



# Studying the impact of cleft of lip and palate among adults using the International Classification of Functioning, Disability and Health framework

Sri Ram Reddy M, Subramaniyan B<sup>1</sup>, Roopa Nagarajan<sup>2</sup>

## ABSTRACT

**Objectives:** The study was conducted to document the impact of the cleft of lip and palate among adults using International Classification of Functioning, Disability and Health (ICF) framework. **Design:** This was a cross-sectional study. **Participants:** A total of 32 adults with cleft lip and palate (CLP) and a matched control group of 32 adults without CLP (non-CLP [NCLP]) were included in the study. **Methods:** To identify a set of items from ICF framework that is relevant to adults with CLP (ICF-CLP item set) from the components of activity participation and environmental factors. Two expert teams were involved in the selection of the final set of items from both the components. Then, the item set (ICF-CLP item set) was developed in Tamil. ICF-CLP item set in Tamil was piloted on 32 adults with repaired CLP and a matched control group of adults without CLP (NCLP) group by self-administering method. **Results:** There was a significant difference ( $P = 0.000$ ) between CLP and NCLP group, in both the components –activity participation and environmental factors. In the item-wise comparison, individuals with CLP had a greater limitation in activity, restriction in participation in the domains of communication, maintaining interpersonal interactions and relationships, employment, and major life areas. In environmental factors, the domains of support, relationship, health services, education training systems and policies, attitudes of authorities, and strangers were projected as barriers by individuals with CLP. **Conclusion:** This study helps us in understanding the overall impact of the cleft of lip and palate among adults in the components of

activity participation and environmental factors using the ICF framework. On the other hand, the ICF-CLP item set developed is clinically relevant in identifying conditions which limit activities/participation and serve as barriers/facilitators in their environments both in CLP population as well as in normal individuals.

**Key words:** Activity participation, cleft lip and palate, environmental factors, ICF framework

## INTRODUCTION

Cleft lip and palate (CLP) is a heterogeneous condition that involves multiple structures and presents with varying degrees of severity. Depending on the time of interference with embryonic development, different types of clefts arise. It is well known that this craniofacial malformation affects both the functional aspects and esthetic appeal of an individual. Individuals with CLP often demonstrate problems such as early feeding difficulties, nutritional issues, developmental delays, errors in speech and/or resonance, orthodontic abnormalities, hearing loss, and psychological issues.<sup>[1]</sup>

The present outcomes of CLP on esthetics, speech, and psychosocial aspects were measured only through one-dimensional tool, which does not provide a

Department of ENT, Maheshwara Medical College and Hospital, Patancheru, Telangana, <sup>1</sup>Department of Speech, Language and Hearing Sciences, Sri Ramachandra University, <sup>2</sup>Department of Speech, Language and Hearing Sciences, Faculty of Allied Health Sciences, Sri Ramachandra University, Chennai, Tamil Nadu, India

### Address for correspondence:

Senior Asst. Prof. Subramaniyan B,  
Department of Speech, Language and Hearing Sciences,  
Sri Ramachandra University, Porur, Chennai,  
Tamil Nadu, India.  
E-mail: [subramaniyanb@sriramachandra.edu.in](mailto:subramaniyanb@sriramachandra.edu.in)

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multidimensional viewpoint on individuals' daily living. Likewise, Health-Related Quality of Life (HRQL) is a tool which may be used in generic, disease-specific, dimension-specific, or research-specific manner. Some of the most popular HRQLs used for individuals with CLP are SF-36, Nottingham Health Profile, and Youth Quality of Life-Facial Differences questionnaire.<sup>[2-4]</sup> While the existing outcome measures are one-dimensional, the International Classification of Functioning, Disability and Health (ICF) framework is multi-dimensional. Thus, ICF framework is found to be a useful tool to study the impact of CLP on adults.

A one-dimensional tool measures the impact of CLP on communication aspects of the individual or on social acceptance as an independent entity. However, a multi-dimensional tool takes into account that if communication is affected, then it may affect an individual's social acceptance, educational, and vocational prospects. Thus, a multi-dimensional tool such as ICF framework helps in understanding the overall impact on life, giving due to importance to the inter-relatedness of various aspects that maybe affected in an individual with CLP. There is a global movement pioneered by the WHO (2001) for purposes of understanding the impact of health and disability on people to obtain a holistic perspective based on common reference points and coding systems. This has been realized through the use of the ICF, a conceptual framework developed by the WHO in the year 2001.<sup>[5]</sup>

ICF describes the complete range of health states and experiences, depicting human functioning on a continuum. ICF has two parts each with two components: Part 1: functioning and disability, comprising the components (a) body function and body structure (b) activity and participation; and Part 2: contextual factors, comprising the components of (a) environmental factors, (b) personal factors. This tool not only helps in understanding impairment in body structure and body function but also demonstrates how an individual's activity is limited or participation is restricted due to the impairment.

