

Evaluation of Services of Cleft Palate/Lip Team Delivered in Lahore, Pakistan

Services of Cleft
Palate/Lip Team
Delivered in Lahore

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ABSTRACT

Objective: The objective of our study was to evaluate services delivered by a cleft palate team in Lahore Pakistan.

Study Design: Descriptive quantitative cross-sectional survey.

Place and Duration of Study: This study was conducted at the A cleft palate team working at Lahore from March 1, 2023 to August 31, 2023.

Methods: After getting ethical approval of the study from Research and Ethical Review Committee of Amna Inayat Medical College Lahore, the study was carried out. The participant team of the study was to assure their responses to be kept anonymous. Convenient sampling was utilized to select cleft palate team of Lahore. Data was collected using close ended questionnaire. And statistical analysis was done using Excel software.

Results: Percentage of patients Age-wise, diagnosis-wise, population of patients for already operated cases, kind of services delivered by cleft palate team each month were evaluated which were shown in the form of graphs.

Conclusion: At present in Lahore paediatric surgeons are mainly performing secondary cleft surgery but the overall procedure number remained small. However cleft palate team of Lahore was providing efficient services.

Key Words: Team, Lahore, Services, Cleft palate/lip, Evaluation, Pakistan

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INTRODUCTION

The most prevalent congenital deformity of the craniofacial region worldwide was an orofacial cleft. Cleft palate management involved multi-disciplinary approaches, there were many publications but specific description of services delivered by these teams was yet to be studied. The most prevalent congenital defect of the craniofacial complex was lip cleft or/and palate cleft (CLP), which estimated affecting 1/500 to 700 live births globally. Cleft palate management involved multi-disciplinary approaches, there were many publications but specific description of services delivered by these teams was yet to be surveyed.¹ The World Health Organization stated that because of

service organization, disparities in care, lack of clarity regarding treatment, and budget constraints, cleft care was still far from optimal.² Children who are affected need to be managed for a long time by a multidisciplinary team of medical professionals, starting with immediate medical attention.³ To achieve both functional and cosmetic well-being, patients with orofacial cleft deformity must receive treatment at the appropriate period and age. The results of the multidisciplinary approach to this subject have steadily improved.⁴ In view of all the data available, there was no survey done in local context. Thus the objective of our study was to evaluate the services provided by cleft palate team of Lahore, Pakistan.

METHODS

After getting ethical approval of the study from the Research and Ethical Review Committee of Amna Inayat Medical College Lahore, the study was carried out in March 1, 2023 to August 31, 2023. The participant team of the study was to assure their responses to be kept anonymous. A descriptive quantitative cross-sectional survey was performed on a cleft team providing services in Lahore. Convenient sampling was utilized to select cleft palate team of Lahore, data was collected using close ended questionnaire and statistical analysis was done using Excel software. The questionnaire sought information on the type of dysfunction of cleft palate, team's

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population of the patients evaluated per month, age of the patients, kind of services delivered by cleft palate team, the availability of parent-patient support group provided by cleft palate team, respondents' opinions about the significance of particular procedures regarding assessment of Velopharyngeal function and the utilization of instrumental procedures. This questionnaire has been taken after validating in local context from the questionnaire used in a research article "Survey of services and practices of cleft palate craniofacial teams by Marry PannBacker". Obtaining consent and briefing, questionnaire was got filled by participant team of Lahore. Statistical analysis was performed using Excel software. Results were shown in the form of graphs.

RESULTS

Cleft Palate Team comprising paediatric surgeons one having 45 years of experience with postgraduate diploma F.C.P.S was established in 2010 in the province of Punjab (Pakistan) evaluated 150 patients per month with cleft of palate and/ or lip and with velopharyngeal dysfunction (patients of cleft included) evaluated 75 per month or 900 per year. The team had 48 meetings annually. The team was not a member of Pakistan Cleft Palate Association and did not have parent-patient support group but considered importance of evaluation of velopharyngeal function. Percentage of patients Age-wise of 0-4 year's age group was found to be = 25-49%, 5-7 years = 1-24%, 18-13 years = 1-24%, 14-18 years = 1-24%, 19-37 years = 0%, 37-above = 0% (Figure 1).

