

# Hemofili Hastası Çocuk ve Gençlerde Ağız Sağlığının Yaşam Kalitesine Etkisi

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## ÖZ

### Hemofili Hastası Çocuk ve Gençlerde Ağız Sağlığının Yaşam Kalitesine Etkisi

**Amaç:** Kanama problemlerinin tedavisinde ağız ve çevre dokularda meydana gelen sorunların giderilmesi önemli bir rol oynar. Bu çalışmanın amacı hemofili hastası çocuk ve gençlerde ağız sağlığı ile ilişkili yaşam kalitesinin değerlendirilmesidir.

**Gereç ve Yöntemler:** POQL (pediatric oral health related quality of life-pediatric ağız sağlığında yaşam kalitesi) ölçeği bu kesitsel çalışmada ağız sağlığı ile ilişkili yaşam kalitesini ölçmek için kullanılmıştır. Ölçek sağlıklı 196 çocuk ve gence uygulanmıştır; diğer taraftan hemofili hastası 64 çocuk ve gence uygulanmıştır. Veri toplama bölümleri demografik bilgilerden, POQL ölçeğinden ve ağız taramalarından meydana gelmiştir. SPSS 23.0 programı verilerin istatistiksel olarak analiz edilmesinde kullanılmıştır.

**Bulgular:** Türkçe POQL'in genç versiyonu cronbach's alfa güvenilirlik katsayısı ve KMO ve Barlett'in testlerine göre geçerli ve güvenilir. DMFT ve çürük (Decay=D) skorları hemofili grubunda kontrol grubundan daha yüksek değerlere sahipti; sırasıyla DMFT ve D ortalamaları hemofili grubunda 7 ve 4,1 iken kontrol grubunda 4,7 ve 2,3 idi ( $p=0,0001$  ve  $p=0,011$ ). 8-14 yaş grubunda ve genç yaş grubunda ağız sağlığında yaşam kalitesi istatistiksel olarak anlamlı bir şekilde hemofili grubunda daha yüksekti, ortalama skorlar 8-14 yaş grubu için 34,0 (hemofili) ve 17,4 (kontrol) olarak hesaplanırken ( $p=0,0001$ ), genç grubu için 37,1(hemofili) ve 26,0 (kontrol) olarak bulunmuştur ( $p=0,043$ ).

**Sonuç:** Türkçe POQL'in genç versiyonu geçerli ve güvenilir bir yaşam kalitesi ölçeğidir. DMFT skorları ve POQL skorları göstermiştir ki hemofili hastası olan çocukların hem ağız sağlıkları hem de ağız sağlığı ile ilişkili yaşam kalitelerinin iyileştirilmeye ihtiyacı vardır.

## ANAHTAR KELİMELER

Hemofili, çocuk, adölesan, kanamaya yatkınlık, ağız sağlığı ile ilişkili yaşam kalitesi

## ABSTRACT

### Oral Health-Related Quality of Life of Children and Adolescents with Hemophilia

**Background:** The problems arising from the teeth and the surrounding tissues in patients with hemophilia have an important role in the treatment planning of bleeding disorder. The aim of this study is to evaluate the oral health related quality of life of children and adolescents with hemophilia.

**Methods:** POQL (pediatric oral health related quality of life) Instrument was used in this cross sectional study for quality of life measurement. The instrument was applied to children and adolescents with (n=64) or without (n=196) hemophilia. The data collected were consist of demographic data, POQL and screening part. SPSS 23.0 was used to analyze the data.

**Results:** The teen version of POQL is valid and reliable according to Cronbach's  $\alpha$  coefficient, KMO and Barlett's test of sphericity. DMFT and decay (D) scores of patients with hemophilia were higher than the control group: mean values of hemophilia group are 7 and 4.1 vs. control group 4.7 and 2.3 are respectively ( $p=0.0001$  and  $p=0.011$ ). Among 8-14 age group and teenage group oral health related quality of life scores were significantly higher among hemophilia group, scores were 34.0 and 17.4 in 8-14 group ( $p=0.0001$ ) and 37.1 and 26.0 in teen group ( $p=0.043$ ), respectively.

**Conclusion:** The Turkish teen POQL is a valid and reliable quality of life instrument. DMFT scores and POQL scores have shown that oral health related quality of life of children with hemophilia is worse than healthy controls.

## KEYWORDS

Hemophilia, child, adolescent, hemorrhagic disorders, oral health related quality of life.