The ICF framework has been applied in various fields of healthcare. With respect to CLP, Neumann and Romonath identified codes from the ICF-Children and Youth (CY) relevant for use among children with CLP and emphasized the potential value of these codes for interprofessional cleft palate-craniofacial teams.<sup>[6]</sup> In addition, Mc Cormack and Worrall chose some of the codes relevant for children with CLP concerning body structures and body functions and outlined

the most important codes in body structures such as structure of nose (S310, i.e., external nose and nasal septum), structure of mouth (S320, i.e., gums, palate, and lips), and structure of pharynx (S330, i.e., nasal and oral) and body functions such as quality of voice (b3101), articulation functions (b320), production of notes (b3400), and sucking (b5100).<sup>[7]</sup> While the existing studies were focused on ICF-CY item set relevant for use among children with CLP on only two components such as body structures and body functions, the present study aims to identify ICF items from the components of activity and participation and environmental factors that are relevant to adults with CLP and to know its impact on quality of life as well.

## Methods

The study was approved by the Institutional Ethics Committee. Informed consent was obtained from all participants.

The purpose of this study was to identify a set of items from the ICF framework that is relevant to adults with CLP (ICF-CLP item set) and administer this item set on both the groups to study the impact of CLP. The study involved two phases:

1. Selection and finalization of ICF-CLP item set in Tamil
2. Administering ICF-CLP item set on cases (CLP) and controls (non-CLP [NCLP]) in Tamil.

### Phase 1: Selection and finalization of International Classification of Functioning, Disability and Health - cleft lip and palate item set in Tamil

ICF framework consists of nine domains under the component of activity participation and five domains under the component of environmental factors. As a first step, the investigator extracted items from ICF that was evidently irrelevant to CLP. For example, items under the domain of "mobility" were removed as this domain is not relevant to the condition of CLP. After extraction of irrelevant items, 68 items (44 items from activity and participation and 24 items from environmental factors) were selected.

Following this preliminary item extraction, two expert teams were involved in further short listing the items. Expert team 1 comprised three speech-language pathologists (SLPs) and expert team 2 comprised five professionals from the "Cleft Care Team." A brief orientation about ICF framework and the aim of the study was explained to both the panels. Experts were provided with the ICF manual to access necessary explanations on ICF terminologies if required.

SLPs working in the area of CLP for 3 years were asked to shortlist from the 68 items based on the appropriateness and clinical relevance of the items with respect to adults with CLP. They were instructed to mark the items which were “relevant” (score 1) and “not relevant” (score 2). Out of the three experts, if two experts rated an item to be “relevant,” then the item was selected. A total of 51 items were selected from activity participation (30 items) and environmental factors (21 items).

Fifty-one items selected by SLPs were framed into statements and presented to expert team 2 (Cleft Care Team) consisting of a plastic surgeon, speech pathologist, prosthodontist, orthodontist, and psychologist. They were instructed to indicate the items as “applicable,” “not applicable,” or “applicable with modifications.” Content Validity Index (CVI) was calculated between the five experts for this set of 51 items which is shown in Table 1.

A CVI score  $\geq 0.80^{[8]}$  was used as the cutoff point to include the item into the final ICF-CLP item set. Five items with CVIs  $< 0.8$  were eliminated. A total of 46 items were shortlisted. Table 2 depicts list of twenty-six items fewer than nine domains of activity and participation and Table 3 depicts list of twenty items in environmental factors, respectively.

The 46 items with statements were translated into Tamil by the investigator. Two linguists, who were experts in Tamil, checked for appropriateness of translation (using translation–reverse translation procedure) and ambiguity of statements. Based on the linguists’ suggestions, two items (d7600 and 7601) that were similar in meaning when translated to Tamil were clubbed together and framed into a single statement. After approval by linguists, ICF-CLP item set containing 45 statements (25 in activity and participation and 20 in environmental factors) in Tamil was finalized. Qualifiers to rate each statement in the ICF-CLP item set were provided. These qualifiers are as described in the ICF manual. Table 4 describes the four qualifiers used to rate 45 statements that address activity limitation and participation restriction and environmental barriers due to CLP.

The final ICF-CLP item set in Tamil consisted of 25 items of activity and participation categorized in Section I and 20 items of environmental factors categorized under Section II along with their corresponding qualifiers [Appendix 1].

## Phase 2: Administering International Classification of Functioning, Disability and Health - cleft lip and palate item set in Tamil on cases and controls

ICF-CLP item set in Tamil was administered to 32 adults with CLP and a matched control group of 32 adults without CLP (NCLP). CLP and NCLP were included in the study based on the following inclusion criteria.

All the CLP adults included in this study had repaired unilateral CLP (nonsyndromic), the patients' age range was between 18 and 40 years, individuals having no difficulty in hearing reported at the time of the study, no observed sensory, cognitive, neurological deficits, psychiatric disorders, and the individuals were native Tamil speakers.

All the NCLP adults included in this study were of same age, gender, and family income per month matched individuals, individuals having no difficulty in hearing reported at the time of the study, no observed sensory, cognitive, neurological deficits, psychiatric disorders, and the individuals were native Tamil speakers.

Participants were informed about the purpose of the study and informed consent was obtained. Instructions were provided regarding the procedure for completing the ICF-CLP item set. Further, the investigator provided clarification and assistance, if needed. The average time taken for the patient to complete the inventory was 10 min.

