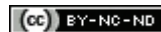


# Oral Health-Related Quality of Life Outcomes for Individuals with Disabilities: A Review

ALBANDARY HASSAN ALJAMEEL



## ABSTRACT

Individuals with disabilities experience poor oral health status and poor access to health care services due to many barriers. This can negatively affect their well-being and Quality of Life (QoL). The important benchmark to determine the impact of oral health conditions were clinical examinations using established indices. Relying only on clinical assessments and objective measures lead to the ignorance of patients' perspectives and subjective aspects of oral health assessments that consequently gave an incomplete picture of patients' experiences. There are various Oral Health-Related Quality of Life (OHRQoL) tools which can determine or measure patient-reported outcomes to assess the impacts of oral diseases and/or conditions among the general population. This article aims at reviewing the commonly-reported OHRQoL measures among adults and children of the general population. The OHRQoL studies conducted among individuals with disabilities, and findings of existing studies are also covered in this paper.

**Keywords:** Barriers, Clinical assessments, Oral health status, Objective measures

## INTRODUCTION

After the World Health Organisation (WHO) defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease" [1], there was an increased interest in studying the concept of QoL and its assessment. Although this definition of health has been claimed to be used in disease assessment by health care professionals from the time it was published, since many years, to find out the oral health status clinical examinations were given priority, without giving any importance to patients point of view and subjective aspects of oral health assessments. The interest in assessing the impact of health on different aspects of peoples' lives started in the field of medicine, and by the early 1980s, oral health researchers reported the need for a more comprehensive measure that captures the social and psychological impact of oral conditions, where they called it socio-dental indicators/impacts [2-6].

### Existing Oral Health-Related Quality of Life (OHRQoL) Measures for Both Adults and Children

Evidence confirms that oral health is an integral part of general health and well-being. Oral health-related diseases and conditions are among the most common preventable diseases worldwide burdening individuals and governments massively [7]. It can lead to not only physical problem but it can also have a negative impact on self-esteem and QoL [8,9].

As mentioned earlier, the notion of OHRQoL appeared only in the early 1980s, where researchers realised that relying solely on clinical assessments of dental care, periodontal diseases and other oral health-related conditions were not comprehensive enough to entirely capture the concept of health. Multiple-items questionnaires are the most widely used method to assess OHRQoL. Researchers have developed many QoL instruments specific to oral health and the number continues to grow to comply with the demand for more specific measures. OHRQoL instruments can be used for many purposes. They can be used cross-sectionally to assess differences in OHRQoL between different groups of patients at a point in time (discriminative instruments), or longitudinally to measure changes in OHRQoL within patients during a period of time (evaluative instruments). There are various methods of distribution of OHRQoL tools which encompass face to face interview, telephonic interview, self-reported or surrogate responders (proxy), but every method

has its own merits and demerits. It is also important to note that OHRQoL measurement has two basic approaches. First, it can be used as a generic instrument that provides a summary of OHRQoL, and second, can be used as a disease-specific instrument that focuses on specific problems associated with a specific condition, disease, patient groups or areas of function [10].

Over the last decades, development of OHRQoL instruments started among the adult population, where several measures were developed for such purposes. Skaret E et al., reviewed the existing OHRQoL instruments and concluded that no single instrument can be regarded as a gold standard, or a comprehensive instrument for measurement of OHRQoL, and recommended future research to improve the existing ones [11]. [Table/Fig-1] presented some of the most commonly used OHRQoL instruments among adults [12-22]. They vary widely in terms of the number and format of questions, and responses. As shown in the table, the specific aim of each instrument, as well as dimensions covered may differ between different OHRQoL tools, but they all shared the common concept of assessing how oral health status among adult patients can affect their aspects of lives.

Years later, after the interest of OHRQoL for adults started to advance, researchers became interested in assessing children's OHRQoL, which resulted in the development of several measures, of which the majority and most commonly used ones are presented in [Table/Fig-2] [23-32]. Although all developed measures shared the concept of measuring how oral health affects different aspects of the daily lives of children, they differ in the dimensions, age of targeted children, number of items included, and methods of reporting OHRQoL (either using proxy, or by children themselves). It is important to note that some of children's OHRQoL measures included items to assess the potential impacts of a child's oral health on their family's QoL as well. The majority of the presented measures were developed among English speaking communities, but a couple of them were validated to be used in other languages and among different communities, such as French, Arabic, Dutch, Chinese, Hindi, etc., [33]. Gilchrist F et al., conducted a systematic review of OHRQoL in children and showed that the most frequently used measure is the Child Perceptions Questionnaire (CPQ) [34]. Another recent systematic review and standardised comparison of available children's OHRQoL instruments showed that the

Early Childhood Oral Health Impact Scale (ECOHIS) was the most commonly used instrument for pre-schoolers, and the CPQ 11-14 was mostly used among school children and adolescents [33].

