

Parent's report on oral health-related quality of life of children with cystic fibrosis

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Abstract

Background: Health-related quality of life (HRQoL) scales are now widely used in children with cystic fibrosis (cwCF) which reflects the course of the disease. In this cross-sectional study, our primary aim was to compare the Pediatric Oral Health-Related Quality of Life (POQL) and Oral Health Score (OHS) between cwCF and healthy group. Our secondary aim was to evaluate the association between *Pseudomonas aeruginosa* (PA) colonization, pulmonary function test, OHS and POQL in cwCF.

Methods: The study population (age ranging 6–14) included 55 cwCF followed at the Marmara University Division of Pediatric Pulmonology compared with 50 healthy peers. A survey consisted of general questions (age, sex, etc.) and the POQL instrument were filled by parents. The decayed, missing, and filled teeth for both primary (dft) and permanent dentition (DMFT) was detected according to WHO criteria. Data like current body mass index (BMI z score), colonization status with PA, predicted value for forced expiratory volume in 1 second (FEV1pp), and any hospitalizations during the previous year were obtained from their medical. Differences between the groups were evaluated using Chi-square and Mann–Whitney *U* test with a significance level set at 0.05.

Results: There was no significant difference between PA-colonized cwCF and healthy controls in DMFT ($p = 0.916$). For all domains of POQL (emotional function, social function, role function), scores of cwCF were significantly better than healthy controls ($p < 0.05$). There were no statistically significant differences between all domains of POQL scores in PA colonized and non-PA colonized cwCF' POQL scores ($p > 0.05$).

Conclusion: Although POQL scores of cwCF were encouraging, dental caries prevention and regular follow-ups should be taken into consideration.

KEYWORDS

cystic fibrosis (CF), oral health, pediatric dentistry, *Pseudomonas aeruginosa* (PA), quality of life

1 | INTRODUCTION

Cystic fibrosis (CF) is one of the most prevalent life-restricting autosomal hereditary diseases amongst Caucasians with the prevalence of 1 in every 3000 live births affecting both sexes similarly.¹ It is a multisystem disorder, affecting lungs, pancreas, liver, and intestine.¹ Chronic pulmonary infections are mainly caused by *Pseudomonas aeruginosa* (PA) in children with CF (cwCF).² PA colonization which is the leading cause of mortality and morbidity in cwCF also associated with decreased quality of life.^{2,3}

Better lung function in people with CF is strongly associated with improved quality of life and survival. The most often used pulmonary function measurement parameter is forced expiratory volume at 1 second percent predicted (FEV1pp) and this is also one of the indicators of CF care quality.^{4,5}

Oral health status (OHS) is affected by CF. However, there is a lack of evidence for the relation between CF and dental caries.⁶ Due to the malabsorption in patients with CF, they frequently consume foods with high-calorie content.⁶ Oral antibiotics used in CF may have high sucrose content, which increases the caries risk and the severity of the dental disease process.⁷ Inhaled corticosteroids may cause decreased salivation and may use lactose as a carrier, which may further increase the patient's caries risk.^{6,8,9} PA infections in CF patients are hard to eradicate, and different antibiotic therapies are used for treatment which may affect patient's caries experience.^{2,6,10,11}

As a result of longer lifespan in CF with the current treatment regimens, maintaining oral hygiene has become a more important issue. Also, the expected connection among oral and systemic infections indicates the significance of the oral wellbeing of people with CF.¹²

Health-related quality of life is critical for understanding the impact of health status on quality of life. For measuring oral health-related quality of life (OHRQoL), different instruments have been used. OHRQoL is significant to reflect how comfortable and confident children are while eating, sleeping, socializing, and how pleased they are with their current oral health condition.¹³⁻¹⁶ The Pediatric Oral Health-Related Quality of Life (POQL) which is a new instrument developed by Huntington et al.¹⁵ was used in our study since it is simple, can be used in preschool, school-aged children from minority populations also it was validated and translated into Turkish.¹⁷

OHRQoL questionnaires have been widely used in nearly all types of diseases and all age groups. However, questionnaires that are exclusively organized for pediatric age groups are not available for every section. POQL is only focusing on pediatric age groups.¹⁵ In our study we aimed to show the value of POQL in our CF patient group. To the best of our knowledge no study has compared POQL scores between cwCF and healthy peers. Also, this is the first study which compares POQL scores according to cwCF's colonization status with PA. Thus, the primary aim of this study was to compare the POQL scores and OHS between cwCF and healthy group. Our secondary aim was to evaluate the association between PA

colonization, pulmonary function test (PFT), OHS and POQL in cwCF. We hypothesized that cwCF would have worse OHS and POQL scores than healthy peers and PA colonization status of cwCF would have an impact on this expected difference.

