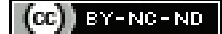


Impact of Oral Health on the Oral Health Related Quality of Life (OHRQoL) among Individuals with Intellectual Disabilities in Chennai, India: A Cross-sectional Study

NIVEDHA SUBBURAMAN¹, VAISHNAVI PRASHANTH², D MOHANRAJ³, SOUNDARYA PRABHAKAR⁴, KUMARA RAJA⁵



ABSTRACT

Introduction: The risk of developing oral diseases is higher among individuals with disabilities compared to those who do not have any form of impairment or disability. Dental caries and periodontal diseases are the two most prevalent diseases among the individuals with disabilities worldwide and dental treatment is considered as the greatest unattended health need and oral diseases can have varying impacts on well-being and life quality of people.

Aim: To assess the impact of oral health on the Oral Health Related Quality of Life (OHRQoL) of patients with intellectual disabilities in Chennai, India.

Materials and Methods: The present cross-sectional school-based study which was conducted in the Department of Public Health Dentistry, Tagore Dental College and Hospital, Chennai, Tamil Nadu, India, from August 2021 to September 2021. Study was conducted among the parents of 12-25-year-old intellectually disabled individuals studying in special schools in Chennai, India. The estimated sample size was 122 with 95% of power and effect size of 0.3. OHRQoL of the participants with intellectual disabilities was assessed using the short-form versions of the Parental-Caregivers Perceptions Questionnaire (P-CPQ) and impact of Oral health on the family life of participants with intellectual disabilities using Family Impact Scale (FIS). Clinical examination of oral health status

was assessed using self-designed proforma based on the World Health Organisation (WHO) basic oral health survey 2013. Data was analysed using Statistical Package for the Social Sciences (SPSS) software version 24.0.

Results: The number of participants between 12-18 years was 111 (91%) and 19-25 years was 11 (9%) and 68 (55.7%) were males and 54 (44.3%) were females. The results showed that most of the parents 83 (68.03%) were concerned about their child's bad breath with regard to P-CPQ and with regard to the FIS highest mean was recorded for child needs more attention from them (2.93±0.89) and sleep disturbances (2.80±0.49) among parents. Most (n=52, 42.6%) of them had decayed teeth compared to filled (n=14, 11.5%) and missing teeth (n=17, 13.9%). Majority (n=83, 68.1%) of the participant had fair oral hygiene. There was a positive correlation of oral symptoms and social well-being with the dentition status, Oral Hygiene Index-Simplified (OHI-S) and gingival index.

Conclusion: A positive correlation was recorded between the oral symptoms of P-CPQ with the oral health status of the study population with stronger correlation recorded for oral hygiene. With regard to functional limitation there was a negative correlation with gingival index and for emotional well-being there was a negative correlation with dentition status and gingival index.

Keywords: Disabled children, Family impact scale, Parental-caregivers perception questionnaire

INTRODUCTION

Disability is a term, covering impairments, limiting activities, and restricting activities. In 1995, the Government of India under "Persons with Disabilities Act" described "handicapped" as a person with one or more disabilities like impaired vision, leprosy-cured, hearing impaired, orthopaedic disability, mental retardation, and mental illness. As per Census 2011, in India, about 2.68 crore persons are disabled which is 2.21% of the total population. In Tamil Nadu, 1.64% of the total population is disabled. Among them 2.1 lacs are between the age group of 20-29 years followed by 1.7 lac between 10-19 years. Around one lac population has some form of mental retardation and 32.9 thousand has some form of mental illness [1]. Oral health needs of people with disabilities are much related to underlying developmental or congenital anomalies and their inability to receive adequate personal and professional care to maintain oral health [2].

The OHRQoL is quickly growing phenomenon which has emerged over past two decades. There are numerous instruments available to measure adult OHRQoL, designing instruments especially for children and adolescents that allows researchers to identify and examine OHRQoL factors that are unique to these populations

(i.e., self-image, social acceptance, and school environment) [3]. The measurement of health-related QoL must be from the child's perspective or their guardian/caretaker (especially for individuals with special needs) and the family [4]. Dental diseases among children might result in lost work days for parents and caregivers as well as time and money spent in accessing dental care [5]. FIS is used to measure the family impact on child's oral and orofacial disorders and it consists of 14 items spreaded over four domains. Thus, the impact of dental disease on the caregivers and families of people with special needs are also important to measure as part of assessing OHRQoL in them [6].

Extensive literature search suggests that there was small-scale evidence regarding assessment of OHRQoL among intellectually disabled population and the impact of their condition on their family life in India [7]. Thus, the present study was contemplated to understand the impact of oral health on the OHRQoL of patients with intellectual disabilities in Chennai.

