

# ***Psychological Distress and Related Factors Among Parents Having Children With Cleft Lip and Palate Disorder: Evidence From Sri Lanka***

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## **Abstract**

*Background:* This study investigates the psychological distress (PPD) experienced by parents of children with cleft lip and palate disorders in Sri Lanka. The challenges associated with societal perceptions, medical interventions, and emotional impact on both parents and the affected child are explored. The research aims to assess PPD prevalence and associated factors, emphasizing the need for tailored support systems in the Sri Lankan context.

*Methodology:* A cross-sectional study was conducted at the Dental Hospital, Peradeniya, the largest dental hospital in Sri Lanka. PPD was measured using the General Health Questionnaire-30 (GHQ-30). Data on cleft site and associated disabilities were collected from clinical records. Chi-square and multivariate logistic regression were employed for data analysis.

*Results:* From 384 parents revealed a 34% prevalence of PPD. Chi-square analysis identified significant associations with the child's age, family income, family structure, prior knowledge on cleft lip and palate disorders (CLPD), cleft site, and associated disabilities. Multivariate logistic regression highlighted that the child's age, family structure, cleft of the hard and soft palate, feeding difficulties, and speech problems were significant predictors of PPD.

*Conclusion:* This study contributes valuable insights into the multifaceted nature of PPD among parents of children with cleft lip and palate disorders in Sri Lanka, emphasizing the necessity for targeted interventions to enhance parental well-being in the face of these challenges.

**Keywords:** Cleft Lip, Cleft Palate, Parental Psychological Distress

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## **Introduction**

Cleft lip and/or palate disorder (CLPD) is a problem that arises from improper closure of facial features throughout the developing stage. Cleft lip, cleft palate, isolated cleft palate, and their combinations are all included in this syndrome. The disease is connected with a number of deficits, including difficulties with feeding, speaking, hearing, frequent ear infections, and oral health. This ailment is frequently associated with other congenital illnesses (Sandy et al., 2020).

The worldwide prevalence rates of cleft lip, cleft palate, and cleft lip and palate were 0.45, 0.3, and 0.33 per 1000 live births, respectively, according to a systematic study conducted by Salari et al. (Salari et al., 2021). The geographical regions exhibit notable variations in these rates. For example, the prevalence of orofacial clefts in the Asian region was 1.57 per 1000 live births (Panamonta et al., 2015).

There is a dearth of epidemiological information on cleft lip and palate in Sri Lanka. Incidences of cleft lip with or without cleft palate were found to be 0.83 per 1000 births in the Central Province, while isolated cleft palate was reported to be 0.19 per 1000 births (Amaratunga & Chandrasekera, 1989). According to De Alwis et al. (2008), there was a greater incidence of oral clefts in Anuradhapura, Sri Lanka, in 2008—2.2 per 1000 live births. Psychological distress is a common occurrence in society, and parents of children with abnormalities like CLPD frequently feel depressed and anxious (Despars et al., 2011), which has an impact on the dynamics of the entire family.

Due to difficulties nursing and a higher risk of respiratory infections, parents of newborns with CLPD frequently experience distress (Tsuchiya et al., 2019). Due to a lack of comprehensive documentation, parents of children affected by CLPD in Sri Lanka have not received enough care for their psychological health. In government hospitals, Sri Lanka uses a self-sustaining multidisciplinary team approach to treat CLPD, with follow-up care provided until aesthetic correction procedures are finished by the time the patient is 18 years old (Lamabadusuriya & Mars, 1988).

Although resources are available to help the psychological development of impacted children, parents who are dealing with many stressors at the same time have not received enough attention.

The study was carried out at the Dental Hospital, Peradeniya (DHP), a national referral center for oral health requirements and a tertiary care dental facility in Sri Lanka. The purpose of the study was to evaluate parental psychological distress (PPD) prevalence and risk variables among parents who attended the cleft lip and palate clinic.

## **Materials and Methods**

The data from a cross-sectional study carried out from January to April 2017 at a hospital are presented in this report. The University of Colombo's Faculty of Medicine's Ethical Review Committee granted ethical approval. Parents who were willing to participate provided written informed consent, guaranteeing privacy and the ability to opt out.