Among the instruments developed for children of any age, the Family Impact Scale (FIS) was the most commonly reported in the literature [33].

Measure	Author/Year	Aim	Dimensions
<b>GOHAI</b> Geriatric Oral health Assessment Index [12]	Atchison KA and Dolan TA, 1990	Psychosocial impacts of dental disease	Physical function Psychosocial function Pain or discomfort
<b>DIP</b> The Dental Impact Profile [13]	Strauss RP and Hunt RJ, 1993	How natural teeth or dentures positively or negatively affects social, psychological and biological well-being and QoL	Eating Health/well-being Social relations Romance
<b>SOSHI</b> Subjective Oral Health Status Indicators [14]	Locker D and Miller Y, 1994	The functional, social and psychological outcomes of oral disorders	Chewing ability Speaking ability Oral and facial pain Eating impact Problems in communication and social relations Limitations in daily activities Worry and concern
<b>OHIP</b> Oral Health Impact Profile [15-17]	1- Slade GD and Spencer AJ, 1994 (OHIP-49) 2- Slade GD, 1997 (OHIP-14) 3- Allen F and Locker D, 2002 (OHIP-20) (OHIP-Edent) for edentulous people	1- Self-reported dysfunction discomfort and disability, attributed to oral conditions 2- a sub-sets of items from OHIP (49) 3- an alternative short form of OHIP with minimal floor effect 4- a short form of OHIP appropriate for edentulous people	Functional limitation Physical pain Psychological discomfort Physical disability Psychological disability Social disability Handicap
<b>DIDL</b> The Dental Impact Profile on Daily Living [18]	Leao A and Sheiham A, 1995	A socio-dental method that measures the impacts of oral health status on the quality of daily living	Comfort Appearance Pain Performance Eating restriction
<b>OIDP</b> Oral Impacts on Daily Performance [19]	Adulyanon S et al., 1996	The serious oral impact on the person's ability to perform daily activities	Eating and enjoying food Speaking and pronouncing clearly Cleaning teeth Sleeping and relaxing Smiling and laughing without embarrassment Maintain usual emotional state Carrying out work and social role Enjoying contact with people
<b>OH-QoL</b> Oral Health Quality of Life Inventory [20]	Cornell JE et al., 1997	Satisfaction and importance of oral health and functional status	Performance Satisfaction
<b>OHQoL-UK</b> UK Oral Health Related Quality of Life [21]	McGrath C and Bedi R, 2001	The impact of oral health on Quality of Life	Physical Social Psychological aspects
<b>OHS</b> Oral Health Score [22]	Burke FJ et al., 2004	To provide numerical measure of the overall state of patient's oral health	Comfort Aesthetics Functional Combined with clinical data

**[Table/Fig-1]:** Oral Health-Related Quality of Life (OHRQoL) measures for adults (12-22). QoL: Quality of Life.

Measure	Author/Year	Aim	Dimensions
<b>CPQ11-14*</b> Child Perception Questionnaire [23]	Jokovic A et al., 2002	The impact of oral and oro-facial conditions	Oral symptoms Functional limitations Emotional well-being Social well-being
<b>FIS*</b> Family Impact Scale [24]	Locker D et al., 2002	The family impact of oral and oro-facial disorders	Parental/family activities Parental emotions Family conflict
<b>P-CPQ*</b> Parental-Caregivers Perceptions Questionnaire [25]	Jokovic A et al., 2003	Parental/care-givers perception of the Oral Health-Related Quality of Life for children	Oral symptoms Functional limitations Emotional well-being Social well-being
<b>CPQ8-10*</b> Child Perception Questionnaire [26]	Jokovic A et al., 2004	The impact of oral and oro-facial condition	Oral symptoms Functional limitations Emotional well-being Social well-being
<b>MOHRQOL</b> Michigan Oral Health-Related Quality of Life Scale [27]	Filstrup SL et al., 2003	The effects of early childhood caries on children's Oral Health-Related Quality of Life	Functional aspects Pain/discomfort, Psychological aspects Social aspects
<b>Child-OIDP</b> Child Oral Impact on Daily Performance [28]	Gherunpong S et al., 2004	The serious oral impact on children's ability to perform daily activities	Eating Speaking Cleaning mouth Sleeping Emotion Smiling Study Social contact

