The Perception of the Quality of Life in Turkish Children Who Have Undergone Surgical Correction of a Congenital Gastrointestinal and Abdominal Anomaly

Doğumsal Gastrointestinal ve Abdominal Anomalisi Cerrahi Olarak Düzeltilmiş Türk Çocuklarında Yaşam Kalitesi Algısı

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ABSTRACT Objective: The first aim of the study was to compare the quality of life (QoL) of 2-12 year old children, who had undergone surgical correction of their congenital abnormality at least 24 months ago, with healthy children. The secondary aim was to evaluate whether there were differences between the QoL perception of parents and children. **Material and Methods:** Children aged between 2-12 years, who had undergone surgical treatment for one of the six congenital abnormality groups at least 24 months ago were included in the study. The Pediatric Quality of Life Inventory 4.0 Turkish version (PedsQL™) was administered to the children and/or parents. The control group consisted of healthy children. **Results:** Parental reports of the Physical Health Summary Scores (PSS) and the Total Scale Scores (TSS) did not differ between the groups; however, the study group scored statistically significantly lower than the control group in the Psychosocial Health Summary Score (PsychoSS). The pediatric self-report scales showed no statistically significant difference between the study and the control groups for these three parameters. Parent proxy and child self-report scale scores showed no statistically significant correlation for PSS in both study and control groups while there was a statistically significant correlation for the Psycho SS and TSS. **Conclusion:** Turkish children and adolescents with surgically corrected congenital anomalies had QoL measures that were similar to their healthy peers after at least 24 months postoperatively.

Key Words: Quality of life; congenital abnormality; treatment outcome; child; adolescent

ÖZET Amaç: Çalışmanın ilk amacı en az 24 ay önce doğumsal anomalisi cerrahi olarak düzeltilmiş, 2-12 yaş çocukların sağlığa bağlı yaşam kalitelerini sağlıklı çocuklarla karşılaştırmaktır. İkinci amaç ise, ebeveyn ve çocukların yaşam kalitesi algılarında fark olup olmadığını araştırmaktır. **Gereç ve Yöntemler:** En az 24 ay önce cerrahi tedavileri tamamlanmış altı doğumsal anomali grubundan 2-12 yaş arasındaki çocuklar çalışmaya dahil edildi. Pediatrik Yaşam Kalitesi Envanteri 4,0-Türkçe (PedsQL™) çocuk ve/veya ebeveynlerine uygulandı. Kontrol grubu sağlıklı çocuklardan oluşturuldu. **Bulgular:** Ebeveynlerin değerlendirildiği Fiziksel Sağlık Toplam Puanı (FSTP) ve Toplam Ölçek Puanı (TÖP) açısından çalışma ve kontrol grupları arasında istatistiksel olarak anlamlı fark yokken, çalışma grubunda Psikososyal Sağlık Toplam Puanı (PSTP) kontrol grubundan anlamlı olarak düşüktü. Çocuk FSTP, PSTP ve ÖTP açısından çalışma ve kontrol grupları arası anlamlı fark yoktu. Hem çalışma hem de kontrol gruplarında ebeveyn ve çocuk değerlendirmeleri arasında FSTP bakımından istatistiksel olarak anlamlı bir korelasyon yokken, PSTP ve ÖTP de anlamlı korelasyon saptandı. **Sonuç:** Doğumsal anomalileri cerrahi olarak en az 24 ay önce düzeltilmiş çocuk ve ergenlerin hastalığa bağlı yaşam kalite algıları, sağlıklı yaşıtlarına benzerdi.

