.04	0.875[b]
School functioning	67.22±22.38	67.22±18.89	0.691[a]	53.16±24.62	45.53±30.04	0.393[b]
Total scale score	60.11±19.37	68.96±15.91	0.282[a]	56.72±21.43	59.47±24.15	0.675[a]
Psychosocial score	71.67±20.20	77.04±15.16	0.594[b]	64.50±16.66	62.79±19.13	0.751[a]
Parents' PedsQL scores	**Novel diagnosis group (n=16)**			**Recurrence/Ongoing treatment group (n=23)**		
	Initial assessment	6-month follow-up	p value	Initial assessment	6-month follow-up	p value
	Mean ± SD	Mean ± SD		Mean ± SD	Mean ± SD	
Physical functioning	37.89±27.07	61.04±20.07	0.013[a]*	43.20±30.38	52.41±34.61	0.112[a]
Emotional functioning	52.96±27.88	78.0±18.30	0.020[b]*	50.43±22.45	60.22±25.47	0.067[a]
Social functioning	75.0±15.91	88.0±12.50	<0.001[a]*	75.65±16.11	79.54±18.05	0.229[b]
School functioning	62.0±24.28	70.5±24.20	0.484[a]	42.14±22.99	47.0±30.10	0.360[a]
Total scale score	52.33±19.39	73.64±11.43	0.002[a]*	52.31±18.62	59.02±24.79	0.123[a]
Psychosocial score	62.78±19.19	80.77±12.79	0.005[a]*	57.10±34.61	62.42±21.14	0.202[a]

[a]Paired sample t-test, [b]Wilcoxon Rank-Sum test, *p<0.05
SD: Standard deviation, PedsQL: Quality-of-Life Scale for Children

Table IV. Levels of agreement for PedsQL total and sub-scores between the children/adolescent's and their parents' reports

Initial interview	Correlation coefficient (r)	p value
PedsQL scores		
Physical functioning	0.683[a]	<0.001*
Emotional functioning	0.735[b]	<0.001*
Social functioning	0.451[a]	0.012*
School functioning	0.693[a]	<0.001*
Total scale score	0.594[b]	<0.001*
Psychosocial health total score	0.632[a]	<0.001*
6-month follow-up interview	**Correlation coefficient (r)**	**p value**
PedsQL scores		
Physical functioning	0.859[a]	<0.001*
Emotional functioning	0.813[a]	<0.001*
Social functioning	0.843[a]	<0.001*
School functioning	0.928[b]	<0.001*
Total scale score	0.908[b]	<0.001*
Psychosocial health total score	0.995[b]	<0.001*

[a]Spearman correlation, [b]Pearson correlation, *p<0.05
PedsQL: Quality-of-Life Scale for Children

Discussion

Although the global burden of pediatric cancers has fallen dramatically compared to the previous decade, their detriment to the QoL of children and their parents remains (14). The most common pediatric cancers in our study population were sarcomas, specifically, rhabdomyosarcoma (n=7, 17.9%) and osteosarcoma (n=7, 17.9%). Sarcomas are generally rare but unfortunately lethal, and were overrepresented in our study population (15). Acute lymphoblastic leukemia (n=4, 10.3%) was the second most common, with medulloblastomas (n=4, 10.3%), which is relatively low compared to the extant literature, as childhood leukemias are reported to be the most common childhood cancers (14). Leukemia patients are primarily treated in the pediatric hematology inpatient unit in our facility. Hence, the low numbers observed in our study might be associated with this.

The most common psychiatric diagnosis was depression (n=20, 51.3%), followed by adjustment disorder (n=7, 17.9%) and anxiety disorder (n=3, 7.7%) in our study. Eight participants did not have any psychiatric disorder (20.5%). Depression is reported frequently in the literature in pediatric

Table V. Multiple linear regression results for children and adolescents' PedsQL total scores in the initial and follow-up interviews

	B	SE	Beta	t	p value	95% CI	
						LL	UL
Initial interview							
Group	-4.799	6.853	-0.117	-0.700	0.490	-18.886	9.289
Psychiatric diagnosis (any)	5.381	8.459	0.107	0.636	0.530	-12.008	22.769
Parent PedsQL total scores	0.671	0.173	0.612	3.869	0.001*	0.314	1.027
Follow-up interview							
Group	5.081	3.990	0.115	1.273	0.215	-3.137	13.299
Psychiatric diagnosis (any)	0.695	4.696	0.013	0.148	0.884	-8.976	10.366
Parent PedsQL total scores	0.976	0.089	0.950	10.975	<0.001*	0.793	1.159

*p<0.05
SE: Standard error, LL: Lower limit, UL: Upper limit, PedsQL: Quality-of-Life Scale for Children, CI: Confidence interval

cancer patients and survivors, as well as adjustment disorder (16). In a meta-analysis, as many as 24.6% of adult patients with cancer were reported to have some depressive disorder, while adjustment disorder rates were reported to be 15.4% (17). The possible overrepresentation of depressive disorders in our study sample could be due to the younger age of our population, which is frequently associated with higher mental distress (16).

