Cukurova Medical Journal
ÇUKUROVA ÜNİVERSİTESİ TIP FAKÜLTESİ

Cukurova Med J 2019;44(3):875-881
DOI: 10.17826/cumj.481607

ARAŞTIRMA / RESEARCH

Health related quality of life in children with cancer and chronic diseases

Kanserli ve kronik hastalığı olan çocuklarda sağlıkla ilgili yaşam kalitesi

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Cukurova Medical Journal 2019;44(3):875-881.

Abstract

Purpose: Health related quality of life (HRQOL) concept is one of the major outcome measures in management of chronic diseases in children. Herein we aimed to review HRQOL by using PedsQL Generic Core Scales in children with cancer and chronic diseases.
Materials and Methods: All patients with cancer under treatment (oncology group), attention deficit hyperactivity disorder (ADHD), nephrological disorders like recurrent urinary tract infections and other endocrinologic disorders such as precocious puberty and growth retardation and their parents who gave consent were included in the study. Turkish version of PedsQL 4.0 Generic Core Scales self and parent proxy-reports were used for all patients of 8-12 and 13-18 years of age.
Results: There were 48 children in oncology group; 44 in non-oncology group. The most common diagnoses were leukemia, non-Hodgkin lymphoma and brain tumors in the oncology group. Children reported significantly higher scores in the school subscale and physical functioning subscale, psychosocial functioning, and total scale scores in the non-oncology group compared to patients with cancer. A strong positive significant correlation was detected between all subscales except for social functioning scores of children and parents in child self-report and parent proxy-report correlations.
Conclusion: Cancer is a devastating disease that impair functioning more than other chronic diseases in all areas of life of children and parents. PedsQL Genereric Core Scales is a usefull tool for evaluating HRQOL in both cancer and other chronic diseases.

Keywords: Health related quality of life, cancer, chronic diseases, children

Öz

Amaç: Sağlıkla ilişkili yaşam kalitesi (HRQOL) kavramı, çocuklarda kronik hastalıkların yönetiminde ana sonuç ölçütlerinden biridir. Bu yazıda, kanserli ve kronik hastalıklı çocuklarda PedsQL Jenerik Temel Skalası kullanılarak HRQOL'u gözden geçirmeyi amaçladık.
Gereç ve Yöntem: Tedavi altındaki tüm kanser hastaları (onkoloji grubu), dikkat eksikliği hiperaktivite bozukluğu (DEHB), tekrarlayan idrar yolu enfeksiyonları gibi nefrolojik bozukluklar ve erken ergenlik ve büyüme geriliği gibi diğer endokrinolojik bozukluklar ve onam veren ebeveynler çalışmaya dahil edildi. Çalışmada PedsQL 4.0 Jenerik Çekirdek Ölçeklerinin Türkçe versiyonu, 8-12 ve 13-18 yaşlarındaki tüm hastalar için kendi kendine ve ebeveyn raporları kullanıldı.
Bulgular: Onkoloji grubunda 48, onkolojik olmayan grupta 44 hasta vardı. En sık tanılar onkoloji grubunda lösemi, non-Hodgkin lenfoma ve beyin tümörleri idi. Onkoloji grubunda non-onkoloji grubundaki çocuklara göre okul alt ölçeği ve fiziksel işlev alt ölçeği, psikososyal fonksiyon ve toplam ölçek puanları anlamlı olarak yüksek bulundu. Çocuk öz-bildiriminde yer alan çocukların ve ebeveynlerin sosyal işlevsellik puanları ve anne rapor korelasyonları dışındaki tüm alt ölçekler arasında güçlü pozitif yönde anlamlı bir ilişki bulunmuştur.
Sonuç: Kanser, çocukların ve ebeveynlerin tüm yaşam alanlarında işleyişi diğer kronik hastalıklardan daha fazla bozan yıkıcı bir hastalıktır. PedsQL Jenerik Temel Skalası, hem kanser hem de diğer kronik hastalıklarda HRQOL'u değerlendirmek için yararlı bir araçtır.

