

The experiences of children and young people with a learning disability/need and a cleft lip and/or palate

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Background

International research suggests 7%-18% of those born with a cleft lip and/or palate (CL±P) also have a learning disability (LD). However, there is no known UK research about the qualitative experiences of living with both conditions, so support needs are unknown.

Methods

Fifteen semi-structured interviews were conducted with CYP with CL±P, ten of whom had LDs/learning needs. Interview topics included cleft clinic experiences/treatment, self-perceptions and social activities. Thematic Analysis was used to identify data patterns.

Findings

Three superordinate themes were found: self-image, resilience and struggles. A range of self-image perceptions were described ('normal', otherness and positive), with bullying victims having a poor self-image. Resilience was evident for CYP without LDs (e.g. quality friendships, control over treatment). There was an association between school type (mainstream/Special Educational Needs and Disability (SEND) schools) and positive/negative experiences. CYP without LDs and CYP with LDs in SEND schools had more positive experiences than CYP with LDs/needs in mainstream schools who frequently reported difficulties. Difficulties encompassed bullying (resulting in a desire for surgery), and treatment burden (e.g. fear of needles/anaesthetic).

Discussion

Having LDs/learning needs were strongly linked with struggles (bullying and treatment burden). However, mediating factors such as how far CYPs' needs and rights were met in hospital and school were pivotal. Further research into these environmental influences, with a view to better supporting CYP with CL±P and LDs/needs, is welcomed.