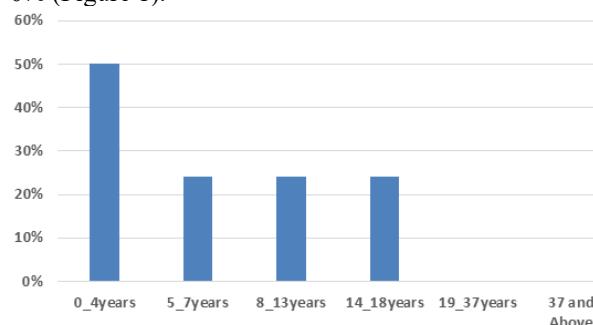


Figure No. 1: Percentage of population of patients Age Group-wise

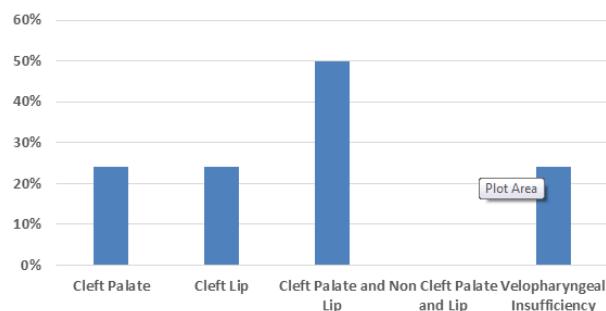


Figure No. 2: Percentage of population of patients Diagnosis-wise

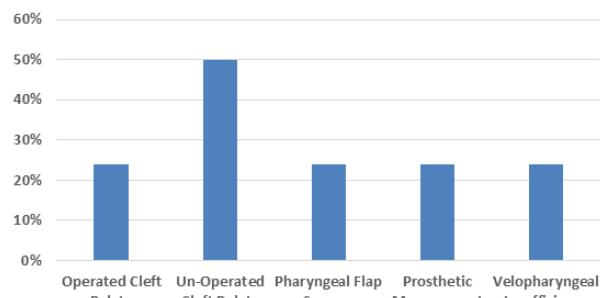


Figure No. 3: Percentage of population of patients Surgical Management –wise

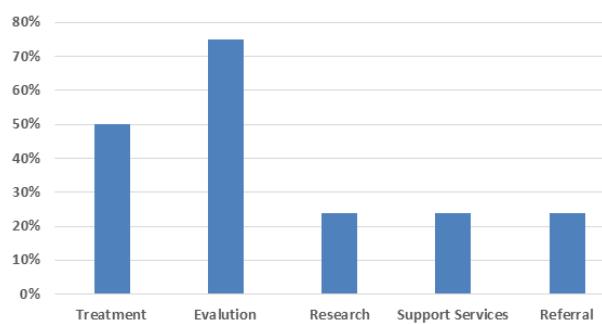


Figure No. 4: Percentage of kind of services delivered

DISCUSSION

As an essential component of a multidisciplinary team, pediatric dental consultants kept a close eye on the dental development and individual's growth having palate cleft and lip cleft.⁵ The pediatric dentist's function in the CLP team and the treatment of Cleft Lip and Palate (CLP) children's teeth are the main topics of research.⁶ The impact of orthodontic treatments on the results of cleft treatment should be the subject of more investigation. Future studies were required to examine feeding knowledge training and practice patterns in settings with fewer patient volumes.⁷ Newborn's mothers having CLP reported nursing their babies at a lower rate in comparison to national estimation for infant's population without clefts. Results of an online poll conducted in one clinic for palate cleft and cleft lip and on social media cleft related platforms in US indicated that there were several obstacles.⁸ Establishing swift system of surveillance for birth about congenital abnormalities was essential in order to support health service planning and policy, as well as to allow for complete management of CLP persons.⁹ It is essential to work in joint venture with a variety of stakeholders, such as hospital administrators, guardians, insurers, and providers, in order to enhance clinical outcomes and patient retention.¹⁰ It was advised for young adults thinking about receiving further treatment. Lastly, providing local practitioners with resources and training may raise public awareness of CL/P services and facilitate adult patients who had persistent CL/P-related problems by increasing their access to specialized care.¹¹ The variety of tactics, further investigation of the differences and their implications

on patient centered outcomes, such as quality of life, satisfaction, cost, and resource utilization was warranted by team clinic administration strategies.¹² Pakistan, Nigeria, Kenya, Nepal, India and Philippines had cleft teams with collaboration of international and national agencies. Zimbabwe had no local NGO for this. One of the ideal measures comprised of initiating school for CL/P children, their enrollment in government authorities for their treatment and monitoring them accordingly for efficiency improvement in their health care.¹³ Speech outcome and surgical correction of cleft palate are doubtful if done after an age of six years because in such case merely primary closure is not sufficient. Pharyngeal flap at that time is of prime importance to improve speech.¹⁴