Anahtar kelimeler: Sağlıkla ilişkili yaşam kalitesi, kanser, kronik hastalıklar, çocuklar

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Geliş tarihi/Received: 12.11.2018 Kabul tarihi/Accepted: 14.01.2019 Çevrimi yayın/Published online: 07.09.2019

INTRODUCTION

Health-related quality of life (HRQOL) has been an emerging concept in all areas of medicine. In especially chronic diseases, attempts to improve HRQOL of children have gained accelaration in generation of long-term treatment plans. Numerous large-scale HRQOL studies have been reported by many study groups[1-5].

Many factors affect HRQOL in children with chronic disease and cancer. Besides disease or treatment related factors, factors related with family especially the parent or relative providing close supervision to the ill child have considerable impact on child's quality of life (6). Therefore inclusion of family members to assessment of HRQOL in children with chronic disease or cancer has been a common approach. PedsQOL provides thorough evaluation with including family members to the HRQOL assessment.

Most of the studies evaluating HRQOL in children with cancer focus on survivors rather than children under treatment[6-10]. Cancer and its treatment have seperate effects on HRQOL at different phases of the treatment or surveillance period. Physical or school functioning impairment may be dominant in the early period of the disease; whereas psychosocial functioning or academic achievement may be disturbed in the late period[11,12].

Individually tailored therapy plan targeting to minimize the long term side effects might cause less impairment in HRQOL in survivors of childhood cancer. However, some degree of impairment in HRQOL during treatment is inevitable in pateints with cancer. Furthermore we hypothesize that this impairment is more prominent in cancer than treatment period of other chronic diseases. Herein, we aimed to evaluate HRQOL of childhood cancer patients who are under treatment and make a comparison to children with other chronic conditions.

MATERIALS AND METHODS

The study was performed at Cukurova University, Deaprtments of Pediatric Oncology, Child Psychiatry, Pediatric Endocrinology departments and Sağlık Bilimleri University, Adana City Education and Research Hospital, Pediatric Oncology department between January-June 2018 after local ethical commitee approval. Oncology group consisted of patients with cancer between 8-18 years old that are in treatment period, with sufficient command of the Turkish language, without evidence of major neurologic deficit such as blindness, aphasia, inability to walk.with cancer.

Non-oncology group consisted of patients with with attention deficit hyperactivity disorder (ADHD), patients with nephrological disorders like recurrent urinary tract infections, and other endocrinologic chronic diseases such as precocious puberty and growth retardation. In both groups parent inclusion criteria were sufficient command of the Turkish language and giving informed consent for the study.

Measures

The Pediatric Quality of Life Inventory (PedsQL)

This scale was developed by Varni and colleagues in pediatric chronic health conditions, including pediatric cancer during the past 20 years. The PedsQL 4.0 Generic Core Scales include child self-report for ages 5–18 years and parent proxy-report for ages 2–18 years. The PedsQL 4.0 Generic Core Scales were designed to measure the core physical, mental, and social health dimensions as delineated by the World Health Organization, as well as role (school) functioning[13-19].

A 5-point Likert response scale was used in child self-report for ages 8–18 years and parent proxy-report (0 = never a problem; 1 = almost never a problem; 2 =sometimes a problem; 3 = often a problem; 4 = almost always a problem). Items are reverse-scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher PedsQL 4.0 scores indicate better HRQOL[19]. Reliability and validity studies and Turkish translation of the scale was performed by Çakın Memik[20,21] in 2005. Turkish version of PedsQL 4.0 Generic Core Scales self and parent proxy-reports were used for all patients of 8-12 and 13-18 years of age.

Sociodemographic characteristics of individuals were obtained via a personal data form including information about the participant parent's age and education status All items of data forms (sociodemographic data form, parent and child PedsQL forms) were recorded electronically by using SPSS version 22.0 for Windows (SPSS Inc. Chicago IL,USA).

