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Parental views of their child's care and experiences when a cleft lip and/or palate co-exists with a learning disability/need.

Bates, A.J., Forrester-Jones, R. and McCarthy, M.

Background

Increased difficulties are reported for children and young people (CYP) with additional condition(s) to a cleft lip and/or palate (CL±P) compared to CYP without additional needs. Little is known however about parental experiences of raising a child with additional conditions such as learning disabilities (LDs)/needs in addition to CL±P, therefore support needs are unknown.

Methods

Eighteen parents of CYP with CL±P, with and without LDs/needs were interviewed about cleft clinic/treatment experiences (including decision-making), and communication/information needs. Parents of CYP with LDs/needs were additionally asked about their cleft team's understanding of their child's needs. Thematic Analysis was employed to search for patterns across the dataset.

Findings

Three superordinate themes were found: family struggles, family resilience and promotion of rights. Family struggles (in hospital/school settings) were typically conveyed by parents of children with LDs/needs (particularly if their child was at a mainstream school, suggesting the significance of the school environment). Family resilience was mostly displayed by parents of children without LDs.

Parents of children with LDs/needs praised the individualized approach to their family displayed by cleft teams and Special Educational Needs and Disability (SEND) schools.

However, data additionally suggested that communication with families be improved within hospital environments.

Discussion

Families of CYP with CL±P and LDs/needs require more support to minimise distress and promote better experiences. Further research into communication/information/access needs in hospital/school environments would be a welcome gateway to such improvements.