<b>ECOHIS</b> Early Childhood Oral Health Impact Scale [29]	Pahel BT et al., 2007	The impact of oral health problems and related treatment experiences on the quality of life of preschool age children (3 to 5 years old) and their families.	Child symptoms Child function Child psychological Child self-image/ social interaction Parent distress Family function
<b>COHIP</b> Child Oral Health Impact Profile [30]	Broder HL et al., 2007	Oral health related quality of life in children with a broad age range (8-15 years) that include positive as well as negative aspects: parallel forms exist for the child and caregiver	Oral health Functional well-being Social-emotional well-being School environment Self-image
<b>POQL</b> Pediatric Oral Health-Related Quality of Life [31]	Huntington NL et al., 2011	A brief measure of Oral Health-Related Quality Of Life in children with a particular focus on input from parents and children from low-income or minority populations	Social Role functioning Physical Emotional
<b>SOHO-5</b> Scale of Oral Health Outcomes [32]	Tsakos G et al., 2012	Self-reported oral health related quality of life measure for 5-year-old children	Eating Drinking Speaking Playing Smiling (because teeth hurt) Smiling (because of the way teeth look) Sleeping

**[Table/Fig-2]:** Oral Health-Related Quality of Life (OHRQoL) measures for children [23-32].

\*Child Oral Health Quality of Life (COHQoL) questionnaires, include: Parental-Caregiver Perceptions Questionnaires (P-CPQ), the Family Impact Scale (FIS) for children aged 6-14 years, and three age-specific Child Perceptions Questionnaires (CPQ)

## Oral Health Status of People with Disabilities

Disability is a complex and multidimensional term; it is an umbrella term for any form of disability that affects a person's daily activities. The World Health Organisation defines a person with disability as anyone who has "a problem in body function or structure, an activity limitation, has a difficulty in executing a task or action; with a participation restriction" [35]. And due to the complexity and variability in defining disability, it has been difficult to have a definitive estimate of its prevalence. Considering the methodological limitations of existing data on disabilities, the World Health Survey and Global Burden of Disease estimated that around 15-20% of the global population have a disability (over a billion people globally) [35].

People with disabilities may suffer more from oral diseases/conditions and their consequences compared to those without such disabilities or impairments, thereby confirming the existence of health inequalities. Evidence also suggests that they have poorer oral health, greater gingival problems, and have different treatment modalities such as fewer fillings, more extractions, and fewer preventive interventions [36]. Additionally, they experience poorer access to services when compared to the general population [36-38]. A review of the literature on the access to oral health care services among adults with learning disabilities revealed that access of people with disabilities, to the needed oral health care services is a multidimensional concept [39]. Additionally, barriers have been classified into three main categories: barriers related to individuals, barriers related to dental professions, and barriers related to policy makers [40-43].

## Existing OHRQoL Studies among People with Disabilities and their Limitations

It is important to note that all above summarised OHRQoL measures of both adults and children were developed for use among general populations; however, some have been used in few studies to assess OHRQoL among individuals with different types of disabilities (physical, mental/intellectual, sensory, etc.). [Table/Fig-3] summarises studies conducted among people (adults and children) with different types of disabilities and aimed at assessing the impact of their oral health status on their quality of lives [44-61]. Some of these studies were cross-sectional descriptive in nature [44,45,47-50,54-61], while others assessed changes on OHRQoL after provision of dental interventions [46,51-53]. In general, findings suggested that individuals with disabilities' poor oral health status negatively affected their QoL and their families as well. Findings also suggested an improvement in their OHRQoL after receiving needed dental treatment.