## Statistical analysis

Descriptive statistics (percentage analysis) was used to summarize responses of both the CLP and NCLP groups. On the other hand, Mann–Whitney U-test was also used to compare overall scores on ICF-CLP item set between CLP and NCLP groups.

## RESULTS

ICF-CLP item set was administered to 64 participants, (32 CLP and 32 NCLP) in the age range of 18–40 years who met the selection criteria. The mean age of both groups was approximately 24 years. There were 20 males and 12 females in each group who were age- and socioeconomic status (SES)-matched. Although education and occupation could not be matched between CLP and NCLP group, family income per month was matched using Kuppuswamy’s SES scale.<sup>[9]</sup> There were five pairs of individuals with income above

**Table 1: Content validity indices for each item rated by expert panel 2 and the status of selection**

Item set	CVI score	Status of selection
Managing and completing the daily routine	0.4	×
Handling responsibilities and stress	0.8	✓
Conveying verbal messages	1	✓
Carrying out discussion	1	✓
Looking after dental hygiene	1	✓
Eating	0.8	✓
Drinking	1	✓
Relating with strangers	0.8	✓
Maintaining relationships with persons in authority	0.8	✓
Maintaining relationships with subordinates	0.8	✓
Maintaining relationships with equals	0.8	✓
Maintaining relationships with friends	0.8	✓
Maintaining relationships with neighbors	0.8	✓
Maintaining relationships with acquaintances	0.8	✓
Maintaining parent-child relationships/child-parent relationships	0.8	✓
Maintaining relationships with siblings (if present)	0.8	✓
Extended family relationships	0.8	✓
Maintaining spousal relationships	0.8	✓
Making efforts in learning informal education	0.8	✓
Making efforts in preschool education	0.4	×
Making efforts in school education	0.4	×
Making efforts in vocational training	0.4	×
Making efforts in learning higher education	0.8	✓
Seeking employment	0.8	✓
Maintaining a job	0.8	✓
Engaging in self-employment	0.8	✓
Economic self-sufficiency	0.8	✓
Surviving in community life	0.8	✓
Involvement in recreational and leisure activities	0.8	✓
Involving in community, social, and civic life others	0.8	✓
Effect of change in climate	0.6	×
Extent of support and relationship from family relations	0.8	✓
Extent of support from friends	0.8	✓
Extent of support and relationship from peers, colleagues, neighbors, and community members	0.8	✓
Extent of support and relationship from people in positions of authority	0.8	✓
Extent of support and relationship from people in subordinate positions	0.8	✓
Extent of support and relationship from personal care providers and personal assistants	0.8	✓
Extent of support and relationship from strangers	0.8	✓
Extent of support and relationship from health-related professionals	0.8	✓
Individual attitudes of immediate family members	0.8	✓
Individual attitudes of extended family members	0.8	✓
Individual attitudes of friends	0.8	✓
Individual attitudes of peers, colleagues, neighbors, and community members	0.8	✓
Individual attitudes of people in positions of authority	0.8	✓
Individual attitudes of people in subordinate positions	0.8	✓
Individual attitudes of personal care providers and personal assistants	0.8	✓
Individual attitudes of strangers	0.8	✓
Individual attitudes of health professionals	0.8	✓
General social support services, systems, and policies	0.8	✓
Health services, systems, and policies	0.8	✓
Education and training services, systems, and policies	0.8	✓

✓: Selected item, ×: Rejected item, CVI: Content Validity Index

Rs. 21,000, ten pairs with income between Rs. 10,000 and Rs. 20,000, fifteen pairs with income between Rs. 8000 and Rs. 10,000, and two pairs with income between Rs. 5000 and Rs. 8000.

Overall comparison of scores on ICF-CLP item set between CLP and NCLP groups was done using Mann-Whitney U-test. Item-wise comparison of responses between CLP and NCLP groups was carried

**Table 2: Final set of items shortlisted from the component of activity and participation**

Domains	Item code	Item	Total number of items in each domain
Learning and applying knowledge	d240	Handling responsibilities and stress	1
Communication	d330	Conveying verbal messages	2
	d355	Carrying out discussion	
Self-care	d520	Looking after dental hygiene	3
	d550	Eating	
	d560	Drinking	
Interpersonal interactions and relationships	d730	Relating with strangers	12
	d7400	Maintaining relationships with persons in authority	
	d7401	Maintaining relationships with subordinates	
	d7402	Maintaining relationships with equals	
	d7500	Maintaining relationships with friends	
	d7501	Maintaining relationships with neighbors	
	d7502	Maintaining relationships with acquaintances	
	d7600	Maintaining parent-child relationships	
	d7601	Maintaining child-parent relationships	
	d7602	Maintaining relationships with siblings (if present)	
	d7603	Extended family relationships	
	d7701	Maintaining spousal relationship	
Major life areas	d810	Making efforts in learning informal education	2
	d830	Making efforts in learning higher education	
Work and employment	d8450	Seeking employment	3
	d8451	Maintaining a job	
	d8500	Engaging in self-employment	
Economic life	d870	Economic self-sufficiency	1
Community social and civic life	d910	Surviving in community life	2
	d920	Involvement in recreational and leisure activities	
Total: 9 domains	26 codes		26 items

out using percentage analysis. This is discussed under the two components of activity and participation, environmental factors.