The aim of the study was to assess the OHRQoL among people with special needs using short-form versions of P-CPQ and to assess the impact of oral health on the family life using FIS.

Also, to assess oral health-dentition status using modified World Health Organisation (WHO) oral health assessment form 2013, OHI-S and Modified Gingival Index (MGI) and to find association between oral health status and OHRQoL of people with special healthcare needs.

MATERIALS AND METHODS

It was a cross-sectional school-based study which was conducted in the Department of Public Health Dentistry, Tagore Dental College and Hospital, Chennai, Tamil Nadu, India, between August 2021 and September 2021 for the duration of two months among the parents of 12-25-year-old intellectually disabled individuals studying in special schools in Chennai, India. Ethical clearance was obtained from Institutional Ethical Committee (IEC/TDCH/030/2021). Informed consent was obtained from the parent/ caretaker before the commencement of the study.

Sample size calculation: Cluster random sampling methodology was employed and five special schools from Chennai were selected. Parents/caretaker of the students who had given consent in those schools was included in the study. Parents/caretakers were accompanying their children in the schools and questionnaire was given and collected after two hours on the same day and a pilot study was conducted among 40 children to estimate the sample size and for testing the data collection format. Based on the results of the pilot study the sample size determined with 5% level of significance and 95% of power and effect size of 0.3 was 122.

Inclusion criteria: Participants with an IQ level of 70 or lesser were included and categorised into each group respectively, participants from the age group of 12-25 years, participants with single or multiple disability were included in the study.

Exclusion criteria: Caretakers who are not a part of the participant's family/providing professional assistance and the participants who are uncooperative and/or absent for long duration were excluded from the study.

Study Procedure

Intellectual disability was assessed using the classification of Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-1V) into four different degrees: mild {Intelligence Quotient (IQ 50-70)}, moderate (IQ 35-49), severe (20-34), and profound (IQ <20) [8]. After obtaining informed consent from the parent/caretaker of the participants, the study was conducted in three parts.

Part A: Assessing the OHRQoL among participants with disabilities using short form versions of the P-CPQ [9]. It consists of sixteen items with four domains: oral symptoms, functional limitations, emotional and social well-being with four questions in each domain. The questions referred to frequency of events that occurred during the previous three months. A five-point Likert scale was used with the following options of response: "Never" (score 0), "Once or twice" (1) "Sometimes" (2) "Often" (3) "Nearly every day" (4). The highest scores indicated the highest levels of negative impact of oral conditions on individual's QoL as perceived by parents.

Part B: Assessing the impact of oral health on family life of participants with intellectual disabilities using FIS [9]. The FIS is an evaluation scale that analyses the impact of children's oral health on the family life of the participants with intellectual disabilities was assessed by their parent/caretakers using the FIS. The FIS consists of fourteen items spread over four domains: five questions on parental/family activities, four questions on parental emotions, four questions on family conflict and one question on financial burden. The global rating has five-point response format ranging from 'never=0' to 'every day or nearly every day=4; higher the scores, worse the impact on family life of the participants with intellectual disabilities. Majority of the informants are mothers and only few number of questionnaires were completed by fathers or other family members like grandmothers.

Part C: Clinical examination of oral health status using self-designed proforma based on the WHO basic oral health survey 2013 to assess dentition status and OHI-S and MGI [10-12].

STATISTICAL ANALYSIS

The collected data from questionnaires were collected into Microsoft excel and analysed using the SPSS version 24.0. Relative frequency (%) and mean±Standard Deviation (SD) of all the variables was obtained for characterisation of sample and the component items of P-CPQ and FIS questionnaire and Indices measuring oral health status. Spearman's correlation coefficient test and Analysis of Variance (ANOVA) was used to assess relationship between oral health status and OHRQoL.

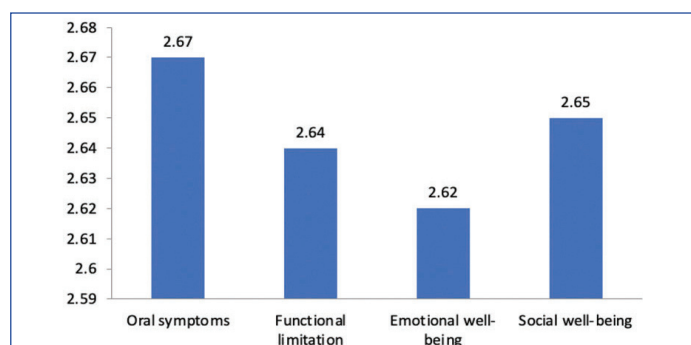
RESULTS

The present study consisted of 122 intellectually disabled individuals studying in special schools and the number of participants between 12-18 years was 111 (91%) and 19-25 years was 11 (9%). Among 122 intellectually disabled individuals 68 (55.7%) were males and 54 (44.3%) were females. An 85 (69.7%) subjects had mild disability, 24 (19.7%) had moderate disability, 8 (6.5%) had severe disability and 5 (4.1%) were profound.