Oral Health Impact Profile (OHIP) is a 49 items scale that was originally developed as an instrument to assess the priorities of care, and provide information for planning for oral health [15]. The shortened version of OHIP (OHIP-14) is a commonly used measure, and it has been tested and validated to be used among different groups and in different languages. OHIP was used in six out of 18 studies summarised in [Table/Fig-3] [46,48,49,51,58,61]. Another shortened version of OHIP (OHIP-G5) was also validated among the German population by John MT et al., and it was found to be valid and reliable to assess OHRQoL in cross-sectional as well as longitudinal studies [62]. Couto P et al., validated a modified version of OHIP-14 to be used among people with mild intellectual disabilities and confirmed its reliability and validity as an OHRQoL measure for people with mild intellectual disabilities [48]. In a recent study, Hillebrecht AL et al., used two versions of OHIP: the first was OHIP-14 and was assessed by proxy; and the second was OHIP-G5-easy, which is a modified version of OHIP-G5 and it was assessed directly from adults with disabilities themselves. Results showed that the OHRQoL of patients with intellectual disabilities improved after dental treatment, and also showed a moderate correlation between self and proxy reported OHRQoL [46]. The second most commonly used measures to assess OHRQoL among individuals with disabilities were the Parental-Caregivers Perceptions Questionnaire (P-CPQ), and Family Impact Scale (FIS), as shown in [Table/Fig-3].

It is important to note that, as shown in [Table/Fig-3], the majority of these studies were conducted without investigating the reliability and suitability of the used OHRQoL measure to be used among individuals with disabilities, knowing that such a measure was originally developed with the aim of assessing the OHRQoL of the mainstream population. Since the concept of patient reported outcomes is mainly to assess disease outcomes from the patients' perspectives, this might be lost if we use a measure among a group of people with different physical, mental, and/or sensory characteristics, and therefore they might differ from the actual and relevant dimensions of OHRQoL when compared to their mainstream peers. This shows the need to first investigate the dimensions of OHRQoL among individuals with chronic conditions or disabilities from their perspectives to be able to understand their perceptions and concerns of their OHRQoL, and afterward decide whether we need to develop new specific measures tailored to their needs, or simply modify and/or adapt an existing one. Additionally, the importance of checking the suitability of an OHRQoL measure might differ with different types of disabilities. For example, individuals with physical disabilities might exhibit similar dimensions of OHRQoL when compared with the general population. However, they might differ on the magnitude of the

impact as their concerns and perceived importance of certain dimensions such as social participation could be different because such a dimension is affected mainly by the existing disability, and

thus, they might report a social participation restriction as a result of poor oral health to a lesser extent, compared to individuals without such a disability.

S. No.	Study author	Publication year	Study type	Country	Target population	Target age (years)	OHRQoL measure	Method of reporting	Findings
1	AlJameel AH et al., [44]	2020	Cross-sectional Qualitative	Saudi Arabia	Children and adolescents with Down Syndrome	12-18	Non-specific Comprehensive topic guide	Proxy	Oral health does have an impact on the life of individuals with Down syndrome and their families and indicated that these impacts affect various aspects of their lives
2	Du RY et al., [45]	2020	Cross-sectional/comparison	China	Children with Autism	2.6-6.4	ECOHIS	Proxy	Autism Spectrum Disorder negatively affected OHRQoL of preschool children and their families
3	Hillebrecht AL et al., [46]	2019	Interventional	Germany	Intellectual disabilities	≥18	OHIP-G5-easy version of OHIP-14	Self and proxy	Significant improvement of OHRQoL in patients with intellectual disabilities after dental treatment under GA
4	Singh A et al., [47]	2019	Cross-sectional	India	Hearing impaired individuals	9-15	Hindi version of C-OIDP	Self	Unfavourable impact of oral disease on OHRQoL
5	Couto P et al., [48]	2018	Cross-sectional	Portugal	Mild intellectual disabilities	≥18	OHIP-14MID-PT OHIP-14	Self	High burden of oral disease with considerable impact on OHRQoL
6	Kele S et al., [49]	2018	Cross-sectional	Turkey	Mild intellectual disabilities	15-22	OHRQoL-UK and OHIP-14	Self	Dental trauma and malocclusions negatively affect the social and psychological sub-domains of OHRQoL scales
7	Singh A et al., [50]	2017	Cross-sectional	India	Visually impaired individuals	9-15	Hindi braille version of C-OIDP	Self	High prevalence of dental diseases in this group and high C-OIDP scores suggestive of unfavourable OHRQoL
8	Pradhan A et al., [51]	2016	Interventional	Australia	Employees with disabilities	≥18	OHIP-14	Self	Urgent referral for treatment and regular oral health education can improve OHRQoL and self-rated oral
9	El-Meligy O et al., [52]	2016	Interventional	Saudi Arabia	Physical, mental, or sensory disability (separately or combined)	5-14	CPQ 11-14	Proxy	Providing full mouth rehabilitation under GA resulted in long term improvement in OHRQoL
10	Chang J et al., [53]	2014	Interventional	Korea	Intellectual and developmental disabilities	> 12	COHIP-14 FIS	Self and Proxy	OHRQoL of adolescents and adults with IDD and neurocognitive disorders was improved by dental treatment under GA
11	Yashoda R and Puranik MP [54]	2014	Cross-sectional/comparison	India	Children with Autism	4-15	P-CPQ	Proxy	OHRQoL scores of autistic children were significantly higher indicating poorer OHRQoL compared to children without autism especially in the functional limitation domain
12	Abanto J et al., [55]	2014	Cross-sectional	Brazil	Children with Cerebral Palsy	6-14	P-CPQ FIS	Proxy	Dental caries and bruxism negatively affect their OHRQoL
13	Pani SC et al., [56]	2013	Cross-sectional/comparison	Saudi Arabia	Children with Autism	8-13	P-CPQ FIS	Proxy	Children with autism have reduced OHRQoL of them and their families
14	Tagelsir A et al., [57]	2013	Cross-sectional	Sudan	Visually impaired children	11-13	C-OIDP	Self	Visually impaired children are burdened by oral health problems that negatively affected their OHRQoL
15	Pradhan A [58]	2013	Cross-sectional	Australia	Physical and intellectual disabilities	18-44	OHIP	Proxy	More than one in 10 care recipients reported that they experienced one or more negative impacts on OHRQoL
16	Du RY et al., [59]	2010	Cross-sectional/comparison	China	Children with Cerebral Palsy	2.5-6.4	ECOHIS	Proxy	OHRQoL was more compromised among children affected by Cerebral Palsy than for preschool children without Cerebral Palsy.
17	Oliveira AC et al., [60]	2010	Cross-sectional Qualitative	Brazil	Children with Down Syndrome	NA	No specific measure	Proxy	Overall health and oral health entailed specificities associated with the absence of illness, the performance of daily activities, and feelings of wellbeing
18	Loureiro A et al., [61]	2007	Cross-sectional	Brazil	Children with Down Syndrome	6-20	OHIP-14	Proxy Self whenever possible	Periodontal conditions had negative effects on the QoL of people with Down Syndrome, and these effects were increased by the increase in the disease severity