Pediatric QoL as measured by PedsQL was not found to be different between those children who had recently been diagnosed with cancer and those with ongoing treatment, in either the first or the second interviews, and it was found not to have changed over time as no statistical differences were found between the initial and the follow-up interviews (all p>0.05). However, the parents' PedsQL School Functioning sub-scores of the novel diagnosis group in the initial interview were higher than the recurrence/ongoing treatment group (p=0.035), and parents' PedsQL total scores (p=0.022) and Emotional Functioning (p=0.022), School Functioning (p=0.041), and Psychosocial Functioning (p=0.002) scores were found to be higher in the novel diagnosis group compared to the recurrence group at the 6-month follow-up interview. Indeed, this difference was found to be attributable to an increase in pediatric QoL by the parents, as the parents' PedsQL scores in the novel diagnosis group were found to have improved between the initial and follow-up interviews for all domains except for the School Functioning domain which was found to be higher in the initial interview. A similar improvement was not detected for the recurrence/ongoing treatment group. Mental health as a composite of the biopsychosocial construct of health in general has a great impact on the perceived QoL. Psychological distress, even in the absence of a life-threatening chronic disease, is associated with poorer reports of QoL (18). Furthermore, cancer as a chronic disease and the chemotherapeutics employed in its treatment are associated with persistent physical, neurocognitive and psychosocial difficulties in addition to their deleterious effects on mental health, during and after treatment (19-21).

The increases in QoL in six months compared to the baseline assessment were different for the novel diagnosis group and recurrence/ongoing treatment group in our study. The parents' attitudes towards their children and their emotional coping capabilities may have impacted their perception of their children's QoL. High levels of parental distress are associated with poorer mental health in children (22). This association can be explained through the complex relationship between genetic susceptibility, the dynamic process of behavioral/emotional learning, and the capacity for the provision of emotional support by the caregiver under duress (23,24). Adjustment to the diagnosis and circumstances probably plays an integral role in the perceived improvement in QoL in our sample.

Although the proxy reports of the parents concerning their children's QoL might differ from the children's accounts, the parental and child reports of health-related QoL are generally reported to be in statistical agreement with one another. However, this correlation between reported QoL seems to be higher for physical performance rather than for emotional and social functioning in other research (9,25). This was not the case for our study, as the PedsQL scores of the patients and their parents were high in agreement.

Study Limitations

The inclusion of both children and their parents, assessments made with a semi-structured clinical tool, and conducting interviews at two points in time are the important strengths of this study. However, the modest sample size is a major limitation for the present study, as this study was conducted in a pediatric oncology inpatient unit. Another significant limitation was the restriction of the children's reports on their own QoL. Further studies concerning the treatment process, taking the patients' own experiences, as well as their caregivers' perspectives and experiences into account should be conducted with greater sample sizes in order to minimize biases.

Conclusion

The present study highlights that there are no significant differences in the QoL of those children with a novel diagnosis of pediatric cancer and those with cancer recurrence/ongoing treatment, according to their own reports. In contrast, the parents reported significant improvements in the QoL of their children with a novel cancer diagnosis after six months. The same improvement was not seen in the recurrence/ongoing treatment group, indicating that adjustment to the diagnosis and circumstances is an important component of QoL. Furthermore, the parents' reports on their children's QoL were highly correlated with the children's own reports. This association remained significant in multiple linear regression analyses in which the novel diagnosis and recurrence, and psychiatric disorders were taken into account, at both the initial and follow-up interview conducted after 6 months. Thus, the parents' reports of their children's QoL can be used in the clinical setting to accurately predict the children's QoL, especially in circumstances where the children are unable to verbalize their own needs.

Acknowledgments

The authors would like to thank RA Ömer Faruk Dadaş for his valuable guidance in the statistical analysis of the data and interpretation of the results.

Ethics

Ethics Committee Approval: This study was conducted at Ege University Faculty of Medicine and Ege University Faculty of Medicine Medical Research Ethics Committee approved the study regarding ethical principles (approval no.: 19-3.1T/45, date: 20.03.2019).

Informed Consent: Children and their parents were verbally informed about the study's design and verbal assent or written informed consent forms were obtained from the children and their parents, where appropriate.

Authorship Contributions

Surgical and Medical Practices: B.Ş.P., S.E., B.Ö., Concept: B.Ş.P., S.E., M.K., E.A., B.Ö., T.B., Design: B.Ş.P., S.E., M.K., E.A., B.Ö., T.B., Data Collection and/or Processing: B.Ş.P., İ.İ.K., Analysis and/or Interpretation: B.Ş.P., İ.İ.K., B.Ö., Literature Search: B.Ş.P., İ.İ.K., E.A., T.B., Writing: B.Ş.P., İ.İ.K., T.B.

Conflict of Interest: The authors declare that there is no conflict of interest regarding the publication of this article.

Financial Disclosure: The authors disclose that this research study was not funded by any specific grants from public, commercial, or not-for-profit sectors. The study was conducted independently without any financial support or sponsorship that could potentially introduce bias or influence the research outcomes.