The oral health related quality of life (OHR-QoL) measurements are important for decision making in clinical conditions. In the lack of quality data and information; the management of oral health of patients with hereditary bleeding disorders and to understand the real effects of oral health problems cause considerable problems.<sup>1-3</sup>

Although congenital bleeding disorders may not directly target oral tissues, oral health can be influenced as a

consequence of general health problems. The children with hemophilia may have the tendency of brushing less frequently because of the fear of bleeding after minor trauma caused by brushing.<sup>4,5</sup> As a result of the prolonged hospital stay and cariogenic dietary habits, children with bleeding disorders may have the risk of gingival diseases and caries.<sup>6</sup>

Huntington et al. developed a brief measure of

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OHR-QoL in children and adolescents, this instrument of pediatric health related quality life (POQL) evaluates the different age periods according to their physical and psychological condition and gives the chance to the researcher to use different items for parents and children according to child's age.<sup>7</sup>

The aims of this study are to compare oral health-related quality of life and the oral health status of children and adolescents with hemophilia and their healthy counterparts.

## Material And Methods

### Design

This study is a cross-sectional study. The children and adolescents with hemophilia were referred to Çukurova University Department of Pediatric Dentistry Clinic, which is a collaborator of Comprehensive Care Centre for Congenital Bleeding Disorders (CBD) in Adana, Çukurova Region, Turkey. The control group was the patients of Çukurova University Faculty of Dentistry Clinics and their data has also used for validity and reliability of teen version of POQL. POQL surveys were applied to participants. Data Collection occurred between March 2013 and May 2015. All participants signed the consent approved by the Çukurova University Ethical Committee. Parents gave written consent for their children and children assented for their own participation. The 8-14 age group answered the POQL children instrument and the group older than 14 answered the POQL teen version. The upper age limit of teen version is 21. The validity and reliability of the 8-14 POQL was done previously.<sup>8</sup> The process of validity and reliability of the Teen POQL instrument is indicated in this paper.

### Study Sample

The determination of the study sample of validity and reliability was  $n=196$  and done due to Convergent Validity of Haemo-QoL (The Quality of life assessment instrument for children and adolescents with haemophilia) results of another study with 95% CI (Confidence Interval) and %90 power 9. This validity and reliability study group was also control group for the research. The hemophilia group ( $n=64$ ) was convenience sample of patients with hemophilia visiting xxxxxx University Clinics of Pediatric Dentistry. The hemophilia group was consist of 37 children with hemophilia A, 13 children with Hemophilia B and 14 children with Von Willebrand Disease.

### Reliability and Validity of Instruments

The Internal consistency, feasibility and factor structure of the "Teen POQL" instrument was evaluated in this part of the study. The reliability and internal consistency of the scale are assessed by Cronbach's Alpha coefficient. Cronbach's Alpha coefficient; within the range of  $\alpha < 0.40$ , the scale is not reliable.

The scale can be considered as very high level reliable, if  $\alpha \geq 0.90$ .<sup>10</sup>

Confirmatory factor analysis was used in this study. Within the scope of the factor analysis, some basic issues are taken into consideration. First of all, there should be a certain correlation relation between scale questions. The scale questions tested with the Barlett's test of sphericity and the statistical significance shows suitable results for factor analysis.

The Kaiser-Meyer-Olkin (KMO) sampling adequacy test on the same scale tests the correspondence of correlations between the factors to the factor analysis. Generally accepted KMO values;  $KMO > 0.80$  and above Excellent; KMO between 0.70 and 0.80 is good; KMO between 0.60 and 0.70 Medium; KMO between 0.50 and 0.60 Bad; the KMO is not accepted below 0.50.

8-14 year self-report instruments of POQL are reliable and valid.<sup>8</sup> The teen self-report for above 14 years old was reliable and valid according to data in the results section.

### Measurements

Each survey consists of demographic data, the POQL (teen and 8-24 version) instrument, general health questions and global oral health questions. Demographic data includes "age", "gender", "school grade", "brushing frequency" and "systemic disease condition". Additionally "general health", "general oral health", "dental health compared one year ago", "experience with dentists", "last dental visit" time and "the reason for last dental visit" questions were evaluated.