The result of Mann-Whitney U-test revealed that the item scores of two components (activity and participation, environmental factors) were significantly different between the groups at  $P < 0.001$  level. In the item-wise comparison, using percentage analysis, the results between the domains of activity participation and environmental factors are summarized in Table 5.

### Activity and participation

#### *Handling responsibilities and stress*

It was observed that 81.25% of NCLP group and 56.25% of the CLP group reported that they did not experience any activity limitation in handling responsibilities and stress. It was also noticed that the remaining 43.65% of CLP group and 18.7% of NCLP group reported overall activity limitation in handling responsibilities and stress ranging in severity from mild to severe.

#### *Conveying verbal messages*

Conveying verbal messages are a complex phenomenon in communication. It was seen that 84.3% of NCLP group showed no activity limitation in conveying messages

verbally. Only 28.12% of the CLP group showed no activity limitation in conveying messages verbally. It was noticed that the rest of the group members in CLP group (43.75%) and NCLP group (18.7%) reported overall activity limitation in conveying verbal messages ranging between mild and complete categories.

#### *Carrying out discussion*

Carrying out discussion is an important part in communication. It may take the form of speaking, listening, reading, and writing and must involve a communicative exchange.

It was seen that 87.5% of the NCLP group and 31.25% of CLP group reported no activity limitation in carrying out discussions. It was also observed that 68.75% of CLP group and 12.5% of NCLP group reported overall activity limitation in carrying out discussions. The extent of activity limitation observed in the CLP group in this item ranged between mild and complete. Results demonstrated that the overall activity limitation was most commonly perceived among CLP group than the NCLP group.

#### *Looking after dental hygiene*

With respect to dental hygiene between the two groups, 93.7% of NCLP group reported of no activity limitation



**Table 3: Final set of items shortlisted from the component of environmental factors**

Domains	Item code	Items	Total no of items in each domain
Support and relationship	e310	Extent of support and relationship from family relations	8
	e320	Extent of support from friends	
	e325	Extent of support and relationship from peers colleagues, neighbors, and community members	
	e330	Extent of support and relationship from people in positions of authority	
	e335	Extent of support and relationship from people in subordinate positions	
	e340	Extent of support and relationship from personal care providers and personal assistants	
	e345	Extent of support and relationship from strangers	
	e360	Extent of support and relationship from health-related professionals	
Services, systems, and policies	e575	General social support services, systems, and policies	3
	e580	Health services, systems, and policies	
	e585	Education and training services, systems, and policies	
Attitudes	e410	Individual attitudes of immediate family members	9
	e415	Individual attitudes of extended family members	
	e420	Individual attitudes of friends	
	e425	Individual attitudes of peers, colleagues, neighbors, and community members	
	e430	Individual attitudes of people in positions of authority	
	e435	Individual attitudes of people in subordinate positions	
	e440	Individual attitudes of personal care providers and personal assistants	
	e445	Individual attitudes of strangers	
	e450	Individual attitudes of health professionals	
Total: 3 domains		20 codes	20 items

**Table 4: Qualifiers for International Classification of Functioning, Disability and Health-cleft lip and palate item set**

Qualifiers	Activity and participation	Environmental factors
0	No problem (none, absent, negligible, and mild problem)	No barrier (none, absent, negligible, and mild problem)
1	Mild problem (slight, low)	Mild barrier (slight, low)
2	Moderate problem (medium, fair)	Moderate barrier (medium, fair)
3	Severe problem (high, extreme)	Severe barrier (high, extreme)
4	Complete problem (total)	Complete barrier (total)
NA	Not applicable	Not applicable

**Table 5: Comparison of overall scores on International Classification of Functioning, Disability and Health - cleft lip and palate item set between cleft lip and palate and noncleft lip and palate groups**

Components	Mean rank		U	P
	CLP	NCLP		
Activity and participation	38.00	13.00	0	0.000
Environmental factors	30.50	10.50	0	0.000

CLP: Cleft lip and palate, NCLP: Noncleft lip and palate, \* $P < 0.001$ 

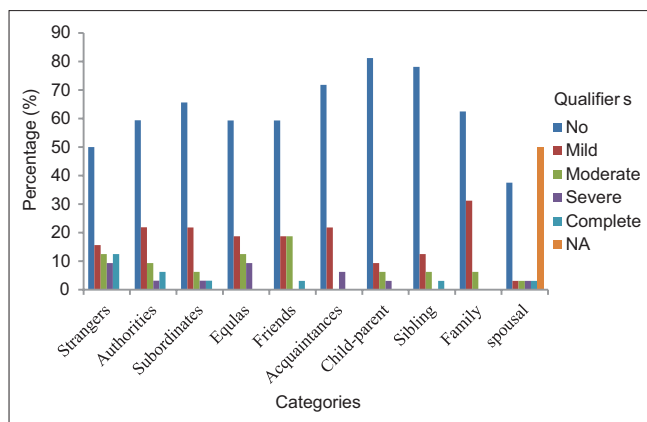
in looking after dental hygiene issues. In contrast, 65.62% of CLP group reported of no activity limitation in looking after dental hygiene. It was observed that 34.32% of CLP group and 6.2% of NCLP group reported of overall activity limitation ranging from mild to complete.