References

1. Steliarova-Foucher E, Colombet M, Ries LAG, et al. International incidence of childhood cancer, 2001–10: a population-based registry study. Lancet Oncol 2017; 18:719-31.
2. Kutluk MT, Yesilipek A. Pediatric cancer registry Turkey: 2009-2016 (TPOG & TPHD). J Clin Oncol 2017; 35:e22015.
3. Kebudi R, Turkish Pediatric Oncology Group. Pediatric oncology in Turkey. J Pediatr Hematol Oncol 2012; 34(Suppl 1):S12-4.
4. Jemal A, Ward EM, Johnson CJ, et al. Annual Report to the Nation on the Status of Cancer, 1975-2014, Featuring Survival. J Natl Cancer Inst 2017; 109:djx030.
5. Siegel RL, Miller KD, Fuchs HE, Jemal A. Cancer statistics, 2022. CA Cancer J Clin 2022; 72:7-33.
6. Racine NM, Khu M, Reynolds K, Guilcher GMT, Schulte FSM. Quality of life in pediatric cancer survivors: contributions of parental distress and psychosocial family risk. Curr Oncol 2018; 25:41-8.
7. Landolt MA, Vollrath M, Niggli FK, Gnehm HE, Sennhauser FH. Health-related quality of life in children with newly diagnosed cancer: a one year follow-up study. Health Qual Life Outcomes 2006; 4:1-8.
8. Fardell JE, Vetsch J, Trahair T, et al. Health-related quality of life of children on treatment for acute lymphoblastic leukemia: A systematic review. Pediatr Blood Cancer 2017; 64. doi: 10.1002/pbc.26489.
9. Eiser C, Morse R. The measurement of quality of life in children: past and future perspectives. J Dev Behav Pediatr JDBP 2001; 22:248-56.
10. Kaufman J, Birmaher B, Brent D, et al. Schedule for Affective Disorders and Schizophrenia for School-Aged Children: Present and Lifetime Version (K-SADS-PL) DSM-5. J Am Acad Child Adolesc Psychiatry 1997; 36:980-8.

11. Ünal F, Öktem F, Çetin Çuhadaroğlu F, et al. [Reliability and Validity of the Schedule for Affective Disorders and Schizophrenia for School-Age Children-Present and Lifetime Version, DSM-5 November 2016-Turkish Adaptation (K-SADS-PL-DSM-5-T)]. Turk Psikiyatri Derg 2019; 30:42-50.

12. Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. Med Care 2001; 39:800-12.

13. Cakin Memik N, Ağaoğlu B, Coşkun A, Uneri OS, Karakaya I. [The validity and reliability of the Turkish Pediatric Quality of Life Inventory for children 13-18 years old]. Turk Psikiyatri Derg Turk J Psychiatry 2007; 18:353-63.

14. Wu Y, Deng Y, Wei B, et al. Global, regional, and national childhood cancer burden, 1990-2019: An analysis based on the Global Burden of Disease Study 2019. J Adv Res 2022; 40:233-47.

15. Burningham Z, Hashibe M, Spector L, Schiffman JD. The Epidemiology of Sarcoma. Clin Sarcoma Res 2012; 2:1-16.

16. Park EM, Rosenstein DL. Depression in adolescents and young adults with cancer. Dialogues Clin Neurosci 2015; 17:171-80.

17. Mitchell AJ, Chan M, Bhatti H, et al. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. Lancet Oncol 2011; 12:160-74.

18. Bastiaansen D, Ferdinand RF, Koot HM. Predictors of quality of life in children and adolescents with psychiatric disorders. Child Psychiatry Hum Dev 2020; 51:104-113.

19. Anderson F, Kunin-Batson A. Neurocognitive late effects of chemotherapy in children: the past 10 years of research on brain structure and function. Pediatr Blood Cancer 2009; 52:159-64.

20. Patenaude AF, Kupst MJ. Psychosocial functioning in pediatric cancer. J Pediatr Psychol 2005; 30:9-27.

21. Speechley KN, Barrera M, Shaw AK, Morrison HI, Maunsell E. Health-related quality of life among child and adolescent survivors of childhood cancer. J Clin Oncol Off J Am Soc Clin Oncol 2006; 24:2536-43.

22. Maurice-Stam H, Oort FJ, Last BF, Brons PPT, Caron HN, Grootenhuis MA. Longitudinal assessment of health-related quality of life in preschool children with non-CNS cancer after the end of successful treatment. Pediatr Blood Cancer 2008; 50:1047-51.

23. Malpert AV, Kimberg C, Luxton J, et al. Emotional distress in parents of long-term survivors of childhood acute lymphoblastic leukemia. Psychooncology 2015; 24:1116-23.

24. Hamner T, Latzman RD, Latzman NE, Elkin TD, Majumdar S. Quality of life among pediatric patients with cancer: contributions of time since diagnosis and parental chronic stress. Pediatr Blood Cancer 2015; 62:1232-6.

25. Pierce L, Hocking MC, Schwartz LA, Alderfer MA, Kazak AE, Barakat LP. Caregiver distress and patient health-related quality of life: psychosocial screening during pediatric cancer treatment. Psychooncology 2017; 26:1555-61.