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Oral Health-Related Quality of Life of Children Born With Orofacial Clefts in Ethiopia and Their Parents

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Oral Health Related Quality of Life of Children Born with Orofacial Clefts in Ethiopia and their Parents.

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Abstract:	<p>Abstract</p> <p>Objective: To assess the oral health-related quality of life (OH-RQoL) using a translated standardized measure in an understudied population of Ethiopian children born with orofacial clefts (OFCs) and their parents.</p> <p>Methods: Using a descriptive study design, we assessed the OH-RQoL of 41 patients with OFCs between the ages of 8 and 17 years and their parents. Participants received multidisciplinary cleft care from 2008 to 2016. They completed an Amharic translation of the Child Oral Health Impact Profile (COHIP).</p> <p>Results: There was strong internal reliability with the translated COHIP for parents and patients. Parents' COHIP scores ranged from 67 to 186, and patients' scores were 78 to 190. The mean for patients and parents was 155, indicating good OH-RQoL.</p> <p>Conclusion: The Amharic translation of the COHIP appears appropriate for use with families in Ethiopia. Both parents and patients reported OH-RQoL at similar levels as other international populations.</p> <p>Key words: Cleft lip and palate, birth defect, oral health-related quality of life, perception, Ethiopia; Child Oral Health Impact Profile</p>

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5 **Oral Health Related Quality of Life of Children Born with Orofacial**
6 **Clefts in Ethiopia and their Parents.**
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10 Abstract

11 Objective: To assess the oral health-related quality of life (OH-RQoL) using a translated
12 standardized measure in an understudied population of Ethiopian children born with
13 orofacial clefts (OFCs) and their parents.
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16 Methods: Using a descriptive study design, we assessed the OH-RQoL of 41 patients with
17 OFCs between the ages of 8 and 17 years and their parents. Participants received
18 multidisciplinary cleft care from 2008 to 2016. They completed an Amharic translation of
19 the Child Oral Health Impact Profile (COHIP).
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22 Results: There was strong internal reliability with the translated COHIP for parents and
23 patients. Parents' COHIP scores ranged from 67 to 186, and patients' scores were 78 to 190.
24 The mean for patients and parents was 155, indicating good OH-RQoL.
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27 Conclusion: The Amharic translation of the COHIP appears appropriate for use with
28 families in Ethiopia. Both parents and patients reported OH-RQoL at similar levels as other
29 international populations.
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38 Key words: Cleft lip and palate, birth defect, oral health-related quality of life, perception,
39 Ethiopia; Child Oral Health Impact Profile
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Introduction

Orofacial clefts (OFCs) are the most common congenital anomalies in the head and neck region and one of the most prevalent birth defects in human beings (Mossey, 2012). The incidence varies from 1 per 2,500 to 1 per 500 births (Mossey, 2009), depending on ancestry, geographic and residential location, maternal age and prenatal exposures to teratogens and socioeconomic status (Clark, 2003; Durning 2007; Mossey 2009).

The psychosocial and economic impact of birth defects, including OFCs on those affected and on the society, is enormous. Early in life, OFCs are associated with complications, such as feeding problems and recurrent ear infections, which can result in increased risks of morbidity and mortality. This is more common in developing countries where early systematic pediatric care may not be commonly accessible (Wehby, 2006). The burden of OFCs on the affected individuals, families, and the society can be improved by understanding the effects of OFCs on the well-being of affected individuals and families. It is also important to identify their healthcare needs and make changes in healthcare practices and public policies in order to improve the well-being of the victims.

Patients born with OFCs usually need multidisciplinary care over a long period of time. Care starts in infancy and continues into adult life depending on the availability of the services and the complexity of the associated cleft-related concerns, such as malocclusion, hearing and speech disorders, facial appearance, and psycho-emotional problems (Konan p et al., 2015). The aim of the multidisciplinary cleft care is to fully rehabilitate the affected individuals, which includes facilitating normal speech, hearing, occlusion, facial appearance satisfaction, and self-confidence.

One outcome of the multidisciplinary cleft care provided can be evaluated by assessing the oral health-related quality of life (OH-RQoL). It is a subjective evaluation of the individual's oral health, functional well-being, emotional well-being, expectations and satisfaction with care, and sense of self (Geels, 2008).