Anahtar Kelimeler: Yaşam kalitesi; doğumsal anomali; tedavi sonucu; çocuk; ergen

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Children and adolescents with congenital anomalies have to cope with substantial functional problems, which often remain after neonatal surgery and affect the quality of life (QoL).[1] Disorders such as

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Hirschsprung's disease (HD), imperforate anus (IA), intestinal atresia , congenital diaphragmatic hernia (CDH), esophageal atresia (EA) and congenital abdominal wall defects (CAWD) that are seen most often in general pediatric surgery practice are not infrequent congenital abnormalities seen once every 1000 to 5000 live births.[2-7] Developing treatment and care has shifted the aim in treating these previously life-threatening disorders to decreasing symptoms and improving quality of life instead of just ensuring survival.[8-10] The Health-Related Quality of Life (HRQoL) is defined as the subjective perception by the individual of the functional changes created by a disorder and its treatment by the individual.[11] HRQoL helps physicians and investigators to understand and compare patients and disease-related states together with the results of relevant interventions, ranging from the health of individuals to that of communities.[12] A literature review has revealed few studies on HRQoL in children with congenital abnormalities and these are mostly from Northern European countries.[1,9,13,14] As QoL is a subjective, multidimensional experience of wellbeing that is culturally constructed more studies are needed to understand HRQoL in children with congenital abnormalities from various communities.[15] We came across only one study from Turkey on the QoL in children with anorectal malformations.[16]

HD is characterized by partial or total absence of ganglion cells in the nerve plexuses of the distal bowel, of varying levels. IA is a deformity of anorectum,with a varying severity from a relatively simple covered anus to the most complex defect of persistent cloaca. Patients with HD or IA have to deal with similar physical problems, such as chronic fecal incontinence and constipation, and they all need surgical correction in early childhood.[1] Studies in IA patients, which predominantly focused on improvements and limitations in specific domains of functioning, suggested a relatively poor long term HRQoL, even after successful surgical reconstruction.[9] Although they often face with life threatening morbidity during the neonatal period, CDH patients generally seem to lead healthy lives finally.[9] In EA, most studies have focused on the functional outcome and on dysphagia and gastroesophageal reflux, and little is known about the effects of long-term sequela on the QoL of the surviving patients.[17]

The first aim of this study was to compare the quality of life of 2- to 12-year-old children, who had undergone surgical correction of their congenital abnormality at least 24 months ago, with QoL of healthy children. The secondary aim was to evaluate whether there was a difference between the QoL perception of parents and children.

MATERIAL AND METHODS

PARTICIPANTS AND PROCEDURE

The study was performed at the Pediatric Surgery Clinic of Dr. Sami Ulus Maternity and Children's Hospital. Children who had undergone surgery between 1990 and 2008 for six congenital abnormality groups (Hirschsprung's disease, imperforate anus, intestinal atresia, congenital diaphragmatic hernia, esophageal atresia and congenital abdominal wall defects) were found from the surgical records. Patients aged 2 to 12 years who had undergone surgery at least 24 months ago (after the final surgery in case of multiple surgeries) were included in the study. We invited those who were alive according to their hospital records when we could find valid contact information. Patients who presented between January 2009 and March 2010 were informed about the study by two of the investigators (YHÇ, BY) and informed consent was obtained from the parents accepting to participate. The Pediatric Quality of Life Inventory 4.0 Turkish version (PedsQL™) was administered to the children and/or parents according to the age groups. The control group consisted of age- and sex-matched children selected randomly from a healthy child database who did not have any chronic or acute diseases within the previous month and had been chosen for another study. Data of children and parents in the healthy group which was equal in number to children in the surgical treatment group were obtained randomly out of the data of 305 healthy children of same sex, age period and their parents previously collected for another study.[18,19] The sociodemographic information form prepared by the investigators and the Ped-

sQL were completed in one session by both groups. The exclusion criteria were parents' ignorance, objection to participation and a mentally retarded or noncompliant child.

Dr. Sami Ulus Children's Hospital is a high-circulation training hospital that accepts patients including those without a health insurance. A total of six pediatric surgery specialists work at the pediatric surgery clinic. The admitted patients were operated on by one or several of these physicians.

Written consent was obtained to use PedsQL™ in this study from J. W. Varni, who developed the scale. The trial was approved by the Dr. Sami Ulus Ethic Committee (#: 2009/2126) and was performed in accordance with the ethical standards laid down in the Declaration of Helsinki.