### ***Eating and drinking***

About 93.7% of NCLP group and 81.25% of CLP group reported no activity limitations in eating. Only a small proportion of the CLP group, 18.75% reported of mild or moderate degrees of activity limitation in eating. With respect to drinking, 84.3% of NCLP group and 65.62% of CLP group reported no activity limitation in drinking. It can be inferred that majority of the population in both the groups did not experience any activity limitation in this item. Eating and drinking were as easy or as difficult for CLPs as it was for NCLPs.

### ***Interpersonal interactions and relationships***

Figures 1 and 2 show that interpersonal interactions and relationships are widely affected among different categories such as relationship with strangers,



**Figure 1: Percentage of population with activity limitation in maintaining interpersonal interactions and relationships in cleft lip and palate group across different categories**

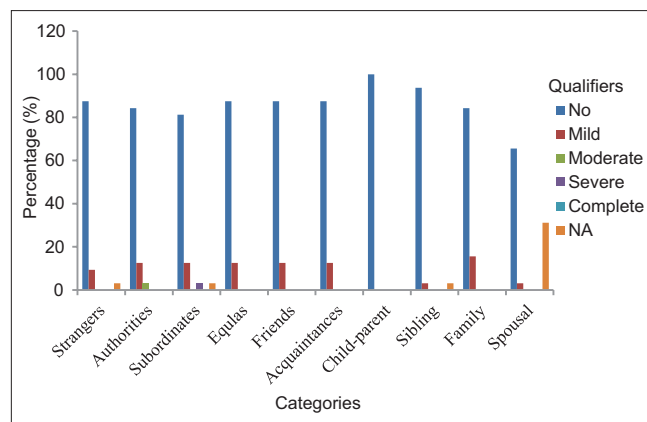
authorities, subordinates, equals, friends, acquaintances, child-parent, sibling, family, and spousal. Among different categories, 31.2% of CLP population showed highest activity limitation in maintaining interpersonal interactions and relationships among family members. Moreover, in the CLP group they had mild problems in maintaining relationships among authorities, friends, and equals. Therefore, the activity limitation among the CLP group in this domain was reported to be 21.8%, 18.75%, and 18.70%, respectively.

#### ***Making efforts in learning informal education and higher education***

About 40.6% of CLP group and 84.3% of NCLP group reported that they did not experience any activity limitation in learning informal education. It was noticed that the remaining 49.8% of CLP group and 6.2% of NCLP group reported of overall activity limitation ranging between mild and complete categories in learning informal education. The results revealed that 84.3% of NCLP group and 40.6% of the CLP group did not experience activity limitation in learning higher education such as completing a university bachelor's or master's course of study, medical school, or other professional schools. However, it was noticed that the remaining 49.8% of CLP group and 6.2% of NCLP group reported of overall activity limitation in learning higher education. The above findings reveal that activity limitation in this item was most commonly perceived in CLP group than the NCLP group with the extent of limitation ranging from mild to complete.

#### ***Seeking employment and maintaining a job***

It was observed that 50% of the NCLP group and 40.6% of CLP group did not experience activity limitation in seeking employment, whereas the remaining 18.7% of the CLP group reported to have activity limitation



**Figure 2: Percentage of population with activity limitation in maintaining interpersonal interactions and relationships in noncleft lip and palate group across different categories**

in seeking employment ranging from mild to severe. However, seeking employment is equally difficult for both NCLP and CLP groups. About 62.5% of NCLP group and 43.7% of CLP group presented with no activity limitation in maintaining a job. However, 25.1% of CLP group reported activity participation ranging from mild to severe and 9.3% of NCLP reported of mild activity limitation. The above findings reveal that activity limitation in this item was most commonly perceived in CLP group than the NCLP group with the extent of limitation ranging from mild to complete.

#### ***Engaging in self-employment and economic self-sufficiency***

Only 9.3% and 6.2% of the CLP group reported that they experienced moderate activity limitation. In the CLP group, 59.3% reported of no limitation. It could be hypothesized that the CLP group was comfortable with self-employment. About 62.5% of CLP group and 75.5% of the NCLP group reported that they did not experience activity limitation in economic self-sufficiency. This would again indicate that both the groups have equal limitations in engaging in self-employment and economic self-sufficiency which can be overlooked to some extent for the treatment plan in this particular domain.

#### ***Surviving in community life and involvement in recreational activities***

Overall 87.5% of the NCLP group and 50% of CLP admitted that they did not experience any activity limitation in surviving in community life. The remaining 46.8% of CLP group and 6.2% of NCLP group reported activity limitation ranging from mild to severe. About 96.8% of NCLP group and 56.2% of CLP group reported that they did not experience any limitation involving in recreational activities. The remaining (43.6%) CLP

group reported activity limitation ranging from mild to complete.