Statistical analysis

Descriptive statistics (means, SD, and frequencies) were calculated for all variables and compared using Chi-square method. Differences between the numerical variables were examined using independent groups Student t-tests. Mann Whitney U test was used for comparison of non-parametric variables. The concordance intercorrelations between child and parent proxy-reports were evaluated by Spearman rank-order correlation method. All analyses were performed with two-sided tests and a value of $p < 0.05$ was considered significant. Analyses were conducted using SPSS version 22.0 for Windows (SPSS Inc. Chicago IL,USA).

RESULTS

48 children with cancer and 44 with other chronic diseases of 8-18 years were enrolled to the study between January-June 2018. Mean age was 12.29 years (Range 8-18years) in the oncology group and 12.66 years (Range 8-17 years) in non-oncology group. There were 19 females (39,6%) 29 males (60.4%) in oncology group and 27 (61.4%) females and 17 males (38.6%) in non-oncology group. Demographic variables of patients and their parents were compared and there was no statistically significant difference between two groups. General demographic characteristics of the patients and their parents were presented in Table 1. General clinical features of the oncology and non-oncology groups were given in Table 2.

Table 1. Demographic characteristics of oncology and non-oncology groups

		Oncology Group		Non-oncology group		p
Age (years)		12.29 ±3.09 (Range: 8-18 years)		12.66 ±2.73 (Range: 8-17 years)		.549*
		n	%	n	%	
Gender						
	Female	19	39.9	27	61.4	.060**
	Male	29	60.4	17	38.6	
	Total	48	52.2	44	47.8	
Respondant parent	Mother	38	79.2	35	79.5	1.00**
	Father	10	20.8	9	20.5	
	Total	48	52.2	44	47.8	

Table 2. Clinical characteristics of oncology and non-oncology patients

	Oncology Group		Non-Oncology group	
		n (%)		n (%)
Diagnosis	Leukemia	11 (22.9)	ADHD	24 (54.55)
	Non-Hodgkin's Lymphoma	9 (18.8)	Nephrologic disorders	11 (25)
	Brain tumor	7 (14.6)	Endocrinologic disorders	9 (20.45)
	Neuroblastoma	4 (8.3)		
	Ewing Sarcoma	4 (8.3)		
	Osteosarcoma	3 (6.3)		
	Germ cell tumors	1(2.1)		
	Rhabdomyosarcoma	1(2.1)		
	Other tumors	3 (6.3)		
Treatment duration	<6	17 (35.4)	<6	16 (36.4)
(months)	>6	31 (64.6)	>6	28 (63.6)
Treatment	Chemotherapy (C)	18 (37.5)	Medical treatment	44 (100)
	Surgery (S)	1 (2.1)		
	C+Radiotherapy (RT)	5 (10.4)		
	C+S	14 (29.2)		
	C+RT+S	10 (20.8)		

ADHD: Attention deficit hyperactivity disorder, C: Chemotherapy, S: Surgery, RT: Radiotherapy

Comparison of the child self-report between the oncology and non-oncology groups revealed significantly higher scores in the school subscale (p=0.037) and physical functioning subscale (p=0.003), psychosocial functioning (p=0.031), and total scale scores (p=0.003) of the non-oncology group. Scores of PedsQL subscales according to child self reports in oncology and non-oncology groups were shown in Table 3.

Comparison of parent-proxy report scores of PedsQL between two groups revealed that parents of non-oncology group reported better results in physical functioning subscales (p<0.001) and total scale scores (p=0.004) than parents of oncology group. Scores of PedsQL subscales according to parent proxy-reports in oncology and non-oncology groups were shown in Table 4.