The POQL for 8-14 is a 10-item instrument. It was designed to measure oral health-related quality of life in children from both the child's and their parents' point of view. In this study the perspective of children's was measured. Children's self-reports (CSR) was used. The teen version of the instrument (self-report) consisted of 17 questions. The impact of the items were calculated with the multiplication of the answers of questions "how often the event occurred" and "how bothered the individual by its occurrence". At the end of the calculation the final scores were provided by the sum of all of the items. Higher scores correlate with worse quality of life. In addition to the instrument, global oral health rating question, global general health rating question, brushing frequency, dental health compared one year ago, the experience with dentists, the time of last dental visit and the reason for last dental visit were asked in the survey.<sup>11</sup>

### Dental Screening

Dental screening was consist of dmft (primary tooth decay, missing and filling) and DMFT according to WHO criteria. The other parameters were treatment urgency and dental hygiene. Those parameters were parts of Association of State and Territorial Dental Directors Basic Screening Survey (ASTDD-BSS). Two examiners were trained for this study according to ASTDD-BSS protocol 12. The dental examinations were completed with a

mirror in daylight. The inter-examiner agreement obtained on-screen parameters such as treatment urgency, hygiene and DMFT on 25% of the children measured by Kappa and was 0.89.

### Statistical Analysis

The data was coded separately for scale items and personal information questions. SPSS 23.0 (IBM SPSS Statistics for Windows, Version 23.0. Armonk, NY: IBM Corp) was used to analyse the data. Data frequency distributions, mean and standard deviations were checked. Cronbach alpha was used in order to test the validity and reliability of the survey.

For comparison of categorical variables the chi-square test was used. The scale score and other continuous measurement comparisons were tested with The Mann Whitney U test.

### Results

The control group (n=196) is consisted of 90 (%45.9) female and 106 (%54.1) male participants (p=0.243) while the hemophilia (n=64) group is 6 (%9.4) female and 58 (%90.6) male (p=0.0001). 8-14 age groups' mean age is 10.8±1.8 and teen group's mean age is 16.9±2.1.

#### The Validity and Reliability of Teen POQL

Cronbach's α coefficient of 8-14 year POQL instrument, Teen POQL instrument and all two instruments are 0.91, 0.94 and 0.92 respectively. For 8-14 year POQL KMO is 0.87 and for teen POQL KMO is 0.83. Barlett's test of sphericity test is p=0.0001. Total (both for 8-14 and teen instruments) KMO is 0.88 and Barlett's test of sphericity is p=0.0001. The teen version of POQL is valid and reliable according to Cronbach's α coefficient, KMO and Barlett's test of sphericity.

#### The Evaluation of POQL of Children with Hemophilia

The general oral health self-perception of teen group is worse than the 8-14 group (p=0.005). "General Health Perception" among hemophilia group is worse than the control group (p=0.002), also "Oral Health Perception" of hemophilia group is worse than the control group (p=0.038). "Brushing frequency" is higher among the control group (p=0.011) and there is no significant difference between groups by "Experiences with Dentists" (p=0.662). The general distribution of data is shown in Table 1.

		control		hemophilia		p
		n	%	n	%	
Gender	Female	90	45.9	6	44660	0.0001
	Male	106	54.1	58	90.6	
Brushing Frequency	Once A Month Or Never	14	7.1	10	15.6	0.01
	A Few Times A Month	14	7.1	11	17.2	
	A Few Times A Week	42	21.4	16	25	
	Once A Day	77	39.3	18	28.1	
	More Than Once A Day	49	25.0	9	14.1	
General Health	Poor	1	0.5	4	6.3	0.002
	Fair	28	14.3	17	26.6	
	Good	91	46.4	29	45.3	
	Very Good	53	27.0	9	14.1	
	Excellent	23	11.7	5	7.8	
General Oral Health	Poor	20	10.2	15	23.4	0.038
	Fair	65	33.2	20	31.3	
	Good	78	39.8	25	39.1	
	Very Good	19	9.7	2	3.1	
	Excellent	14	7.1	2	3.1	
Dental Health Compared One Year Ago	Much Worse	7	3.6	8	12.5	0.002
	Somewhat Worse	36	18.4	15	23.4	
	About The Same	50	25.5	24	37.5	
	Somewhat Better	58	29.6	11	17.2	
	Much Better	45	23	6	9.4	
Experience with Dentists	Poor	8	4.1	3	4.7	0.662
	Fair	28	14.3	12	18.8	
	Good	84	42.9	27	42.2	
	Very Good	30	15.3	12	18.8	
	Excellent	46	23.5	10	15.6	
Last Dentist Visit	Less Than 6 Months Ago	112	57.1	12	18.8	<0.0001
	6-12 Months Ago	39	19.9	10	15.6	
	More Than 1 Year But Less than 2 Years Ago	22	11.2	20	31.3	
	2-5 Years ago	11	5.6	11	17.2	
	More Than 5 Years Ago Or Never	12	6.1	11	17.2	
The Reason for Last Dental Visit	Routine Exam And/Or Cleaning	36	18.4	5	7.8	<0.0001
	Emergency (Tooth Injury)	4	2	1	1.6	
	Emergency (Toothache)	21	10.7	16	25	
	Having Tooth (Teeth) Pulled	40	20.4	20	31.3	
	Filling	79	40.3	13	20.3	
	Root Canal	9	4.6	10	1.6	
	Prosthodontics	2	1	3	1.6	
	Braces/ Space Maintainers	5	2.6	5	10.9	
Other	0	0	7	0		