With regard to the P-CPQ, 83 (68.03%) of caregivers had indicated that their child had bad breath sometime, often or nearly every day with mean of 2.98±0.918 and 73 (59.8%) of caregivers replied that their child had been anxious or fearful with mean of 2.84±1.031 which have negative impact on OHRQoL and lowest mean was recorded for acted shy or embarrassed with mean of 2.25±0.829 and prevalence of 41 (33.6%). The data for OHRQoL was reported based on the mean of the P-CPQ as indicated in [Table/Fig-1]. The data for OHRQoL was reported based on the domain scores of P-CPQ and among all the four domains recorded in P-CPQ, highest mean was recorded for oral symptoms which is shown in [Table/Fig-2].

Parental-Caregivers Perceptions Questionnaire (P-CPQ)	Mean	SD
Pain in the teeth, lips, jaws or mouth	2.57	0.881
Food caught in or between the teeth	2.30	0.842
Been upset	2.75	0.903
Bad breath	2.98	0.918
Been irritable or frustrated	2.64	0.824
Difficulty biting or chewing firm foods	2.61	0.858
Taken longer than others to eat a meal	2.66	0.809
Had trouble sleeping	2.67	0.983
Had difficulty in drinking or eating hot or cold food mouth	2.63	0.855
Been anxious or fearful	2.84	1.031
Acted shy or embarrassed	2.25	0.829
Missed school or preschool	2.60	0.942
Food stuck in the roof of the mouth	2.77	0.925
Not wanted to talk to other children	2.61	0.849
Had a hard time paying attention in school	2.85	0.933
Avoided smiling or laughing when around other children	2.63	0.795

[Table/Fig-1]: Mean, Standard Deviations (SD) of parent-caregiver perception questionnaire scores.



[Table/Fig-2]: Mean of different domains of P-CPQ.

With regard to the FIS highest mean was recorded for children requiring more attention from parent and sleep disturbance of parent and lowest mean was recorded for parents taken time off work which is depicted in [Table/Fig-3].

Family Impact Scale (FIS)	Mean	SD
Have you or the other parent taken time off work?	2.27	0.78
Has your child required more attention from you or the other parent?	2.93	0.89
Have you or the other parent had less time for yourselves or the other family members?	2.49	0.67
Has your sleep or that of the other parent been disrupted?	2.80	0.49
Have family activities been interrupted?	2.70	0.77
Have you or the other parent been upset?	2.57	0.88
Have you or the other parent felt guilty?	2.34	0.83
Have you or the other parent worried that your child will have fewer life opportunities?	2.71	0.58
Have you felt uncomfortable in public places?	2.60	0.90
Has your child argued with you or the other parent?	2.78	0.86
Has your child been jealous of you or another family member?	2.64	0.80
Has your child's condition caused disagreement or conflict in the family?	2.30	0.72
Has your child blamed you or the other parent?	2.48	1.07
Has your child's condition caused financial difficulties for your family?	2.52	0.67

[Table/Fig-3]: Mean and SD for questionnaire on family impact scale.

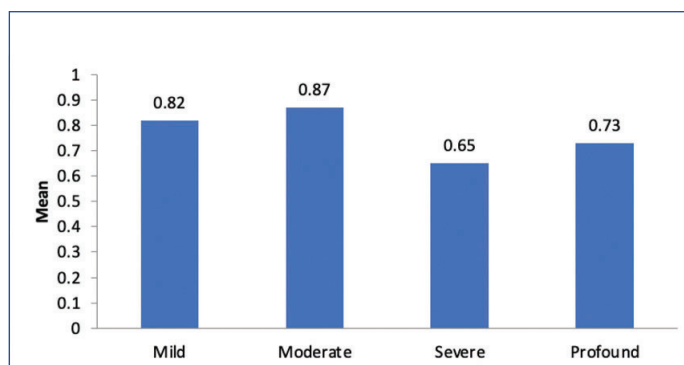
With regard to dentition status majority (n=52, 42.6%) of them had decayed teeth, 14 (11.5%) had filled teeth with no decay, 17 (13.9%) had missing teeth due to caries, 15 (12.3%) had missing teeth for any other reason and 24 (19.7%) had fractured teeth due to trauma.