Statistical analysis was performed using the Statistical Package for Social Sciences (SPSS) 16 software for Windows (SPSS Inc., Chicago, IL, USA). Continuous variables were expressed as mean ± standard deviation. Nominal data were shown as number of cases and percentage. The Independent-Samples t-test was used if continuous variables were normally distributed and the Mann-Whitney U-test if not. Categorical data analysis was performed using the Pearson Chi-square or Fisher's Exact test, where applicable. Pearson Correlation Coefficients were used for correlation analysis. A p value <0.05 was considered as statistically significant.

MEASURES

The Pediatric Quality of Life Inventory (PedsQL™) has been developed in 1999 by Varni et al. and is a general quality of life scale used in children and adolescents aged 2 to 18 years.[20] The Turkish validity and reliability study has been performed for all age groups.[18,19,21-23] The PedsQL™ scales are comprised of parallel child self-report and parent proxy-report formats. The child self-reports includes age groups of 5-7 and 8-12 years. The scale's reliability for the child age group has been found to be low in children aged 5 to 7 in Turkish validity and reliability studies and it is therefore suggested to use only the parent form for Turkish studies in this age group.[18] The parent proxy-report includes age groups of 2-4, 5-7, 8-12 years and assesses the parent's perception of their child's HRQOL. The parent and child complete the questionnaires independently of each other. A 5-point Likert scale is used (0=never, 1=almost never, 2= sometimes, 3=often, 4=almost always). Items are reverse scored and linearly transformed into a 0-100 scale (0=100, 1=75, 2=50, 3=25, 4=0). Higher scores indicate better HRQOL. The scores of the items in the physical functioning section are linearly converted and divided into the number of items completed to obtain the Physical Health Summary Score (PSS). The Psychosocial Health Summary Score (Psycho SS) is calculated by linearly converting the scores of the items in the emotional functioning, social functioning and school functioning sections and dividing the total into the number of items completed, while the corresponding procedure is used for the Total Scale Score (TSS) except that all the scale item scores are linearly converted and added and then divided into the number of completed items. The Scale Scores are not computed if more than 50% of the items in the scale are missing.

RESULTS

According to our records there were 104 eligible patients to participate the study. Sixty nine of them could be invited. Four patients were mentally retarded, seven families objected and in nine of the patients no scale scores were computed because of missing items.

The study and control groups consisted of 49 children each. The average time between last operation and administration of scales was 36.4 ± 15.2 (range: 24-99) months. There was no statistically significant difference between the groups for the sociodemographic variables (Table 1).

The parent proxy scales revealed no statistically significant difference between the study and control groups for the PSS and TSS while there was a statistically significant difference for the Psycho SS. The study group parent proxy Psycho SS was lower than the control group. The pediatric self-report scales showed no statistically significant difference between the study and control groups for PSS, PsychoSS and TSS (Table 2).

TABLE 1: Sociodemographic characteristics of the children and parents in the study and control groups.

	Study group n=49	Control group n=49	p
Age of child median years (range)	4.0 (2-12)	4.0 (2-14)	0.820#
Male/female	26/23	27/22	0.500‡
Age group			
2-4 years	28(57%)	28(57%)	
5-7 years	13(27%)	13(27%)	
8-12 years	8(16%)	8(16%)	
Mother's education status			0.377†
Primary school	30 (65%)	37 (76%)	
Secondary school	5 (11%)	2 (4%)	
High school and higher	11 (24%)	10 (20%)	
Mother's employment status			0.181‡
Working	1 (2%)	4 (8%)	
Not working	48 (98%)	45 (92%)	
Age of mother median years (range)	28 (22-48)	30 (22-42)	0.294#
Age of father years ± SD (range)	33.8±6.5 (24-53)	34.3±4.3 (24-43)	0.673*
Congenital anomaly			
Imperforate anus	16 (33%)		
Hirschsprung's disease	14 (29%)		
Esophageal atresia	8 (16%)		
Intestinal atresia	5 (10%)		
Diaphragmatic hernia	3 (6%)		
Abdominal wall defects	3 (6%)		

*Independent-samples t test; †Pearson chi-square; ‡Fisher's exact test; #Mann-whitney U.