Parents whose children have CLPD participated in the study by visiting the Oral and Maxillofacial Unit, DHP, in the Central Province of Sri Lanka for clinic visits. Each impacted

child only had one parent participate. Assuming a 50% prevalence of PPD, the sample size of 384 was determined using the formula for determining population proportions with absolute certainty.

Because CLPD is not very common, a non-probability consecutive sampling method was employed. Parents who were attending the cleft lip and palate clinics and whose children had CLPD were considered eligible. We did not include parents of children with other birth abnormalities. A pretested interviewer-administered questionnaire covering sociodemographic data, prior awareness of CLPD, and the General Health Questionnaire-30 (GHQ-30) to measure PPD were among the tools used to collect data. Children's clinical records were examined to identify the type of cleft and any related impairments.

The questionnaire's validity and reliability were confirmed by professional validation, parent pretesting at Lady Ridgeway Hospital for Children, and strict data management procedures.

The analysis of the data was done with SPSS 21. To investigate the connections between PPD and categorical factors, chi-square tests were employed. To find significant predictors of PPD, multivariate logistic regression analysis included variables with  $p < 0.05$ .

### **Sample Characteristics**

384 children with CLPD were included in the current study group, and their parents answered the questionnaire given by the interviewer. The sample's children with CLPD were 58.8 months (SD+ 43 months) old on average. Mothers accompanied 62.8% of the children among the parents in the research. Seventy-eight percent of the participants were Sinhalese. The majority of parents lived with extended families (51.3%), had a family income of less than Rs. 25,000/month (53.9%), and were educated up to grade 11 (66.1%). Among the children that were affected, solitary cleft of the soft palate (8.3%) was the least common type of cleft, whereas cleft including lip and palate (32.3%) was the most prevalent. Speech issues were the most often cited handicap (41.4%).

### **Sample and Parental Psychological Distress Characteristics**

34.4% of people reported having psychological distress. PPD was higher in fathers than in mothers, as Table 1 illustrates, but the difference is not statistically significant. The child's age ( $p < 0.000$ ), family income ( $p = 0.011$ ), family structure ( $p < 0.000$ ), prior knowledge of CLPD ( $p = 0.045$ ), the location of the cleft ( $p < 0.000$ ), and the limitations related to that specific cleft ( $p < 0.000$ ) were all substantially correlated with the PPD.

Table 1: Factors associated with parental psychological distress of the study population

Variable		Total (n = 384)	Parenting distress		$\chi^2$ test	p
			Yes (n = 132; 34.4 %)	No (n = 252; 65.6 %)		
		N (%)	N (%)	N (%)		
Gender of the parent	Female	241 (62.8%)	78 (32.4%)	163 (67.6%)	1.159	0.282
	Male	143 (37.2%)	54 (37.8%)	89 (62.2%)		
Ethnicity of the parent	Sinhalese	303 (78.9%)	101 (33.3 %)	202 (66.7 %)	1.184	0.553
	Muslim	62 (16.1%)	25 (40.3 %)	37 (59.7 %)		
	Other	19 (4.9%)	6 (31.6 %)	13 (68.4 %)		
Level of education of the parent	Up to grade 11	254 (66.1%)	88 (34.6 %)	166 (65.4 %)	2.666	0.264
	Passed grade 13	97 (25.3%)	29 (29.9 %)	68 (70.1 %)		
	Higher education	33 (8.6%)	15 (45.5 %)	18 (54.5 %)		
Age of the child	Less than 2 years	110 (28.6%)	91 (82.7%)	19 (17.3%)	159.770	0.000
	2 years or more	274 (71.4%)	41 (15.0%)	233 (85.0%)		
Living with spouse	Yes	340 (88.5%)	113 (33.2%)	227 (66.8%)	1.709	0.191
	No	44 (11.5%)	19 (43.2%)	25 (56.8%)		
Family income	Less than Rs. 25,000	207(53.9%)	83 (40.1%)	124 (59.9%)	6.517	0.011
	Rs. 25,000 or more	177(46.1%)	49 (27.7%)	128 (72.3%)		
Family structure	Nuclear	197(51.3%)	87(44.2%)	110(55.8%)	17.178	0.000
	Extended	187(48.7%)	45 (24.1%)	142 (75.9%)		
Previous knowledge on CLPD	No	151 (39.3%)	61 (40.4%)	90 (59.6%)	4.001	0.045
	Yes	233 (60.7%)	71 (30.5%)	162 (69.5%)		
Site of the cleft	Lip only	83 (21.6%)	7 (8.4%)	76 (91.6%)	37.192	0.000
	Hard and soft palate	73 (19.0%)	25 (34.2%)	48 (65.8%)		
	Lip and hard palate	124 (32.3%)	49 (39.5%)	75 (60.5%)		
	Complete bilateral	72 (18.8%)	33 (45.8%)	39 (54.2%)		
	Soft palate only	32 (8.3%)	18 (56.3%)	14 (43.8%)		
Associated disabilities	Other problems	85 (22.1%)	10 (11.8%)	75 (88.2%)	124.228	0.000
	Feeding difficulties	140 (36.5%)	98 (70.0%)	42 (30.0%)		
	Speech problems	159 (41.4%)	24 (15.1%)	135 (84.9%)		