In Ethiopia, there are 31 hospitals, which provide surgical treatment to patients with a cleft,

1 but only Yekatit 12 Hospital Medical College provides multidisciplinary cleft care. As
2 there is only one cleft unit serving all of Ethiopia and is limited to seeing a small portion of
3 patients with in the institution the vast majority of Ethiopian children born with OFCs do
4 not receive multidisciplinary cleft care. There is also lack of information on the quality of
5 life, long-term health, and healthcare use and costs of affected individuals and families in
6 Ethiopia.
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14 We evaluated the OH-RQoL of Ethiopian children born with OFCs who received
15 multidisciplinary cleft care from December 2008 to December 2016 at Yekatit 12 Hospital
16 Medical College cleft unit and the perception of their parents using an Amharic translation
17 of the Child Oral Health Impact Profile (COHIP). **Jokovic et al, evaluated a questionnaire
18 used to measure the OH-RQoL of children, and found it to be valid and reliable. They
19 showed that oral and oro-facial conditions have a substantial effect on functional and
20 psychosocial well-being of the affected. It was also shown that children are able to give
21 psychometrically acceptable accounts of that effect (Jokovic et al, 2002).** During the
22 study period 1,427 children and adults born with OFCs received surgical treatment at this
23 unit, but only 41 patients with OFCs received multidisciplinary cleft care due **to mainly
24 lack of awareness and distance needed to travel to get the service.**
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33 **Methods**

34 **Study area and setting**

35 This study was conducted at Yekatit 12 Hospital Medical College cleft unit and the
36 orthodontics unit of Dental Department of the School of Medicine at Addis Ababa
37 University. These two institutions provide multidisciplinary cleft care in collaboration with
38 Charity organizations (Transforming Faces and Smile Train). The main services provided
39 by these two institutions are primary and secondary surgeries, speech therapy, orthodontics
40 care, basic dental care, oral hygiene, ear nose and throat care, pediatrics care and
41 psychosocial support for all cleft lip and palate patients coming from all over the country.
42 The participants **were 41 children who were born with OFCs and received the
43 multidisciplinary cleft care provided at our unit.**
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54 **Study design**

55 We performed a hospital based descriptive study design and evaluated the OH-QoL of
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2 Ethiopian patients with OFCs who received multidisciplinary care at the study institution.
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4 The treatment started by counseling their parents, followed by primary surgery, and when
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6 needed, secondary surgeries, and follow-up and treatment by a team of professionals
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8 working for the two units. Forty-one patients and their parents participated in this study and
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10 completed the COHIP, which consists of parallel enquiries for children and for parents. The
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12 participants were asked to come to the speech therapy unit at any convenient time during
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14 the week and weekends. The data was collected from September 2016-March 2017

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16 **Inclusion Criteria:** Patients with non-syndromic cleft lip and/ or palate aged between 8
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18 and 17 years old who received multidisciplinary cleft care at some point in time during the
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20 eight years period at our institutions.

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22 **Exclusion Criteria:** we have assessed 123 patients for possible inclusion in this study and
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24 excluded 79 patients: 20 patients were excluded because they need secondary surgery
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26 (speech surgery, Lip revision, rhinoplasty) during the coming three months, 23 had
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28 secondly surgery during the past three months (fistula closure, lip revision, speech surgery
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30 rhinoplasty) and thirty patients just started the multidisciplinary cleft care, six had
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32 syndromic clefts and rare clefts (Vander woude syndrome two patients, Tessier 7 three
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34 patients and Tessier 3 one patient and three parents did not feel comfortable to participate
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36 and excluded.

37 38 **Data Collection**

39 Patients and their parents who were found to be eligible for this study according to the
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41 inclusion criteria were invited to participate. We used the translated COHIP questionnaire,
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43 which consists of children and parent inquiries to evaluate the OH-RQoL. **The translation**
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45 **was to Amharic language, which is spoken by most of our patients and their families.**
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47 **Two professional translators made the translation independently. Both the**
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49 **translators' mother tongue was Amharic language. One of the translators had an**
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51 **experience in translating medical records like medical certificates. The translation**
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53 **was checked by another professional translator for accuracy, the principal**
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55 **investigator and two other plastic and reconstructive surgeons who have experience**
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57 **working with cleft patients and also involved in cleft and related researches.** The
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59 questions for the patients and their parents consisted of the 38 items of COHIP, which were
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1 divided into: Oral symptoms and emotional well-being (each contained 10 items),
2 Functional well-being (eight items), School (four items), and Peer interaction (six items).
3 The items were answered on a 5- point Likert scale (1=very often and 5=never, with the
4 additional response option of 0=I don't know). Poor oral health-related quality of life was
5 indicated by a low response. The general health of the patients was assessed by one more
6 additional question, which was added to both the parent and the child questionnaire. It had
7 the following response categories: 1= bad, 5=great and 0=I do not know. The patients and
8 the parents completed the measures in separate rooms with the principal investigator and
9 research assistant orienting both the children and parents to the questionnaire and assisted
10 them whenever they had difficulty. Ethical clearance was obtained from the Institutional
11 Review Board (IRB) College of Health Sciences, Addis Ababa University (10/027/2015).
12 We also obtained informed consent from all the parents and assent from the children who
13 were above 12 years old.
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26 **Data analysis**