Parent proxy and child self-report scale scores showed no statistically significant correlation for Physical Health Summary Scores in both the study and control groups while there was a statistically significant correlation for the Psychosocial Health Summary Score and Total Scale Score (Table 3).

The effect of gender on the quality of life was evaluated in the study group and no statistically significant difference was found between the groups (Table 4).

DISCUSSION

Our main aim in this study was to evaluate the quality of life in children aged 2 to 12 years who had undergone surgical correction of their congenital anomaly at least 24 months ago and to compare it with healthy children. The HRQoL literature regarding children shows that the QoL decreases in chronic diseases, the early periods of diagnosis and the treatment initiation stages while it increases as the child and family adapt to the disorder and treatment and that QoL scale scores obtained from forms for children reach a level similar to that of healthy subjects after the adaptation period if the limitations caused by the disorder are not very significant.[12,24] Poley et al. have reported worse QoL scores in children aged 1-4 years with anorectal malformation compared to healthy children of the same age, but these values became similar to their healthy counterparts with time.[9] This has also been supported by the 2007 Hartman et al. study.[1] The similar results except for parent Psycho SS in our study support this finding. The lower Psycho SS in the parent proxy report in the study group may indicate a QoL decrease due to the congenital anomaly corrected by surgery. In studies evaluating QoL and its causes in children born with congenital anomalies, QoL after treatment of children especially born with cardiac and neurologic

TABLE 2: Comparison of the QoL scale scores between the children and parents in the study group and the control group (median or mean ± SD, range, n)

	Study group	Control group	p
Parent PSS	81.25 (3.13-100) 46	81.25 (53.13-100) 49	0.417*
Parent Psycho SS	74.17 (32.50-100) 46	85.00 (52.78-100) 49	0.005*
Parent TSS	75.69 (30.56-100) 46	81.25 (53.26-100) 49	0.050*
Child PSS	80.30±12.33 (60-100) 13	78.13±14.94 (43.75-100) 18	0.672†
Child Psycho SS	72.31±18.86 (40-100) 13	74.63±11.27 (55-95) 18	0.672†
Child TSS	75.34±15.22 (50-100) 13	76.11±11.72 (51.09-95) 18	0.875†

*Mann-Whitney U test; †Independent-Samples T test; PSS: Physical Health Summary Score; Psycho PSS: Psychosocial Health Summary Score; TSS: Total Scale Score.

TABLE 3: Correlation between the PSS, Psycho PSS and TSS of the children and parents in the study group (mean ± SD).

	Parents	Child	r*	p
Study group				
PSS	72.37±25.96	82.72±13.09	-	0.082
Psycho PSS	70.14±19.76	73.33±18.56	0.816	0.004
TSS	71.06±20.64	76.82±15.04	0.808	0.005
Control group				
PSS	80.63±13.55	76.56±14.96	-	0.265
Psycho PSS	81.54±13.07	73.58±11.14	0.525	0.025
TSS	80.95±12.00	74.86±11.75	0.478	0.045

*Pearson correlation; PSS: Physical Health Summary Score; Psycho PSS: Psychosocial Health Summary Score; TSS: Total Scale Score.

anomalies are lower but, the decrease in QoL in children with surgically correctable congenital anomalies is minimal or QoL is similar with healthy peers. Although children who had undergone operation for congenital cardiac anomaly, respond for QoL and self perception parameters more negative than those of control group, no information could be found on decrease of self perception in children with gastrointestinal anomalies.[25] In our study, in children who had undergone surgical correction of their congenital anomaly at least 24 months ago, QoL is similar with their peers in most of function, because the anomalies in our study is about low risk of decrease in self perception and have no major deformities could not be corrected operatively.