2 | METHODS

2.1 | Study design

This cross-sectional study was conducted in accordance with the Declaration of Helsinki and it was approved by the Marmara University Dentistry Faculty Clinical Research Ethics Committee (reference number 2021-26).

The informed consent was signed from all parents. Data were collected between July 2019 and October 2021.

The study population (age ranging 6-14) included 55 cwCF followed at the Marmara University Division of Pediatric Pulmonology and a control group of 50 healthy peers without any systemic diseases were selected from siblings or children of the patients' who attended Marmara University Dental Clinics. Control subjects' socioeconomic and demographic factors (e.g., age, sex, household income, health insurance status, ethnicity) were matched. They were selected from the residents living in the same neighborhood or siblings. After informed consent obtained, caregivers of the patients were asked to fill out the questionnaire form. cwCF were grouped according to their forced expiratory volume in one % predicted (FEV1pp). Two subgroups were made for cwCF whose FEV1pp values were less than 80% predicted and higher than 80% predicted.

Caregivers were separately asked questions to rate their child's both general and OHS, "In general, how would you rate your child's general health?," "In general, how would you rate the oral health of your child?" with responses on a Likert-type scale 1 = Excellent, 2 = Very Good, 3 = Good, 4 = Fair, and 5 = Poor. "Dental health of children compared to previous year" was questioned with responses 1 = Much worse, 2 = Somewhat worse, 3 = About the same, 4 = Somewhat better, 5 = Much better.

CF diagnosis was confirmed by positive sweat chloride testing of 60 meq/L and/or 2 CF disease-causing mutations.¹⁸ Study population was recruited by sequential sampling during the study period. None of the patients declined to complete the questionnaires. Patients with acute respiratory infection, other chronic diseases, or mental retardation were excluded.

2.2 | Dental screening

All CF and control groups' participants were examined by same pediatric dentist (HI). Both study and control group had dental examinations and their decayed, missing and filled teeth for both primary (dft) and permanent dentition (DMFT) was detected according to criteria developed by WHO.¹⁹

2.3 | Study measures

The survey consisted of general questions (age, sex, etc.), the POQL instrument and general questions about OHS. Objective measurements of CF included PFTs (FEV1pp), body mass index (BMI) z-score, any hospitalizations during the previous year and PA colonization status were obtained from their medical records.

PFT was measured using a spirometer (WinspiroPRO 2.8 MIR) in accordance with internationally agreed standards. PFT was performed after applying a nose clip in an upright sitting position using the same device. Only results which met ERS/ATS standards for interpretation were included in the project for analysis.²⁰

BMI z-score was calculated by an established online program developed for Turkish children.²¹

Any hospitalization during the last year was recorded only if the reason was associated with pulmonary exacerbation or any other pulmonary complication.

cwCF were grouped according to the bacterial colonization in their sputum culture. Colonization of PA was determined according to the Leeds Criteria.² According to Leeds Criteria, having positive PA in more than 50% of the cultures in the preceding year is described as colonization.²

The POQL has been designed to measure OHRQoL in children from both the children and their parents' viewpoints.¹⁵ POQL contains three domains: role function (four items), social impact (three items), and emotional impact (three items) in the Turkish version.¹⁷ In addition to the original version, in the Turkish version, the Role Function domain consists of a combination of the Physical and Role Function.^{15,17} In POQL, response to "how often" question (0–3) is multiplied by "how bothered" response (0–4), and the "impact" scores are found. Overall POQL scores are between 0 and 100, higher scores show worse POQL. Patients were excluded if less than two-thirds of the questions were answered by the participant.¹⁵

To prove our hypothesis, we established a theoretical framework. CF is a chronic respiratory disorder affecting all aspects of life and CF patients are using continuous medications including inhaled steroids. Chronic condition of cwCF and medications they use may

affect their oral health. In the end; these factors will be contributing to declining their OHRQoL. FEV1pp, BMI z-score, PA colonization status, and any hospitalization during the last year were also can be other affecting factors. Only socioeconomic status remains as a confounding factor, and we added that to the limitations. To decrease the effect of socioeconomic status as a confounding factor, we selected control group from surroundings.