**[Table/Fig-3]:** Summary of studies on OHRQoL and individuals with disabilities [44-61].

OHRQoL: Oral health related quality of Life; OHIP: Oral health impact profile; ECOHIS:-Early childhood oral health impact scale; C-OIDP: Child oral impacts on daily performances; OHIP: Oral health impact profile; P-CPQ: Parental-caregivers perceptions questionnaire; CPQ: Caregivers perceptions questionnaire; FIS: Family impact scale

When trying to assess OHRQoL among individuals with an intellectual disability, the case is even more challenging for different reasons. First, people with intellectual disabilities needed special considerations if they were chosen to participate by themselves (e.g., pre-evaluation of the intellectual abilities), especially given that they rarely come with the same degree of intellectual functioning. Secondly, if proxy measures were used (either their parents or direct caregivers), and this is the situation in many cases especially among those with severe intellectual disabilities, it is important to assess the level of agreement and correlation between actual self-reported and proxy measures [63,64]. It is also of prime importance to assess the proxy's psychological state and other confounding factors that might influence proxy reports (e.g., acceptance concept and its impact on the proxy perceptions and expectations).

## CONCLUSION(S)

Evidence suggests that oral health diseases and conditions are very prevalent among people with disabilities. Although there are few studies that have aimed at assessing the impacts of oral health status on individuals with disabilities and their families' quality of life, existing studies have reported a negative impact of their oral health status on their quality of lives as well as their families. Nevertheless, there are some methodological considerations and limitations that need to be considered when interpreting these results. Future research on the OHRQoL of individuals with disabilities should consider the impact of the existing disability itself to be able to accurately assess OHRQoL. Future research should also modify the existing OHRQoL measures developed among the general population accordingly before using them, or develop specific measures that can capture all possible impacts of their oral health on their quality of lives from their own perspectives.

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**PARTICULARS OF CONTRIBUTORS:**

1. Assistant Professor, Department of Periodontics and Community Dentistry, College of Dentistry, King Saud University, Riyadh, Saudi Arabia.

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

AlBandyary Hassan AlJameel,  
College of Dentistry, King Saud University, Riyadh, Saudi Arabia.  
E-mail: aaljameel55@gmail.com

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