27 Internal consistencies of the overall scale and for all the subscales responses from both the
28 parents and patients were examined by defining Cronbach's alpha. The do not know (DK)
29 responses frequency of each item of each subscale was analyzed. We summed the
30 responses of all items of each subscale to determine the subscale scores and summed the
31 subscale scores to determine the overall OHRQoL Score. Both the parents and patients
32 answered all the questions. Comparing their overall and subscale scores using independent
33 sample t-test determined the similarity between parents and patients. We calculated Pearson
34 correlations coefficients and intraclass correlation coefficients (ICCs) between subscales of
35 parents and patients. We also examined the differences between boys and girls using
36 independent t-tests.
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45 **Results**

46 In this study 41 children and adolescents born with OFCs and treated by a team of
47 Professionals at our unit and their parents participated. There were 21 (51.21%) males and
48 20 (48.78%) females. The mean age of the patients' was 12.37 years (SD = 2.5), with more
49 adolescents (60.97%) than children (39.02%). The majority of the parents were mothers
50 (70.73%) The parents' age ranged between 27 and 53 years and 74% were under the age 40
51 years. The phenotype of the cleft patients included in this study were as follows: 24
52 (58.5%) children born with unilateral cleft lip and palate (UCLP), nine (22.0%) with
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2 bilateral cleft lip and palate (BCLP), three (7.3%) with unilateral cleft lip only (CLO), two
3 (4.9%) with bilateral cleft lip only (BCLO), and three (7.3%) with cleft palate only (CPO).
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5 The analysis of the DK response revealed that both the parents and the patients gave the
6 highest DK response for the emotional wellbeing.
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10 The Internal consistencies using Cronbach's alpha of the overall scale (0.958 for parents
11 and 0.979 for children) and for the majority of the subscales responses were excellent
12 ranging from: 0.829 to 0.971 for parents, and 0.961, to 0.979 for children. The one subscale
13 with a lower internal consistency of 0.678 was for children's school, which appears to be
14 due to the small number of items in this subscale. There is no Cronbach's alpha for
15 "General Health" because it contains only one item.
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22 Parents and patients COHIP scores appear in Table 1. The minimum overall score the
23 parents obtained on the COHIP was 67 and the maximum was 186. The minimum score
24 patients obtained was 78 and the maximum was 190. The mean overall score of both the
25 patients and parents was 155. There are minor differences between patients and parents on
26 subscales, but no significant differences were shown between patients and parents on
27 overall scores.
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34 Intraclass correlation coefficients between the parents and the patients were calculated to
35 show their agreement across subscales and significant correlation was found with $p < 0.05$
36 (Table 2). The correlation coefficient for the emotional well-being was found to be high
37 followed by oral symptoms and functional wellbeing subscales. The correlation on school
38 environment and general health was found to be relatively low.
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45 Pearson's correlation coefficients between subscale scores, overall and general health in the
46 parent and patient group are shown in Table 3. There were significant correlations between
47 the subscales, overall, and general health. Similarly, the results of the children showed
48 significant correlations between the subscales.
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55 Discussion

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2 The main objective of this study was to evaluate the oral health-related quality of life of
3 children born with OFCs and their parents with the use of an Amharic translation of the
4 COHIP. The study included those patients with non-syndromic OFCs that received
5 multidisciplinary cleft care and their parents. The findings in this study indicated good oral
6 health-related quality of life, which was shown by the high overall score parents and
7 patients obtained. Geels et al. (2008) reported similar findings in Rotterdam, Amsterdam.
8 Munz et al., (2011) also found similar positive OH-RQoL for young patients with cleft lip
9 and palate who completed treatment using the Michigan Oral Health-Related Quality of
10 Life Scale (MOH-RQoL). Wilson-Genderson et al., (2007) assessed the similarity of the
11 responses of children born with orofacial clefts and their caregivers using the COHIP;
12 however, they found low to modest rates of similarity between child and caregiver
13 responses for the sample overall. This contrast with our findings, which showed high
14 similarity between child, and caregiver responses. This might be due to cultural differences,
15 which might have resulted in expectation differences. In our study, the proportion of the
16 mean scores to the maximum scores were the same as those reported by Bos et al. (2011) in
17 their Dutch sample. Their sample also had similar overall mean scores for patients and
18 parents; however, there were significant differences between patients and parents were
19 found on the emotional well being, oral symptoms and school subscales.
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35 Our study indicated that it is possible to use an Amharic translation COHIP scores to assess
36 the oral health-related quality of life of children affected with orofacial clefts and their
37 parents; however, some of the questions need to be expressed differently based on
38 culture/language. For instance, “Felt that you were attractive (good looking) because of
39 your teeth, mouth or face”. Geels et al. (2008) also emphasized the importance of
40 formulating these questions when administering COHIP in children born with OFCs.
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47 The number of patients and parents included in this study based on the inclusion criteria of
48 having received team care is far fewer than the patients who received surgical treatment at
49 our unit. The importance of rehabilitative care in improving OH-RQoL for patients born
50 with a cleft is not well understood by the communities, families of cleft patients providers
51 and planners. Even though all the cleft care at our unit is provided free of charge with the
52 support of charity organizations (Transforming Faces and Smile Train), we have not
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2 received many patients for full rehabilitation. The reason for this could be lack of
3 knowledge on the importance of holistic cleft care and the need for long term follows up.
4 The distance needed to travel to get the service could also contribute to low utilization.
5 Awoyale et al. (2016) also reported similar concerns in the quality of life of family
6 caregivers of children with OFCs in Nigeria. This could be improved through teaching of
7 families of patients with orofacial clefts and the community at large about the importance
8 of comprehensive multidisciplinary cleft care. It is also very important to involve the
9 primary health care providers so that they will appreciate the need for team cleft care.
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17 **Limitations of the study**