2.4 | Statistics

SPSS v.25 was used for statistical analysis (SPSS, Inc.). The level of significance was set at 5% ($p < 0.05$). Continuous variables (FEV1pp, number of daily medications, BMI z-score, age) were expressed as mean \pm standard deviation. Chi-square test was used for comparison of categorical variables (hospitalization) and were presented as percentages. Mann–Whitney U test was used to scale scores and other continuous measurement comparisons between healthy controls and CF children.

3 | RESULTS

A total of 105 parents completed the survey. The mean age of 55 CF children (21 girls and 34 boys) was 9.7 ± 2.6 years whereas the mean age of 50 healthy controls (23 girls and 27 boys) was 10.7 ± 2.0 years.

CF children were divided into two subgroups according to the PA colonization in their sputum culture. The number of PA colonized group was 26 and non-PA colonized group was 29. FEV1pp, BMI z score, hospitalization rate were investigated according to the PA colonization. FEV1 values were $75.92 \pm 22.18\%$ predicted, $90.48 \pm 13.02\%$ predicted, respectively and difference between two groups was found statistically significant ($p = 0.009$) (Table 1).

Difference between DMFT and POQL scores of cwCF whose FEV1pp values were less than 80% predicted and higher than 80% predicted were not statistically significant ($p > 0.05$).

TABLE 1 General characteristics of the CF group

CF	PA colonized (N = 26)	Non-PA colonized (N = 29)	<i>p</i>
Age in years (mean \pm SD)	10.4 \pm 2.4	9.0 \pm 2.6	0.050^a
FEV1% pred (mean \pm SD)	75.9 \pm 22.2%	90.5 \pm 13.0%	0.009^a
BMI z score (mean \pm SD)	-0.5 \pm 1.1	-0.2 \pm 1.0	0.320 ^a
Number of daily medications (mean \pm SD)	8.0 \pm 2.3	4.7 \pm 2.2	0.003^a
At least 1 hospital admission/year	9.0 (34.6%)	6.0 (20.7%)	0.247 ^b

Note: $p < 0.05$ is statistically significant. Bold values indicate statistically significant differences ($p < 0.05$).

Abbreviations: BMI, body mass index; CF, cystic fibrosis; FEV1, forced expiratory volume at one second; PA, *Pseudomonas aeruginosa*.

^aMann–Whitney U test.

^bChi-square.

TABLE 2 General distribution of the groups

	Control (n = 50) N %		CF (n = 55) N %		p
General health (child)					0.002
Poor	0	0	10.0	18.2	
Fair					
Good	50.0	100.0	45.0	81.8	
Very Good					
Excellent					
General oral Health (child)					<0.001
Poor	38.0	76.0	23.0	41.8	
Fair					
Good	12.0	24.0	32.0	58.2	
Very Good					
Excellent					
Dental health compared to previous year (child)					0.218
Much worse	12.0	24.0	8.0	14.5	
Somewhat worse					
About the same	38.0	76.0	47.0	85.5	
Somewhat better					
Much better					
Last Dentist Visit (children)					<0.001
Less than 6 months ago	23.0	46.0	8.0	14.6	
6–12 months ago	10.0	20.0	4.0	7.3	
More than 1 year but less than 2 years ago	4.0	8.0	13.0	23.6	
2–5 years ago	7.0	14.0	9.0	16.4	
More than 5 years ago or never	6.0	12.0	21.0	38.2	

Note: $p < 0.05$ is statistically significant. Bold values indicate statistically significant differences ($p < 0.05$) based on the Chi-square test.

Abbreviation: CF, cystic fibrosis.

Last dentists visit of children “less than 6 months ago” was 46.0% in healthy controls and 14.6% in cwCF ($p < 0.05$). Among the CF group, 41.8% of parents described their children's oral health as poor or fair while 76% of the healthy groups' parents described their children's oral health as poor or fair ($p < 0.05$). Table 2 shows the general and oral health perceptions of children and their parents.

DMFT of cwCF group was 2.3 ± 2.2 and 3.1 ± 2.2 in control group and difference between two groups were not statistically significant ($p = 0.071$).

Dft score of CF group was 2.7 ± 2.8 and dft score of healthy controls was 2.1 ± 2.9 . There was no statistically significant

TABLE 3 DMFT, and dft scores of the children with cystic fibrosis and control group

	CF (n = 55) Mean \pm SD	Control (n = 50) Mean \pm SD	Total (n = 105) Mean \pm SD	p
Age	9.67 ± 2.60	10.74 ± 2.00	10.18 ± 2.4	0.029
DMFT	2.33 ± 2.16	3.08 ± 2.24	2.69 ± 2.22	0.071
D	2.18 ± 2.14	2.32 ± 2.03	2.25 ± 2.08	0.611
M	0.04 ± 0.19	0	0.02 ± 0.14	0.175
F	0.11 ± 0.50	0.76 ± 1.22	0.42 ± 0.97	<0.001
dft	2.65 ± 2.80	2.12 ± 2.92	2.40 ± 2.87	0.147
d	2.56 ± 2.84	1.90 ± 2.74	2.25 ± 2.80	0.111
f	0.09 ± 0.40	0.22 ± 0.62	0.15 ± 0.52	0.144

Note: Bold values indicate statistically significant differences ($p < 0.05$) based on the Mann-Whitney U test.