Most (n=83, 68.1%) of the children has fair oral hygiene followed by good oral hygiene in 27 (22.1%) and poor oral hygiene in 12 (9.8%) and the mean OHI-S score for all the four groups was shown in [Table/Fig-4]. Highest mean was recorded for children with severe disability (2.39±0.45) and no statistically significant difference was found when comparing all the four groups with p-value of 0.43.

Disability	Oral Hygiene Index-Simplified (OHI-S)		F	p-value
	Mean	SD		
Mild	2.01	0.86	0.923	0.43
Moderate	1.85	0.69		
Severe	2.39	0.45		
Profound	1.97	0.60		

[Table/Fig-4]: Mean Oral Hygiene Index (OHI-S)-simplified among various disabilities. ANOVA test used

With regard to the MGI, 101 (82.8%) had mild gingivitis, 11 (9.0%) had moderate gingivitis and 10 (8.2%) had severe gingivitis and no statistically significant difference exists between all the four groups with p-value of 0.82 and mean MGI score was higher among the moderately disabled children (0.87±0.68) when compared to the others as shown in [Table/Fig-5]. Spearman Rho correlation coefficient was used to measure the association between oral health and P-CPQ scores and the results are displayed in [Table/Fig-6] where significant difference was noted in domain scores of oral symptoms, with the overall OHRQoL with regard to the dentition status, OHI-S and gingival index. There was a positive correlation of oral symptoms and social well-being with the dentition status, OHI-S and gingival index. With regard to functional limitation there was a negative correlation with gingival index and for emotional well-being there was a negative correlation with dentition status and gingival index.



[Table/Fig-5]: Mean Modified Gingival Index (MGI) among various disabilities.

P-CPQ	Dentition status		OHI-S		Gingival index	
	r	p	r	p	r	p
Oral symptoms	0.246	0.05*	0.26	0.04*	0.44	0.05*
Functional limitation	0.231	0.36	0.98	0.40	-0.17	0.17
Emotional well-being	-0.083	0.23	0.94	0.20	-0.46	0.10
Social well-being	0.252	0.12	0.89	0.51	0.73	0.44

[Table/Fig-6]: Correlation between variables of oral health status and domains of OHRQoL.

Spearman's correlation coefficient; *Significant at p<0.05

DISCUSSION

The findings of the present study showed that there exists positive correlation of oral symptoms and social well-being with the dentition status, OHI-S and gingival index with stronger association was noted between oral symptoms with OHI-S. Oral diseases play a major role in affecting QoL and daily life and WHO has recognised OHRQoL as a component of general health [13]. It is important to maintain oral health to prevent many diseases like dental caries and periodontal disease. But it is challenging for the disabled people because of many factors like the underlying disease, limited access to the dental care, fear of oral health procedures, medication and difficulty in communication which might worsen the oral health. Because of the bad oral health, their QoL might get affected [14]. There are only limited studies conducted to assess the oral health's impact on the OHRQoL among individuals with intellectual disabilities [11,15].

Therefore, the present study was conducted to assess oral health's impact on the OHRQoL among individuals with intellectual disabilities, who are attending special schools in Chennai from the natural home set-up. The present study showed that there was a significant contribution of the oral health on OHRQoL with regard to (P-CPQ), highest mean was recorded for bad breath, had a hard time paying attention in school and have been anxious or fearful and lowest mean was recorded for having acted shy or embarrassed. It showed that parents are more worried about their child's bad breath which might be caused due to the improper oral hygiene or dry mouth, that might be caused due to dehydration, mouth breathing or usage of certain medications for their disability whereas in a study conducted by Nqocobo C et al., majority of the caregivers (91%) indicated that there was a negative impact of oral conditions on the OHRQoL [16].

With regard to the FIS most of the caregivers had reported that their child needs more attention from their parents which might be because of the nature of the disability and insecure feeling among them, whereas in a study conducted by Barbosa Tde S and Gavião MB, in Brazil most of the parents or caregivers reported that they had less time for themselves and in both the studies majority of the caregivers reported that their sleep is getting disturbed which might be because of their child's irregular sleeping pattern [17].