## Associations of Parental Psychological Distress

The multiple logistic regression analysis includes all PPD-related factors with p values less than 0.05. According to the results of the Omnibus Tests of Model Coefficients, the model is a significant predictor of PPD, with a Chi square value of 222.074 and a p value of less than 0.000. The predictor factors were able to predict 60.7% of the variance in the PPD, as indicated by the Nagelkerke R Square of 0.607.

Table 2: Multivariate analyses: Selected factors associated with parental psychological distress

Variable	Category	Adjusted Odds Ratio (CI)	P value
Age of the child	2 years or more	1.0	< 0.000*
	Less than 2 years	16.327 (7.158-37.238)	
Family income	Less than Rs. 25,000	1.0	0.394
	Rs. 25,000 or more	0.761 (.407- 1.424)	
Family structure	Nuclear	1.0	0.001
	Extended	0.344 (0.182- 0.649)	
Previous knowledge of CLPD	No	1.0	.077
	Yes	0.566 (0.302- 1.063)	
Site of the cleft	Lip only	1.0	0.002
	Hard and soft palate	9.984 (2.313-43.107)	
	Lip and hard palate	2.572 (0.714-9.264)	
	Complete bilateral	1.577 (0.477-5.215)	
	Soft palate only	0.623 (0.180-2.154)	
Associated disabilities	Other problems	1.0	0.038
	Feeding difficulties	2.758 (1.056-7.206)	
	Speech problems	0.435 (0.196- 0.967)	

\*p < 0.05

The adjusted relationships between other health-related variables and sociodemographic characteristics and PPD are displayed in Table 2. After adjusting for confounding variables, parents of CLPD children under the age of two had significantly greater PPD (adjusted odds ratio (AOR), 16.327; 95% confidence interval (7.158-37.238). Compared to nuclear families, parents who live with their extended family have a considerably lower likelihood of having PPD (AOR, 0.344; 95% CI, 0.182- 0.649). Only the hard and soft palate clefts (AOR, 9.984; 95% CI, 2.313-43.107) among the children's cleft types were found to have a significant effect on PPD. Among the linked disabilities, cleft-related speech issues (AOR 0.435; 95% CI, 0.196-0.967) and eating difficulties (AOR 2.758; 95% CI, 1.056-7.206) were significant predictors.

## Conclusions

The psychological distress experienced by parents of children with CLPD has not been given nearly as much attention in Sri Lankan medical literature. According to the current study, which involved a hospital-based sample of parents, 34% of the study population had PPD. The study's unrefined analysis revealed a strong correlation between PPD and the child's age, family income, family structure, prior knowledge of CLPD, the location of the cleft, and problems linked to specific clefts. Nevertheless, age of the kid, family structure, cleft in the

hard and soft palate, feeding issues related to the cleft, and speech issues related to the cleft were found to be the most significant variables among all of these.