### Environmental factors

#### Support and relationship

It was noted that about 49.9% of CLP group and 12.4% of NCLP group admitted that they received inadequate support from strangers which is shown in Figures 3 and 4. About 40.4% of CLP group and 15.6% of NCLP group reported that they received inadequate support from authorities, thus affecting the relationship with authorities. 34.3% of CLP group and 15.6% of NCLP group reported that they received inadequate support from their subordinates, thus affecting the relationships with subordinates. 40% of CLP group and 12.5% of NCLP group reported of inadequate support affecting the relationships with equals. Nearly 40.5% of CLP group and 12.5% of NCLP reported that they received less support even from their friends, thus affecting the relationships with friends. About 18.6% of CLP group reported that they received less support from their parents and children, thus affecting the child-parent relationships.

#### General social support, health, education, and training services systems and policies

It was observed that about 45.8% of the total CLP group reported that they have difficulties in accessing social support systems and policies ranging from mild to severe. However, only 6.2% of NCLP group reported that they had very mild barriers in this item. It is also interesting to note that 46.8% of the CLP reported that they were able to use the support systems available. It was observed that 41% of the CLP group felt that they had barriers and 96.8% of the NCLP group reported that they did not have any barriers in accessing this item. In the CLP group, approximately 50% of the population reported that they did not feel any barrier in accessing this item. About 46.7% of the CLP population revealed that they were dissatisfied with the educational systems and policies.

#### Attitudes

Attitudes could influence individual behavior and in social life. Individual attitudes are categorized according to the kinds of relationships. Figures 5 and 6 represent the percentage of CLP and NCLP population facing environmental barriers due to individual's attitudes. It was noted that a major proportion of population in CLP group face barriers due to attitudes of individuals in their community. It is observed that this problem was perceived more with authorities (56.2%), followed by strangers (49.9%), friends (31.2%), and family

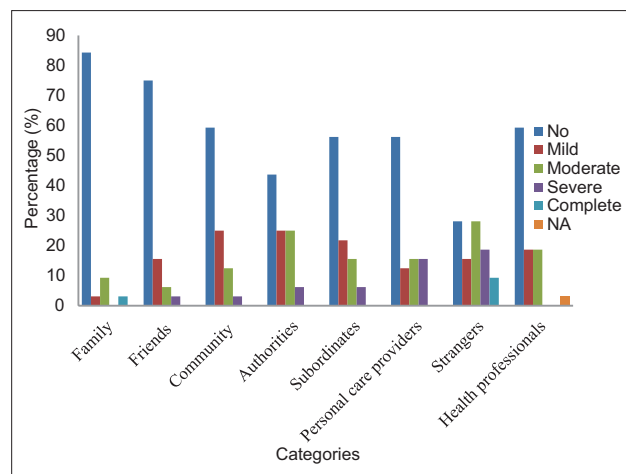


Figure 3: Percentage of population facing environmental barriers with support and relationship in cleft lip and palate group across different categories

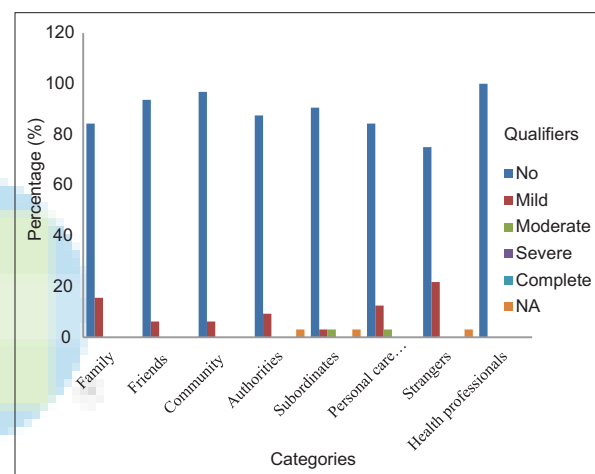


Figure 4: Percentage of population facing environmental barriers with support and relationship in noncleft lip and palate group across different categories

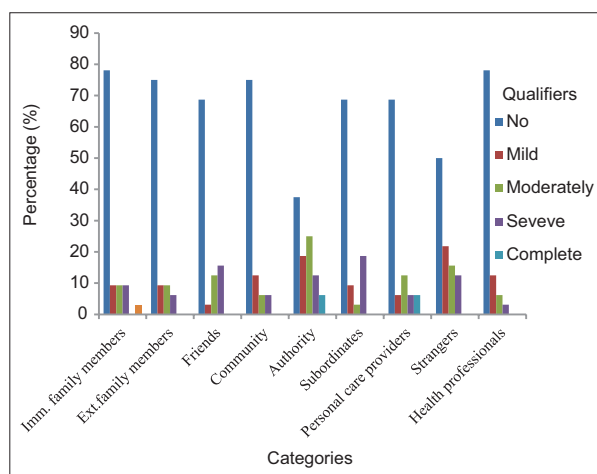
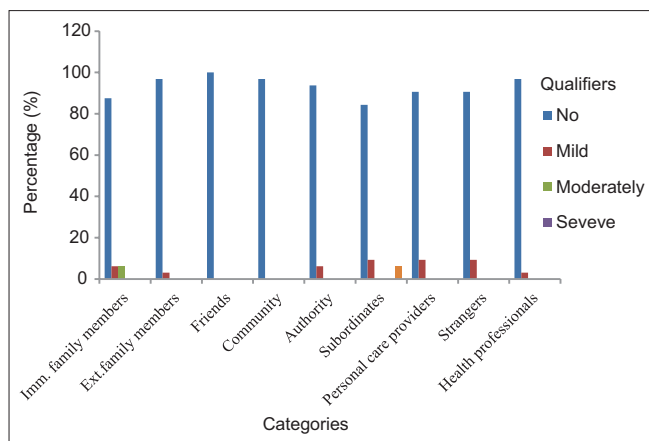