Table 3. Comparison of the child self-report between the oncology and non-oncology groups

Subscale scores	Grops	N	Mean	Total	u	p
Physical health	Oncology	48	38.52	1849.00	673.00	0.003
	Non-oncology	44	55.20	2429.00		
Emotional functioning	Oncology	48	43.45	2085.50	909.50	0.250
	Non-oncology	44	49.83	2192.50		
Social functioning	Oncology	48	42.16	2013.50	847.50	0.100
	Non-oncology	44	51.24	2254.50		
School functioning	Oncology	48	40.97	1966.50	790.50	0.037
	Non-oncology	44	52.53	2311.50		
Psychosocial functioning	Oncology	48	40.76	1956.50	780.50	0.031
	Non-oncology	44	52.76	2321.50		
Scale total score	Oncology	48	38.55	1850.50	674.50	0.003
	Non-oncology	44	55.17	2427.50		

Table 4. Comparison of the parent proxy-report between the oncology and non-oncology groups

Subscale scores	Grops	N	Mean	Total	u	p
Physical health	Oncology	48	35.90	1723.00	547.00	0.000
	Non-oncology	44	58.7	2555.00		
Emotional functioning	Oncology	48	46.60	2237.00	1051.00	0.969
	Non-oncology	44	46.39	2041.00		
Social functioning	Oncology	48	42.95	2061.50	885.50	0.179
	Non-oncology	44	50.38	2216.50		
School functioning	Oncology	48	41.99	2015.50	839.50	0.089
	Non-oncology	44	51.42	2262.50		
Psychosocial functioning	Oncology	48	43.04	2066.00	890.00	0.194
	Non-oncology	44	50.27	2212.00		
Scale total score	Oncology	48	38.90	1867.00	691.00	0.004
	Non-oncology	44	54.80	2411.00		

Child self-report and parent proxy-report correlations revealed that correlation coefficients (r) were between 0.35-0.72 in the oncology group. Comparison of child self-report and parent proxy-report correlations revealed that a strong positive and significant correlation (r=0.72, p<0.001) between total scale scores of parents and and children. A strong positive significant correlation was detected between all subscales except for social functioning scores of children and parents. The parent/child concordance intercorrelations matrix is shown in Table 5.

Table 5. Parent/child concordance intercorrelations matrix

		Parents					
		Physical health	**Emotional functioning**	**Social functioning**	**School functioning**	**Psychosocial functioning**	**Total Scale Score**
Children	Physical health	0.69**	0.31*	0.29*	0.33*	0.40**	0.61**
	Emotional functioning	0.40**	0.62**	0.51**	0.26	0.55**	0.53**
	Social functioning	0.25	0.18	0.35*	0.21	0.34*	0.33*
	School functioning	0.32*	0.34*	0.31*	0.69**	0.59**	0.51**
	Psychosocial functioning	0.38**	0.48**	0.48**	0.52**	0.64**	0.57**
	Total Scale Score	0.66**	0.49**	0.45**	0.50**	0.62**	0.72**

**: p<0.001, *: p>0.05

DISCUSSION

Health related quality of life concept has been one of the major measures in management of chronic diseases and cancer in both children and adults[2,6]. The main focus is not to impair or to improve baseline QOL of patients with chronic diseases at diagnosis, treatment, and long term follow-up period. Cancer is one of the most devastating diseases in children and their family. The disease itself and tough treatment duration have considerable limiting effects on QOL. On the other hand, precisely planned therapeutic interventions may prevent impairment in QOL to some degree that QOL in children with cancer may not differ form children with other chronic diseases. In our study, we tried to find out whether cancer affects HRQOL in a similar manner with other chronic diseases or not.

QOL in children is a multidimensional concept with numerous components. A child has functional roles in family, school, and social life and he/she should be pysically and emotionally healty in order to fulfill the needs of these missions. A thorough QOL evaluation should include the evaluation of all of these dimensions. Varni et al. have also developed numerous disease specific scales[22-26]. A cancer module of PedsQL is also available for children with cancer[19]. However, Turkish validity and reliability studies were performed only for 2-7 year-old-patients[27]. We used PedsQL 4.0 Generic Core Scale for evaluation as our patients were 8-18 years old.

In our study we found better scores in the school, physical functioning, psychosocial functioning, and total scale scores according to self reports in the non-oncology group that consisted of patients with ADHD, recurrent urinary tract infections, precocious puberty and growth retardation. PedsQL 4.0 Generic Core Scales was also used to evaluate QOL in patients with ADHD and it was shown to be feasible, reliable and valid in another study[28]. In that study, worse total scale scores in patients with ADHD and their parents compared to cancer patients were detected in contrast to our findings showing better total scale scores in non-oncology group. The authors reported that QOL impairment was correlated with symptom severity of ADHD. Probably, our study included ADHD patients with mild symptoms. Worse physical functioning scores in pediatric cancer patients were reported in the same study similar to our study.