The mean values of DMFT and decay (D) are higher among hemophilia group, 7 and 4.1, vs. control group, 4.7 and 2.3, respectively ( $p=0.0001$ ,  $p=0.011$ ). Numbers of filling is significantly higher in the control group ( $p=0.001$ ). The OHR-QoL scores of control and hemophilia group are significantly different for Role Function ( $p=0.0001$ ), Emotional Function ( $p=0.003$ ) and Social Function (0.001), **Table 2**.

**Table 2.**

**The differences of Hemophilia Group vs. Control group by DMFT, Decay, Missing, Filling, Role Function (POQL), Physiological Function (POQL) and Social Function (POQL).**

	Control Group		Hemophilia Group		p
	Mean±SD	Med (IQR)	Mean±SD	Med (IQR)	
DMFT	4.7±3.7	4 (4)	7.0±4.6	6 (4)	0.0001
Decay	<b>2.3±2.7</b>	<b>1 (3)</b>	<b>4.1±3.5</b>	<b>3 (5)</b>	<b>0.011</b>
Missing	0.24±0.6	0 (0)	0.70±1.1	0(1)	0.598
Filling	<b>2.2±2.2</b>	<b>2 (2)</b>	<b>2.2±3.6</b>	<b>1 (3)</b>	<b>0.001</b>
Role Function	29.8±23.8	26.1 (29.7)	38.7±25.5	33.3 (35.9)	0.0001
Emotional Function	<b>22.6±22.9</b>	<b>15.3 (30.6)</b>	<b>33.5±26.9</b>	<b>25.0 (30.6)</b>	<b>0.003</b>
Social Function	24.6±29.9	8.3 (33.3)	37.1±34.1	29.2 (54.8)	0.001

p: Mann Whitney U test,  $p<0.05$

POQL mean scores were significantly different between hemophilia and control group, 34.0 and 17.4 in 8-14 group ( $p=0.0001$ ) and 37.1 and 26.0 in teen group ( $p=0.043$ ). Regardless of the age group, the hemophilia and the control population showed statistically significant differences by POQL scores ( $p=0.0001$ ), **Table 3**.

**Table 3.**

**Oral Hygiene and Treatment Urgency by groups.**

	Control Group		Hemophilia Group		p
	n	%	n	%	
<b>Oral Hygiene</b>					
good	84	42.9	14	21.9	<b>0.002</b>
fair	80	40.8	29	45.3	
bad	32	44.636	21	32.8	
<b>Treatment Urgency</b>					
No obvious problems	73	37.2	12	18.8	<b>0.004</b>
Needs early treatment	102	52.0	37	57.8	
Needs immediate treatment	21	44.752	15	23.4	

p: Chi-Square,  $p<0.05$

“Oral Hygiene” were worse among control group (bad: %16.3) than hemophilia group (bad: %32.8) ( $p=0.002$ ). “Urgent Treatment Need” was higher among hemophilia (urgent treatment need: %23.4) group than control group (urgent treatment need: %10.7) ( $p=0.004$ ), **Table 4**.