Figure 5: Percentage of population facing environmental barriers with individual's attitudes in cleft lip and palate group across different categories





**Figure 6: Percentage of population facing environmental barriers with individual's attitudes in noncleft lip and palate group across different categories**

members (27.9%). In contrast, only 6.2% of NCLP group reported that they encountered negative attitudes toward them in their community.

## DISCUSSION

In the item-wise comparison, using percentage analysis, individuals with CLP had greater limitation in activity, restriction in participation in the domains of communication, maintaining interpersonal interactions and relationships, employment, and major life areas. With respect to the communication, the difference noticed could be attributed to the atypical speech production observed in these individuals. These results are in agreement with the findings of Lefebvre and Arndt who reported difficulties in verbal communication in individuals with CLP.<sup>[10]</sup> Among different categories of interpersonal interactions and relationships, CLP population showed highest activity limitation in maintaining interpersonal interactions and relationships among family members. This could be due to fear and anxiety in individuals with CLP. The results obtained in this area are closely connected to the study done by Van Demark and Van Demark.<sup>[11]</sup> They stated that individuals with CLP feel neglected due to their handicap and also appear to be observers rather than active participants in social interactions. This could be attributed to the psychological adjustment of individuals with CLP. The results also highlighted the limited activity participation in both groups indicating that the challenges faced in seeking employment are common for both the groups. This is in agreement with the study done by Ramstad *et al.*, who reported that there are no significant differences in employment of adults with CLP and NCLP.<sup>[12]</sup> Whereas, activity limitation in maintaining the job was most commonly perceived in CLP group than the NCLP group with the

extent of limitation ranging from mild to complete. The probable reason could be that some of them were still continuing their higher education or who were working as daily wage workers or housewives. In relation with the above findings, Broder *et al.* and Topolski *et al.*, in their studies, stated that adolescents with cleft may have difficulty in maintaining a job due to noticeable facial characteristics and speech problems.<sup>[13,14]</sup>

Major life areas such as surviving in community life and involvement in recreational activities suggest that individuals with CLP encounter difficulties in their community. This could be attributed to less involvement in participating in social meetings/functions such as attending meetings, social functions, and engaging in charitable organizations. Presence of scarred facial appearance could have led to development of an inferiority complex among them, thereby restricting them from participating in community activities. In a study Robinson *et al.*, discussed a "negative social interactional cycle," in which individuals with facial disfigurement avoid social interaction in anticipation that social interactions will be damaging and painful.<sup>[15]</sup>

In addition to the above findings, the activity limitation involving in recreational activities was also more seriously perceived in the CLP group. It can be hypothesized that limitations reported could be possibly due to low levels of self-esteem, less challenging behaviors, and inadequate socialization skills.

In environmental factors, the domains of support, relationship, health services, education training systems and policies, attitudes of authorities, and strangers were projected as barriers by individuals with CLP. All NCLP groups reported that they received good support from child/parent.

Whereas, a major proportion of CLP population reported that they received inadequate support from health professionals, affecting the relationship with the professionals. From the findings of this study, it can be understood that the CLP group did not receive inadequate support from their immediate environment. It could be hypothesized that this could possibly become a barrier which could affect their career. Strauss and Fenson<sup>[16]</sup> reported that social support is an important factor in the CLP individuals' life.

In domains such as health services, education training systems, and policies CLP population revealed that they were dissatisfied with the services. It could be attributed to many factors such as awareness in the family about the condition, motivation and support of the family members, literacy level in the family, and SES of the

family. Further, it is assumed that lack of knowledge about the available treatment options and schemes provided by the local administration could have possibly limited the CLP group in seeking support of the health systems/policy for treatment. A major proportion of population in CLP group face barriers due to attitudes of individuals in their community such as authorities, strangers, friends, and family members. It is evident from the results that CLP group encounters barriers in the environment due to the negative attitude of people in their community. It is possible that the attitudes of all these individuals in the community can influence the individuals with CLP negatively. It is evident from the literature that it is not only the individuals own perception of the condition that contributes to the effects but also the reactions of all the people in his/her environment too.<sup>[17,18]</sup>

With the information obtained from this study, it may be concluded that individuals clearly feel that cleft has influenced important aspects of their lives. Using the ICF-CLP item set, perspectives of the adult CLP group regarding lives concerning global aspects, well-being, and social life can be studied. Adopting a comprehensive but multidimensional measure will aid the cleft care team in understanding the unmet needs of the patient and in delivering quality healthcare. It can be concluded that the ICF-CLP item set used in this study is clinically relevant in identifying the conditions which limit their activities/participation and barriers/facilitators in their environments.