We showed that parent reports revelaed more impairent in QOL in physical functioning subscale and total sale scores in the oncology group. Child self-report and parent proxy-report correlations revealed strong positive significant correlations between total scale scores and all subscales except for social functioning subscale. These results show that PedsQL 4.0 Generic Core Scales provided concordant results on HRQOL of children with cancer between children and parent aspects. In other studies various degrees of correlation were reported between children and parents[6,29,30]. Parental aspect towards child's QOL may change according to individual factors such as anxiety and depression emerging as a result of child's illness. A previous study reported that parental psychopathology had significant effect on QOL of survivors of childhood cancer[6]. A close supervision of parents of children with chronic diseases is needed in order to identify symptoms of depression or anxiety and to treat these conditions on time to prevent impairment of QOL of their children.

Cancer types and treatment strategies have significant effects on HRQOL in children. Central nervous system tumors has been shown to impair QOL more than other tumors in children[6]. Chemotherapeutics or radiotherapy cause different degrees and types of functional impairment in short or long term. Chemotherapy may affect school, physical or emtional functioning in acute phase; whereas radiotherapy shows its adverse effect on school functioning in long time and it has minimal effects on most functions in short term. School subscale scores of PedsQL 4.0 Generic Scale was reported to be worse in survivors who were treated with radiotherapy compared to patients in whom radiotherapy was not given[6]. Furthermore, treatment intensity was also shown to affect QOL in children treated for cancer. In a study by Kobayashi et al reported that QOL of children with acute lymphoblastic leukemia during consolidation phase was signficantly worse compared to healthy children[11]. Due to small sample size of our study population, comparisons according to treatment intensity, treatment modalities or cancer types could not be made.

In conclusion, QOL can be easily impaired in children with chronic diseases or cancer. Each disease and its treatment develop distinct and variable consequences that affect normal functioning in many areas of children's and parents' life. Better understanding of factors affecting QOL in children with chronic illnesses may help to prevent further impairment of QOL during treatment and follow-up processes of the disease. Addionally, medical or psychological professional assistance to parents and children may change negative perception of the disease and disease-related facts. Strategies improving QOL of children with chronic diseases or cancer will probably have a positive affect both on survival and long term outcome in near future.

Yazar Katkıları: Çalışma konsepti/Tasarımı: BYK, KHA, FU, SK; Veri toplama: KHA, FU; Veri analizi ve yorumlama: BYK, KHA, FU, SK; Yazı taslağı: BYK, SK; İçeriğin eleştirel incelenmesi: BYK, KHA, FU, SK; Son onay ve sorumluluk: BYK, KHA, FU, SK; Teknik ve malzeme desteği: BYK, KHA, SK; Süpervizyon: BYK, KHA, FU, SK; Fon sağlama (mevcut ise): yok.
Bilgilendirilmiş Onam: Katılımcılardan yazılı onam alınmıştır.
Hakem Değerlendirmesi: Dış bağımsız.
Çıkar Çatışması: Yazarlar çıkar çatışması beyan etmemişlerdir.
Finansal Destek: Yazarlar finansal destek beyan etmemişlerdir.
Author Contributions: Concept/Design : BYK, KHA, FU, SK; Data acquisition: KHA, FU; Data analysis and interpretation: : BYK, KHA, FU, SK; Drafting manuscript: BYK, SK; Critical revision of manuscript: GÖ; Final approval and accountability: BYK, KHA, FU, SK; Technical or material support: BYK, KHA, SK; Supervision: BYK, KHA, FU, SK; Securing funding (if available): n/a.
Informed Consent: Written consent was obtained from the participants.
Peer-review: Externally peer-reviewed.
Conflict of Interest: Authors declared no conflict of interest.
Financial Disclosure: Authors declared no financial support

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