18 This study has several limitations. The number of patients included in this study was small
19 and limited the types of appropriate analyses that could be completed with the data. In
20 addition, the sample included only a small proportion of less than 3% of the total number of
21 patients who received surgical treatment at our unit. We therefore cannot generalize these
22 results to other cleft populations in Ethiopia. We did not complete measures with patients
23 outside of team care and therefore cannot comment on the OH-RQoL for the majority of
24 our patients. Another limitation could be that the sample of children born with OFCs and
25 their parents may have not fully expressed their feelings and experience, with the
26 possibility of social desirability in their responses.
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36 **Conclusion and recommendation**

37 This study found that the parents and children's responses were similar when evaluating the
38 child OH-RQoL using an Amharic translation of the COHIP that had strong internal
39 consistency. While the OH-RQoL was high in this sample of patients who received
40 multidisciplinary care, they represent less than 3% of patients with a cleft at our institution.
41 We recommend that the cleft care at selected hospitals in Addis Ababa and other regions
42 should be expanded to provide multidisciplinary cleft care.
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Peer Review

Table 1. Mean Subscale and Overall Scale for Parents and Patients, t, P- values

Subscale	Parents				Patients				t	P
	Mean	SD	Min	Max	Mean	SD	Min	Max		
Oral Symptoms (10 Items)	39.90	7.47	19.00	49.00	39.14	5.81	25.00	50.00	0.512	0.610
Functional Wellbeing (8Items)	33.58	6.95	12.00	40.00	35.60	6.23	14.00	40.00	1.388	0.781
Emotional Wellbeing (10 Items)	40.00	10.11	14.00	50.00	39.88	9.22	17.00	50.00	0.057	0.980
School Environment (4 items)	16.61	4.37	4.00	20.00	16.93	4.61	2.00	20.00	0-.320	0.938
Peer Interaction (6 Items)	26.39	5.29	10.00	30.00	24.60	5.88	6.00	30.00	1.441	0.488
COHIP Overall (38 Items)	155.51	30.79	67.00	186.00	155.56	26.20	78	190.00	0-008	0.386

Table 2 Intraclass Correlation Coefficients (ICCs) Between Parents and Children on COHIP Subscale and Overall Scores

	ICC	95% Confidence Interval	
		Lower Bound	Upper Bound
Overall Subscales	.982*	.976	.987
Oral symptoms	.941*	.920	.958
Functional well-being	.930*	.905	.951
Emotional well-being	.961*	.947	.972
School environment	.769*	.676	.841
Peer interaction	.916*	.884	.941
General Health	.807*	.701	.876

Table 3 Correlations between overall, subscale scores, and general health for parents (below the diagonal) and patients (above the diagonal)

Correlations							
	S1	S2	S3	S4	S5	S6	Overall
S1	1	.693**	.908**	.698**	.859**	.799**	.913**
S2	.875**	1	.777**	.281**	.585**	.600**	.757**
S3	.938**	.830**	1	.654**	.915**	.743**	.953**
S4	.914**	.830**	.939**	1	.744**	.522**	.736**
S5	.770**	.936**	.700**	.767**	1	.649**	.893**
S6	.628**	.569**	.557**	.450**	.479**	1	.748**
Overall	.945**	.923**	.933**	.905**	.825**	.617**	1

** . Correlation is significant at the 0.01 level (2-tailed).

S1= Oral symptoms, S2=Functional well-being, S3=Emotional well-being, S4=School, S5= Peer interaction and S6=General Health