## CONCLUSION

The purpose of this study was to identify a set of items from ICF framework that is relevant to adults with CLP (ICF-CLP item set) and administer the item set to study the impact of CLP.

It is observed that the ICF-CLP item set used in this study aided in identifying limitations in activities/participation and barriers/facilitators in the environment of adults not only with CLP but also in individuals without CLP. Results of revealed significant differences ( $P = 0.000$ ) between CLP and NCLP groups in both the components of activity participation and environmental factors. In the item-wise comparison, using percentage analysis, it was observed that individuals with CLP had greater limitation in activity and restriction in participation in the domains of communication, maintaining interpersonal interactions and relationships, employment, and major life areas. In environmental factors, the domains of support and relationship, health services, systems and policies,

education training systems and policies, attitudes of authorities, and strangers were projected as barriers by individuals with CLP. The results of this study suggest that the ICF-CLP item set has been useful in identifying activity limitation and participation restriction and barriers in the environment for adults with CLP. It is also proved that ICF item set used in this study not only examined the extent of disease in abnormal individuals but also helped us to compare the prognosis of the treatment among the normal population. Further, this ICF-CLP item set may be standardized to serve as a multidimensional outcome measure for adults with CLP, which could be used for clinical and research purpose in cleft and craniofacial centers.

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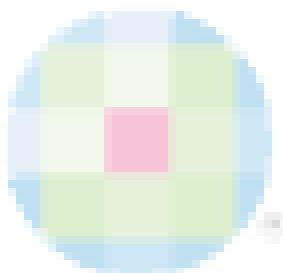
## Conflicts of interest

There are no conflicts of interest.

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## APPENDIX I

### ICF- CLP INVENTORY FOR ADULTS (English)

Name: Age/Sex:  
Occupation: Socio economic status:  
Type of Cleft:  
Date of Surgery:

### ACTIVITY PARTICIPATION

#### Rating:

- 0- No Problem (None, Absent, Negligible)
- 1- Mild Problem (Slight, Low)
- 2- Moderate Problem (Medium, Fair)
- 3- Severe Problem (High, Extreme)
- 4- Complete Problem (Total)
- NA- Not applicable

Kindly rate the statements with respect to the condition of Cleft lip and palate

S. No	Items	0	1	2	3	4	NA
1	Handling responsibilities and stress						
2	Conveying verbal messages						
3	Carrying out discussion						
4	Looking after dental hygiene						
5	Eating						
6	Drinking						
7	Relating with strangers						
8	Maintaining relationships with persons in authority						
9	Maintaining relationships with subordinates						
10	Maintaining relationships with equals						
11	Maintaining relationships with friends						
12	Maintaining relationships with acquaintances						
13	Maintaining parent child relationships/child parent relationships						
14	Maintaining sibling relationships (if present)						
15	Extended family relationships						
16	Maintaining spousal relationships						
17	Making efforts in learning informal education ( <i>Learning at home or in some non-institutional setting such as learning crafts and other skills from parents</i> )						
18	Making efforts in learning higher education ( <i>Engaging in activities of advanced educational programs in universities, colleges and professional schools</i> )						
19	Seeking employment						
20	Maintaining a job						
21	Engaging in self-employment						
22	Economic self-sufficiency ( <i>Inclusions: personal economic resources &amp; public economic entitlements</i> )						
23	Surviving in community life ( <i>Inclusions: informal &amp; formal associations; ceremonies</i> )						
24	Involvement in recreational & leisure activities ( <i>Inclusions: play, sports, arts &amp; culture, crafts, hobbies &amp; socializing</i> )						
25	Involving in community, social & civic life others						

**TOTAL SCORE:**

## ICF- CLP INVENTORY FOR ADULTS (English)

Name:

Age/Sex:

Occupation:

Socio economic status:

Type of Cleft:

Date of Surgery:

### ENVIRONMENTAL FACTORS

#### Rating:

- 1- No Barrier (None, Absent, Negligible)
- 2- Mild Barrier (Slight, Low)
- 2- Moderate Barrier (Medium, Fair)
- 3- Severe Barrier (High, Extreme)
- 4- Complete Barrier (Total)
- NA- Not applicable

**Kindly respond to the statements mentioned below with respect to the condition of Cleft lip and palate**

S. No	Items	0	1	2	3	4	NA
1	Extent of support & relationship from family relations						
2	Extent of support from friends						
3	Extent of support & relationship from peers colleagues, neighbors & community members						
4	Extent of support & relationship from people in positions of authority						
5	Extent of support & relationship from people in subordinate positions						
6	Extent of support & relationship from personal care providers & personal assistants						
7	Extent of support & relationship from strangers						
8	Extent of support & relationship from health-related professionals						
9	General social support services, systems & policies						
10	Health services, systems & policies						
11	Education & training services, systems & policies						
12	Individual attitudes of immediate family members						
13	Individual attitudes of extended family members						
14	Individual attitudes of friends						
15	Individual attitudes of peers, colleagues, neighbors & community members						
16	Individual attitudes of people in positions of authority						
17	Individual attitudes of people in subordinate positions						
18	Individual attitudes of personal care providers & personal assistants						
19	Individual attitudes of strangers						
20	Individual attitudes of health professionals						

**TOTAL SCORE:**