A study in Pakistan concluded that mostly there are cases of cleft palate and lip (74%) instead of isolated cases of either palate or lip.¹⁵ Even the standards of care had been published; the variations and inequities in UK had been noted regarding delivery of specialist care. Services of cleft palate and lip had been exemplified for identification of usual obstacles in delivery of prompt specialist service and to locate facilitators in this respect.¹⁶ Merits of multidisciplinary team to system-wise manage cleft palate and cleft lip patients with their families have been emphasized. Ideally a team should help families at all stages of child development and amend to cater newer problems which arise in growth process. In the initial stages a dietician should have been taken on board to make sure that child consumed enough intakes of macronutrients to enhance development and growth. Ideally cleft palate teams focus collaboration and family focused approach for complicated surgical and medical requirements of children of cleft palate or cleft lip when they grow young. These teams may vary according to location and background but they have central tenets which make them ideal. Going through different recommendations and guidelines for cleft palate and cleft lip teams, organizational structure and composition of care team could be decided.¹⁷ In U.S.A isolated cleft palate a congenital defect affects around six out of ten thousand live births which are distinct genetically and at embryological levels from both isolated lip cleft and cleft palate and lip. Around fifty percent patients of cleft palate also suffer from a syndrome involving orofacial cleft and different structural anomalies. In comparison to general population, none syndrome cleft palate children have higher middle ear pathologies, language and speech problems and psychological requirements. Hence they need multidisciplinary care starting from birth till adolescence. On single visits families can manage to contact multiple specialists for their patients in case of team care which reduces their burden. Coordination in these teams also reduces the cost involved. Any way various cleft centers have different team components which have different patterns of care. Protocols of long term care and its cost are scarce. Despite cleft teams have reduced lot of

burden, yet longitudinal visit requirement is challenging for many families. Data indicated that cleft palate and lip patients usually are absent for follow up and usually quit team care before the time recommended by American Cleft Palate- Craniofacial Association guidelines. Because specific data about time length for follow up of isolated cleft palate patients is not available and the factors affecting their follow up span are unknown, for standardization of care of cleft palate patients, the role of multidisciplinary team visits require to be examined closely.¹⁸ In U.K the multidisciplinary care of cleft palate or/and lip is provided by National Health Service which is free of cost and its pathway is started at prenatal and postnatal referral to its specialist and goes lifelong. Apart from surgeries at primary levels, treatment by clinical psychologists, language/speech specialists, nurse specialists and geneticists is involved as per indication.¹⁹ Cleft palate patients have complex requirements. Appointment attendance could be improved by early referring towards ancillary services. Factors involving socioeconomics still hinder to access such services even if they have been referred.²⁰ In low and middle income countries, despite multiple international organizations and cleft professionals have created concrete cleft treatment and speech therapy paradigms to cater shortage of services, specific speech requirements at individual cleft palate and cleft lip cases remained obscure.²¹ Compact cleft care is multidisciplinary team effort. In remote areas it could be efficiently provided but involving risks of perioperative morbidities. For sustainable delivery of effective and safe cleft palate and lip care in remote underserved areas, ten domains were defined: (1)Assessment of site (2) Community partnership establishment (3) Credentialing and team composition (4) preparing mission and team training (5) Implementing guidelines of operation safety checklist, quality assurance and protocols of emergency responses (6) Postoperative care both instant and long-term (7) Keeping medical record (8) Evaluation of outcomes (9) Provide education (10) Sustainability and building capacity.²²

CONCLUSION

At present in Lahore paediatric surgeons are mainly performing secondary cleft surgery but the overall procedure number remained small. However cleft palate team of Lahore was providing efficient services.