**Table 4.**

**Total POQL scores by age groups**

Age Groups	Sytemic condition	N	POQL	POQL	P
			Mean±SD	Median (IQR)	
8-14	hemophilia	44	34.0±23.6	30.4 (34.6)	<b>0.0001</b>
	control	105	17.4±13.6	13.6 (22.0)	
Teen	hemophilia	20	37.1±23.9	32.1 (32.3)	<b>0.043</b>
	control	91	26.0±21.7	23.5 (26.5)	
Total	hemophilia	64	34.9±23.6	18.3 (24.2)	<b>0.0001</b>
	control	196	21.4±18.3	31.1 (32.8)	

p: Mann Whitney U test,  $p<0.05$

## Discussion

Problems related to dental and oral tissues have an important impact on the treatment process of patients with hemophilia. This study evaluates the OHR-QoL, dental and oral health status of those patients; particularly to determine the effects of oral health problems for children in the hemophilia population. The pediatric oral health related quality of life (POHR-QoL) aims to evaluate the impacts of oral health in daily activities, functioning, social life, aesthetic perception, learning and emotional wellbeing. This measure differentiates from traditional objective medical assessment methods by evaluating social, emotional experience and physical functioning of an individual.<sup>4</sup> The QoL among patients with hemophilia is influenced by clinical aspects, such as treatment regimen and bleeding frequency and by psychosocial variables, such as social support and self-esteem.<sup>13</sup> Measuring POHR-QoL, especially of younger ones, is more difficult than the assessment of adults. To report the feelings and behaviors of children in a reliable and validated concept is not easy. To choose the appropriate domains of the QoL in children is another challenge, an increasing effort has been made in the field of the QoL to assess well-being and functioning.<sup>14</sup>

In this study the number of “filling” was significantly lower among the children with hemophilia and the DMFT scores were higher than healthy controls. The situation may be a sign of emergency dental visits (for extraction) instead of routine dental visits. It may show the difficulties of accessing to dentists for teen and children with hemophilia. The caries experience among children with hemophilia from Lithuania, North Ireland and Poland was better.<sup>5,15,16</sup> The results may be related with the frequent dental examinations in those countries. In this study, correspondingly to the DMFT scores, hemophilia group showed lower brushing frequency. This outcome was similar with previous studies that show classical oral hygiene education alone is not sufficient for children with hemophilia.<sup>17-21</sup> The oral hygiene education can conduct with strict dental visits and examinations in order to be successful.

Previous studies revealed that, from the parent's perspective, children with hemophilia have poor brushing habits even though they don't have any limitations about accessing dental treatment and dental team.<sup>11</sup> Psychological and sociological barriers against tooth brushing should be considered and the professional dental team should try new dental hygiene education models.<sup>22</sup> In accordance with brushing frequency, oral hygiene scores of patients with hemophilia were worse than their healthy counterparts. Another important finding was the frequency of brushing, it increased with age among both of the groups.

POQL results showed that the patients with hemophilia have worse OHR-QoL comparing with the control group and perception of oral health is poor in comparison with the control group. These outcomes were similar with Baskirt et al.'s study showing that patients with hemophilia were in need of dental treatment according to the assessment of their perceived oral-dental health level and treatment need.<sup>17</sup> A QoL study in Austria, carried out with severe hemophilia patients, presented the worst QoL score values in subgroups; physical function, role-physicals, body pain and general health.<sup>23</sup> There were no statistically significant difference by domains (symptoms, physicals, physiological and self-image items) between hemophilia and control groups in another study carried out in Salem.<sup>4</sup> The present study showed higher total and subgroups scores of POQL by hemophilia group which means worse OHR-QoL and worse scores of DMFT. In parallel with higher DMFT scores, oral health treatment needs and treatment urgency of patients with hemophilia were higher than healthy children and teen groups. The lower scores of oral health perception may link with the situation of urgent treatment need and higher DMFT scores. Correspondingly, results of the global oral health perception question indicated that perception of patients with hemophilia regarding their oral health is not better than the healthy control group. The results of general health question additionally exhibited that the patients with hemophilia tend to be skeptic regarding their overall health in comparison with the healthy group.

"The last dental treatment reason" of hemophilia group was generally dental extraction and filling. Their routine dental visit frequency is lower than the control group. General health perception is also different from their healthy counterparts, this situation may result with the neglect of dental health. The most important part of the oral health of the children with bleeding disorders is not the treatment part but the conservation of the healthy teeth and oral tissues.

The dentists can avoid the dental problems by understanding the psychological determinants of dental behavior of those children. At the end barriers, such as the lack of routine dental visits and lower brushing frequency, against sustainable dental programs for children and teen with bleeding disorders can be eliminated by the collaboration of dental and medical team.

## Conclusion

DMFT scores and POQL scores of children with hemophilia have shown that OHR-QoL need to be improved by the dental team, but different methods are also in need to reduce urgent treatment needs and improve oral hygiene levels of children and teen with hemophilia.

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