Our second aim was to determine whether there was a difference between the QoL perception of the parents and children. It is reported that a one-to-one correlation is not expected when child and parent QoL forms are compared but a higher correlation is usual in the physical health area as it is easier to observe.[12] There are studies both supportive and not supportive of this notion.[26-29] We found a statistically significant correlation between the parent proxy and child self report scale scores except for PSS, supporting other studies which have not found a high correlation in the physical health domain. In fact, children might deny or prefer to re-

TABLE 4: Comparison of the QoL scale scores between genders in the study group [median, (range), n) (Mann-Whitney U test].

Study group	Male	Female	P
Parent PSS	84.38 (3.13-100) 24	79.69 (21.88-100) 22	0.965
Parent Psycho SS	73.75 (32.50-100) 24	74.17 (40.38-100) 22	0.809
Parent TSS	78.47 (30.56-100) 24	75.00 (33.33-100) 22	0.930
Child PSS	79.68 (60-100) 8	71.88 (68.75-100) 5	0.378
Child Psycho SS	80.00 (45-100) 8	68.33 (40-76.67) 5	0.107
Child TSS	79.71 (58.33-100) 8	69.57 (50-84.78) 5	0.143

PSS: Physical Health Summary Score; Psycho PSS: Psychosocial Health Summary Score; TSS: Total Scale Score.

port less functional deficiency in physical health. Parent proxy reports are said to be affected by many conditions other than the child's health such as the parent's health, previous life experiences, value judgments regarding the child's disease, perception of ability to provide parenting and the family structure.[30] The parents may therefore have evaluated the physical abilities of the child differently than the child himself/herself, leading to our study findings. There were only a few children who could complete the self-report scale in our study, and this finding may therefore also be specific to the sample. Other studies with larger samples are required.

A study on cancer and epilepsy patients in Austria using PedsQL has similarly shown a mean physical function score in forms for children similar to that of healthy subjects. This was thought to be due to the fact that the cancer group consisted of children in remission and there were few epileptic subjects with severe disease.[26] The patient group in our study had completed their treatment at least 24 months ago. It may be thought that this period of time is adequate for bringing the perception of QoL in children to a level similar to that of healthy subjects. It can also be said that the PedsQL used in our study is a general QoL scale and may therefore not measure characteristics related to physical function in detail. When we evaluate both the disease-specific and general QoL scale features, we see that general QoL scales are measurement tools that can be used in both healthy and sick individuals, enable making comparisons and can be administered to large populations.[31] General scales are superior to specific scales for studies aiming to develop population norms but their main disadvantage is the low sensitivity to small changes. It is therefore recommended to use disease-specific QoL scales, if any, instead of general QoL scales for disease-specific evaluations.[12] However, it is said that general QoL scales can be used when there are no disease-specific scales for that disorder.[32] There are no QoL scales in our country that have undergone Turkish validity and reliability studies and are specific for children with congenital abnormalities, therefore we used the general QoL scale PedsQL for evaluations. This is a limitation of our study.

The effect of gender on QoL has been extensively studied in adults but there are only a few such studies in children. Some studies report an influence of gender on QoL while other have found no effect.[27,33-35] Our results support the second group.

LIMITATIONS

The lower Psycho SS in the parent proxy report in the study group compared to the healthy group and the lack of a significant correlation for the Physical Health Summary Score values between the parent proxy and child-self report scales may be specific to our sample. New studies are required for more detailed interpretation of such results. The small sample size, wide age spread, the specific congenital anomaly group, the lack of evaluation regarding the severity of the disease, also lack of specific evaluation of the psychopathology of the children and the 24-month duration following corrective surgery, and the absence of a disease-specific QoL scale evaluation may be considered among the limitations of our study.

CONCLUSION

We found similar QoL values for Turkish children aged 2-18 with a congenital anomaly after at least 24 months had passed after corrective surgery and the healthy control group. The sample is limited but we feel this result is still important because it might relieve the future-related anxiety of the parents for children with congenital abnormalities as it demonstrates QoL values similar to healthy peers. A prospective study design that also evaluates the time-related change in HRQOL in different patient groups is needed for future studies on children who have undergone corrective surgery for their congenital anomaly.

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