Dental caries is a major public health problem with most of the previous studies having reported the higher prevalence of dental caries among people with disabilities than without disability [13,16]. In the present study, two components i.e., decayed and filled with decay were combined together. Among 122 study subjects 52 (42.6%) of them had dental caries in one or more teeth which is lesser than the study conducted by Altun C et al., where the prevalence of dental caries was 84.6% which might be because of the age groups taken from two years whereas as in the present study age groups were taken only from 12 years [18]. A 17 (13.9%) of the study population had missing teeth due to dental caries in their permanent dentition which might have major impact on their QoL due to difficulty in chewing food and previous studies reported that compared to the children without disability these children not only have more decayed teeth but also missing teeth [18]. This showed that the parents should be educated about the importance of treating dental caries.

Majority (n=83, 68.1%) of the study population in the present study had fair oral hygiene with most of them had debris more than the calculus and similar to the study conducted by Dheepthasri S et al., among intellectually disabled people in Madurai where (57.9%) of them had fair oral hygiene [19].

The mean OHI-S was reported to be 2.39 among individuals with severe disability which was higher than the study conducted by Shukla D et al., among mentally challenged individuals where the mean OHI-S was 1.75 and almost similar (2.09) to the study conducted by Richa et al., among autism disorder and all these studies implies fair oral hygiene which is according to the criteria given in 1964 by Greene JC and Vermillion JR [20,21]. Compared to the normal children, people with intellectual disabilities have poor oral hygiene which was reported in the study conducted by Richa et al., and Ivancić Jokić N et al., [21,22]. With regard to the MGI most of the study participants had mild gingivitis (81.2%).

In a study conducted by Shivakumar KM et al., overall, 35% of the study participants had bleeding in gingiva oral health status and in the present study 10 (8.2%) of the study participants had severe gingivitis which might be because of the poor oral hygiene as a result of lacking manual skills [23]. With regard to the correlation of P-CPQ with dentition status, OHI-S and gingival index among the four domains of P-CPQ only oral symptoms were positively correlated and it was statistically significant.

Highest correlation was recorded for oral symptoms with OHI-S. The questionnaire included under oral symptoms is pain in the lips, teeth, jaw or mouth, food stuck in the roof of mouth, bad breath and sores in the mouth. This showed that parents of individuals with intellectual disabilities are more worried about their oral symptoms especially bad breath, whereas in a study conducted by Richa et al., functional limitation was significantly higher among the children with autism compared to children without autism. These differences might be because of the differences in the perception of parents [21]. Thus, the study showed that child's oral health has an impact on their OHRQoL and on their family.

Limitation(s)

The limitation of the study is that parents/caregivers were considered as "proxy raters" for their child which may not clearly reflect children's feeling and conditions and only children attending the special schools with intellectual disabilities were considered in the study and children who were not attending special schools were beyond the scope of the study and the smaller sample size and the recruited convenience sample, unequal distribution of type of disabilities could be the other limitations of the study.

CONCLUSION(S)

Most of the study subjects had mild disability and their parents were more concerned about their child's bad breath with regard to P-CPQ and with regard to the FIS most of the parents replied that their child needs more attention from them and sleep disturbances among parents. There was a positive correlation of oral symptoms and social well-being with the dentition status, OHI-S and gingival index. With regard to functional limitation there was a negative correlation with gingival index and for emotional well-being there was a negative correlation with dentition status and gingival index. Dental check-ups on regular basis are mandatory to achieve as well as also to maintain the appropriate standard of oral health. Among patients with disabilities oral health problems may occur due to poor oral hygiene, which might lead to dental caries and gingivitis. Further research is needed to identify the barriers in providing preventive and curative services for the betterment of oral health among people with intellectual disabilities which might be helpful in developing effective education/training modules for dental health professionals which helps in improving their oral health.

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PARTICULARS OF CONTRIBUTORS:

1. Research Assistant, Department of Pedagogy and Research, Chrysalis, Chennai, Tamil Nadu, India.
2. Associate Professor, Department of Public Health Dentistry, Tagore Dental College and Hospital, Chennai, Tamil Nadu, India.
3. Private Practitioner, Praba Dental Clinic, Chennai, Tamil Nadu, India.
4. Senior Lecturer, Department of Public Health Dentistry, Tagore Dental College and Hospital, Chennai, Tamil Nadu, India.
5. Senior Lecturer, Department of Public Health Dentistry, Tagore Dental College and Hospital, Chennai, Tamil Nadu, India.

NAME, ADDRESS, E-MAIL ID OF THE CORRESPONDING AUTHOR:

Dr. Vaishnavi Prashanth,
Associate Professor, Department of Public Health Dentistry, Tagore Dental College and Hospital, Chennai-600048, Tamil Nadu, India.
E-mail: vaishnaviprashanth1@gmail.com

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