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REFERENCES

1. Jensen SW, Jensen ED, Kaminer-Levin G, Caro C, Stevens K. Presurgical cleft management of infants: A survey of ACPA approved and international cleft palate and craniofacial teams. *The Cleft Palate-Craniofacial J* 2022;1055665 6221109416.
2. Francisco I, Antonarakis GS, Caramelo F, Paula AB, Marto CM, Carrilho E, et al. Current treatment of cleft patients in Europe from a provider perspective: A cross-sectional survey. *Int J Environ Res Public Health* 2022;19(17):10638.
3. Hlongwa P, Dandajena T, Rispel L. Comparative analysis of healthcare provision to individuals with cleft lip and/or palate at specialised academic centres in South Africa. *South Afr Med J* 2019;109(6):426-30.
4. Vyas T, Gupta P, Kumar S, Gupta R, Gupta T, Singh HP. Cleft of lip and palate: A review. *J Family Med Primary Care* 2020;9(6):2621.
5. Viswanathan A, Patel N, Vaidyanathan M, Bhujel N. Utilizing teledentistry to manage cleft lip and palate patients in an outpatient setting. *The Cleft Palate-Craniofacial J* 2022;59(5):675-9.
6. Luzzi V, Zumbo G, Guaragna M, Di Carlo G, Ierardo G, Sfasciotti GL, et al. The role of the pediatric dentist in the multidisciplinary management of the cleft lip palate patient. *Int J Environmental Research Public Health* 2021;18(18):9487.
7. Kotlarek KJ, Benson M, Williams J. Current Practice Patterns and Training Pathways for Feeding Infants with Cleft Palate. *The Cleft Palate Craniofacial J* 2023;10556656231152358.
8. Madhoun LL, Crerand CE, Keim S, Baylis AL. Breast milk feeding practices and barriers and supports experienced by mother-infant dyads with cleft lip and/or palate. *The Cleft Palate-Craniofacial J* 2020;57(4):477-86.
9. Hlongwa P, Levin J, Rispel LC. Epidemiology and clinical profile of individuals with cleft lip and palate utilising specialised academic treatment centres in South Africa. *PloS One* 2019; 14(5):e0215931.
10. Lee J, Skolnick GB, Naidoo SD, Scheve S, Grellner C, Snyder-Warwick A, et al. Cost of cleft team care at an academic children's hospital. *The Cleft Palate-Craniofacial J* 2022;59(11):1428-32.
11. Ardouin K, Drake D, Popat S, Stock NM. Treatment experiences in adults born with cleft lip and/or palate: a whole of life survey in the United Kingdom. *The Cleft Palate-Craniofacial J* 2021;58(7):864-71.
12. Pfeifauf KD, Patel KB, Snyder-Warwick A, Skolnick GB, Scheve S, Naidoo SD. Survey of North American multidisciplinary cleft palate and craniofacial team clinic administration. *The Cleft Palate-Craniofacial J* 2019;56(4):508-13.
13. Reddy NK, Shah ND, Weissman JP, Chwa ES, Gosain AK. Evaluation of Global Cleft Care Initiatives Among the Top Searched Low-and Middle-Income Countries. *The Cleft Palate Craniofacial J* 2023;10556656231160399.
14. Gill NA, Fayyaz GQ, Bashir MM, Ganatra MA, Sohail M, Jan SN, et al. Primary pharyngeal flap with palate repair improves speech outcome in older children and adults: a comparative study. *Annals of Plastic Surg* 2021;86(5):540-6.
15. Memon A, Khidri FF, Waryah YM, Nigar R, Bhinder MA, Shaikh AM, et al. Association of MSX1 Gene Variants with Nonsyndromic Cleft Lip and/or Palate in the Pakistani Population. *The Cleft Palate Craniofacial J* 2023;1055665 6231185218.
16. Stock NM, Zucchelli F, Hammond V, Hudson N, Sell D. Facilitators and barriers to delivering an optimal specialist service: an example from cleft lip and/or palate care. *Br J Healthcare Management* 2022;28(8):1-10.
17. Frederick R, Hogan AC, Seabolt N, Stocks RMS. An ideal multidisciplinary cleft lip and cleft palate care team. *Oral Diseases* 2022;28(5):1412-7.
18. Trivedi PB, Padovano WM, Skolnick GB, Menezes MD, Grames LM, Cheung S, et al. Evaluation of Discipline-Specific Outcomes Through a Multidisciplinary Team Clinic for Patients With Isolated Cleft Palate. *The Cleft Palate-Craniofacial J* 2021;58(12):1517-25.
19. McWilliams D, Costa B, Blighe S, Swan MC, Hotton M, Hudson N, et al. The Impact of the Covid-19 Pandemic on Cleft Lip and Palate Service Delivery for New Families in the United Kingdom: Medical and Community Service Provider Perspectives. *The Cleft Palate Craniofacial J* 2023;60(5):551-61.
20. Kay HG, Lipscomb B, Zhao S, Shannon C, Phillips JD. Utilization of part C early intervention services for patients with cleft palate. *Int J Pediatr Otorhinolaryngol* 2021;151:110961.
21. Baigorri M, Crowley CJ, Sommer CL, Moya-Galé G. Barriers and resources to cleft lip and palate speech services globally: a descriptive study. *J Craniofacial Surg* 2021;32(8):2802.
22. Chahine EM, Ramly EP, Marston AP, Teng SN, Nader M, Kassam SN, et al. Quality assurance standards for outreach cleft lip and cleft palate repair programs in low-resource settings. *The Cleft Palate Craniofacial J* 2023;60(6):773-9.