Abbreviations: CF, cystic fibrosis; dft, sum of the number of decayed and filled teeth in the primary teeth; DMFT, sum of the number of Decayed, Missing due to caries, and Filled Teeth in the permanent teeth.

TABLE 4 POQL scores of the groups

	Control (N = 50) Median (Min–Max)	Cystic fibrosis (CF) (N = 55) Median (Min–Max)	p
Role function	16.7 (0–66.7)	6.3 (0–50.0)	<0.001
Emotional function	16.7 (0–61.1)	0 (0–50.0)	0.019
Social function	0 (0–61.1)	0 (0–27.8)	<0.001
Total POQL	16.3 (0–40.8)	5.0 (0–30.0)	<0.001

Note: Bold values indicate statistically significant differences ($p < 0.05$) based on the Mann-Whitney U test.

Abbreviation: POQL, Pediatric Oral Health-Related Quality of Life.

difference between the groups ($p = 0.147$). Table 3 shows the DMFT, dft scores and the distribution of decayed, missing, and filled teeth of the cwCF and the control group.

The impact of PA colonization of the cwCF on DMFT scores and POQL was assessed. DMFT scores of PA colonized and non-PA colonized group were 3.19 ± 2.33 and 1.55 ± 1.66 , respectively. The difference between the DMFT scores of the groups were statistically significant ($p = 0.007$).

DMFT score of non-PA colonized cwCF was significantly lower than healthy controls ($p = 0.003$). However, there was no significant difference between PA colonized and healthy controls ($p = 0.916$).

Total POQL and the subgroups which are Role Function, Emotional Function, Social Function were significantly different between the control and CF groups respectively; $p = 0.000$, $p = 0.000$, $p = 0.019$, $p = 0.000$. Table 4 shows the distribution of domains of POQL and total POQL.

There were no statistically significant differences between all domains of POQL scores in PA colonized and non-PA colonized

groups' POQL scores ($p > 0.05$). However, both PA colonized and non-PA colonized groups' POQL scores between all domains were significantly better than healthy controls ($p < 0.05$).

4 | DISCUSSION

Current study demonstrated that POQL scores of cwCF was better than healthy controls. Caries prevalence of non-PA colonized group was significantly lower than both PA colonized cwCF and healthy group. Additionally, tooth decay was similar between PA colonized cwCF and healthy peers. All these findings are in contrary to our hypothesis. To the best of our knowledge, our study is the first study to compare the POQL scores of cwCF with healthy peers.

HRQoL scales are now widely used in cwCF which reflects the course of the disease.^{22,23} A recent study showed that a decreased FEV1pp causes a deterioration in the HRQoL.²⁴ Bodnar et al. suggested that malnutrition, hospitalization rate, and PA colonization were the most significant factors to have a huge negative impact on the HRQoL of CF patients.³

Severe chronic diseases such as hemophilia and severe asthma mostly have a negative impact on the OHS and OHRQoL of the patients compared to healthy controls.^{25,26} In CF Patrick et al. reported that older CF patients reported statistically significant poorer OHRQoL than younger patients.²⁷ There are various methods to measure the effect of OHRQoL in children.^{15,27,28} However, POQL is simpler and shorter compared to other similar OHRQoL measures like Broder et al.'s COHIP.²⁸

In our study POQL of cwCF was found significantly better than healthy peers. Higher caries prevalence of healthy peers compared to non-PA colonized cwCF may be the reason of their poorer POQL results. PA colonized cwCF caries prevalence was higher than non-PA colonized cwCF and not significantly different than healthy controls. However, POQL scores of PA colonized cwCF was better than healthy group and not significantly different than non-PA colonized cwCF. A recent study demonstrated that the presence of major problems can minimize the negative perception about the impact of oral problems on the individual's life.²⁹ This may indicate that because of the difficulty of the disease or treatments cwCF especially PA colonized group may neglect the importance of oral health. Our study results showed that after PA colonization OHS of cwCF getting worse, to prevent oral infections cwCF should be informed about the importance of oral health and routine dental controls. Also, more attention should be paid to the preventive dental treatments of cwCF.

