Prevalence and Outcomes of Newborns with Orofacial Clefts: A Facility-Based Surveillance Study in Karachi, Pakistan

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Introduction

Orofacial clefts (OFCs) affect 1 in 700 newborns globally, but in the absence of active newborn screening (NBS) programmes in low-middle-income countries, prevalence estimates are often derived from surgical data[1,2]. Presurgical outcomes are often undocumented, including mortality from unrepaired OFCs. We aimed to establish the prevalence of OFCs in a facility-based birth cohort and to determine the neonatal mortality in affected infants.

Methods

Health-worker-led NBS for external congenital anomalies was conducted from July 2023 to June 2024 at three facilities in Karachi, Pakistan. At the end of the neonatal period, a follow-up telephone interview was conducted to determine anomalies that manifest late and to record neonatal mortalities. Telephonic verbal autopsies were conducted to determine the cause of death.

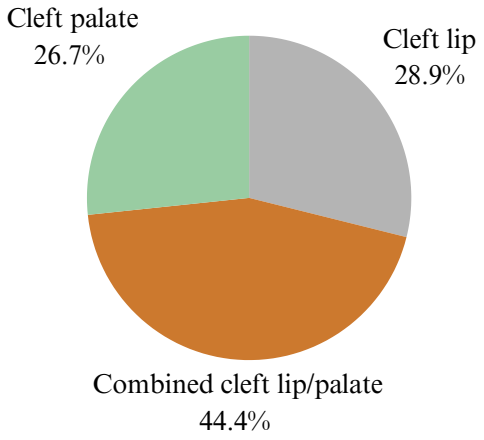
Results

Prevalence:

Of 18,728 births screened:

45 babies identified with OFCs

OFCs prevalence: 1 in 417 births



Outcomes:

One child was stillborn, and another died before the mother's hospital discharge. Of the 43 remaining babies, nine died during the neonatal period.

Overall mortality rate in babies born with OFCs: 24.4%

Pneumonia secondary to OFCs was determined to be the cause of death in five neonates, three succumbed to ***multiple anomalies***, while one was uncontactable

Conclusion

We document a higher prevalence of OFCs than previously reported, underlining the importance of NBS. Children with OFCs are at a high risk for malnutrition and infections, leading to mortality. Newborn pre-operative support is essential to ensure better outcomes.

[1]World Health Organization. Global registry and database on craniofacial anomalies: report of a WHO Registry Meeting on Craniofacial Anomalies, Baurú, Brazil, 4–6 December 2001. Geneva: World Health Organization; 2003.
[2]Bhide, P., & Kar, A. (2018). A national estimate of the birth prevalence of congenital anomalies in India: systematic review and meta-analysis. BMC pediatrics, 18(1), 175. https://doi.org/10.1186/s12887-018-1149-0