In the current study there were strong predictors of PPD. In terms of controlling the PPD, these findings might provide useful information for multidisciplinary cleft care professionals.

Parents' emotional and social challenges to cope with their child's condition have been highlighted in previous study in the field of CLPD (Nelson et al. 2012). Mothers may experience significant anguish due to feelings of social marginalization and stigmatizing reactions from others, which can cause them to worry for their child's future. The medical literature has emphasized the need of managing parental distress in order to lower the likelihood that children with cleft lip and palate may experience psychological issues. The timing of CLPD treatment may have an impact on improving mother-child interactions (Murray et al., 2008).

Overall, the present study demonstrates the importance of the concept of family. Fathers were more distressed than mothers regarding the condition of their children. Those living with the spouse and those living with extended family had lower scores of PPD. Although fathers play a key role in supporting their families through the treatment process of the affected children, they are underrepresented in the research literature (Stock & Rumsey 2015). Further, fathers may present the strong moral support of their family following the initial CLPD diagnosis and not share their own concerns until a later stage. Efforts should therefore be made to involve fathers in clinical care wherever possible. The findings of the study done by Stock et al. (2016) suggested that encompassing all members of the family is essential for optimal familial adjustment to improve the psychosocial impact of CL/P on affected individuals (Stock et al., 2016).

Rarely is the effect on the extended family examined. Guest et al. (2019) examined the role grandparents play in caring for their grandkids with CLPD and emphasized the significance of include them in offering moral support to the child's parents.

According to this study, a patient's age can accurately predict how distressed their parents will feel psychologically. Aslan et al.'s (2018) and Yuan et al.'s (2022) research have also validated the impact of the psychological states of caregivers of patients with CLPD. Once the first shock and distress wear off, parents of a child born with a cleft usually want to know what the cause is, what the best therapies are (and where to get them), and what the kid's future holds. When the child in this study was more than two years old, the parents' degree of distress decreased dramatically. The primary reason for this is, as the patient grows up and the treatment progresses, the parents can take care of their children more easily. Nonetheless, the child's psychological and developmental issues are a concern that we must overlook. A considerable number of parents whose children have CLPD focus excessively on their look and function, neglecting their interpersonal communication skills and personality development (Yuan et al., 2022). While the cost of medical treatment for parents of patients with CLPD decreases as the patients reach adulthood, parents still require assistance from appropriate professional services to support the positive development of the patients' psyche and society.

In people with CLPD, the functions of the nasal and oral cavities are compromised. The ability to generate negative pressure required for sucking is diminished by oronasal

communication. The clinician's first worry when it comes to infants with CLPD problems is feeding (Bessell et al., 2011).

Nasal regurgitation of food and excessive air intake, which involves frequent burping and choking, further complicate the feeding process. The lengthier feeding times wear down the mother and the infant (Muthu 2000).

Ensuring proper nutrition is the top goal for all infants during their first few months of life. Parents' psychological discomfort is exacerbated by feeding issues that newborns with CLPD frequently experience. The current study and numerous other studies that can be found in the medical literature both unequivocally show this relationship (Devi et al., 2012).

The current study found that cleft-related speech issues were a major predictor of PPD. Some children have "cleft palate speech," which is defined by unusual consonant sounds, abnormal nasal resonance, and abnormal nasal airflow, even with early cleft surgery. Speech therapy can be used to correct these aspects (Nagarajan et al., 2009). To guarantee that prompt assessments and suitable care are given, the speech therapist must collaborate closely with the surgeon and other team members as a member of the cleft care team. Reducing the parents' distress is much easier when this communication issue in people with CLPD is improved.

The best results for cleft care come from multidisciplinary, comprehensive services. As a result, each team member must comprehend the basic concepts of care in the domain of expertise of the other team members.

This study emphasizes how crucial it is to screen parents of children with CLPD for characteristics that contribute to PPD in pediatric care settings and to start early intervention referrals when these risk factors exist. Regarding PPD management, it offers a wealth of knowledge to multidisciplinary cleft care professionals.

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