According to the questionnaire results, the general OHS and the last dentist visit time were similar between CF and healthy group; and it indicates that only a very small proportion of the CF group visited the dentist less than 6 months ago. Contrary to our result, in the previous studies, 68%–70% of CF children attended regular dental check-ups every 6 months^{27,30} and the remaining 30% visited the dentist only once a year.³⁰

In our study, OHS of cwCF was not significantly different between control group. Similarly, previous systematic reviews generally showed that, prevalence of dental caries scores of cwCF were lower or significantly not different compared to healthy controls.^{6,31} On the other hand, in a different research there was a higher incidence of caries in CF patients between the ages of 6–12 than control group.³² Also, Chi et al. remarked that "adolescents with CF may not be at lower caries than those without CF."⁶

CwCF use antibiotics for long term, and this may reduce caries prevalence.^{33,34} Theory that antibiotics decreases intra-oral levels of *Streptococcus mutans* which is positively associated with tooth decay rates, may be acceptable for non-PA colonized cwCF.^{6,33,34} Since, as PA becomes the predominant pulmonary pathogen, different antibiotics are started to be used like tobramycin which is an aminoglycoside that targets PA. In a previous study from our group Peker et al. could not find a significant difference between DMFT scores of adolescents with CF who take inhaled tobramycin for any reason and children who take other antibiotics.¹⁰ Other previous studies showed that, inhaled tobramycin does not affect *S. mutans* thereby in PA-colonized CF people caries risk may be increased.^{6,11,35,36} Similarly, in our study, DMFT score of non-PA colonized cwCF was significantly lower than both healthy and PA colonized cwCF.

In our study, difference between DMFT scores of cwCF whose FEV1 values were $< 80\%$ predicted, $> 80\%$ were not statistically significant. Contrary to our results, Chi et al.³⁶ found that lower FEV1 values were associated with more caries. They stated that advanced CF disease has a greater negative impact on oral health.³⁶ Even though lower FEV1 value has a negative effect on HRQoL of cwCF there was no significant effect of this objective measurement on POQL was found in our study.^{36–38}

This study has various limitations. First one is to measure HRQoL only from parent's perspective. As this perspective might be dependent on the parental emotional situation, this may exaggerate or underestimate the patients' real condition. Second, the possibility of not detecting interproximal caries due to the lack of radiographic examination. Third limitation is the small size of the study population. Another limitation is difficulty in interpreting the findings due to the difference in sample size between groups. We were not able to include socioeconomic status as a direct question in the questionnaire. This may be accepted as a limitation but choosing the control group from surroundings may be decreasing the effect of this confounding factor. A major strength of this study is the use of high-quality and reliable indexes and questionnaires. Also, this is the first study to compare the POQL scores of cwCF with healthy peers.

Even though current study demonstrated that POQL scores of cwCF were better than healthy controls, dental caries prevention and regular follow-ups should be taken into consideration. Within the limitations of our study, PA colonization status were found to increase the caries prevalence in cwCF. Since dental caries is a multifactorial disease; further studies should investigate other potential risk factors. Interdisciplinary approaches are needed to support oral health and to increase OHRQoL in cwCF.

AUTHOR CONTRIBUTIONS

Hande Ilgin Sisman: Data curation (equal); Investigation (equal); Methodology (equal); Project administration (equal); Validation (equal); Visualization (equal); Writing – original draft (equal); Writing – review and editing (equal). **Sertac Peker:** Conceptualization (equal); Investigation (equal); Methodology (equal); Validation (equal); Writing – original draft (equal); Writing – review & editing (equal). **Yasemin Gokdemir:** Conceptualization (equal); Data curation (equal); Investigation (equal); Methodology (equal); Validation (equal); Writing – original draft (equal); Writing – review and editing (equal). **Ela Erdem Eralp:** Conceptualization (equal); Data curation (equal); Investigation (equal); Methodology (equal); Validation (equal); Writing – original draft (equal); Writing – review and editing (equal). **Bulent Karadag:** Conceptualization (equal); Data curation (equal); Investigation (equal); Methodology (equal); Validation (equal); Writing – original draft (equal); Writing – review and editing (equal). **Betul Kargul:** Conceptualization (equal); Data curation (equal); Investigation (equal); Methodology (equal); Validation (equal); Writing – original draft (equal); Writing – review and editing (equal).

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data openly available in a public repository that issues datasets with DOIs.

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