

Project Number: CC017

Title: Evaluating the psychological wellbeing and behavioural development of children with cleft lip and/or palate at age 5 and 8

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Scientific Outline:

Background:

Cleft lip and/or palate (CLP) or orofacial cleft is a group of congenital birth defects affecting 1 in 700 newborns annually [1]. Commonly associated with structural problems relating to feeding, hearing, speech, and tooth development, recent research shows that affected individuals may also be at an elevated risk for psychological, social, and behavioral challenges [1],[2]. While many studies have sought to investigate the psychosocial effects of CLP, a 2005 systematic review was inconclusive, citing a dearth of longitudinal research and a lack of consistency and uniformity between studies [3]. In 2017, a Cleft Care UK study of five-year old children with unilateral CLP (UCLP) found that children born with UCLP had higher levels of behavioral problems than the general population, but that these findings required replication [1]. Researchers also suggest that children born with CLP may experience heightened psychosocial challenges around the school transition, and that this is worthy of investigation [1]. All of the contributing research cites a sufficient lack of large, longitudinal studies, focused on the psychological development of children born with CLP, and that this research is critical to the development of appropriate interventions for this population [1],[3].

Aims and Objectives:

- 1) Describe and summarize psychological and behavioural outcomes in five-year old children born with CLP using parent-reported SDQ data and compare to general population averages.
- 2) Describe and summarize psychological and behavioural outcomes in eight-year old children born with CLP using parent-reported SDQ data and compare to general population averages
- 3) Describe psychological and behavioural development patterns in children born with CLP during a three year period, between the ages of five and eight, and compare to general population
- 4) Evaluate outcomes and development by cleft subtype
- 5) Explore the potential predictors/confounders of psychological and behavioural outcomes, and developmental patterns (maternal age at birth, parity, parental smoking and alcohol consumption, parental wellbeing, socioeconomic position)

Methods:

The SDQ (Strength and Development Questionnaire) completed by parents for children born with CLP at ages 5 and 8 will be used to evaluate the psychological wellbeing and

Behavioural development of children [4]. Quantitative descriptive statistics will be used to describe the prevalence of psychological and behavioural issues across the five domains of the SDQ in children at two time points, and these summary statistics will be compared to national averages. For individuals with SDQ data at two time points, a longitudinal analysis will be undertaken to track changes.

References:

[1] Waylen A, Mahmoud O, Wills AK, Sell D, Sandy JR, Ness AR. Centre-level variation in behaviour and the predictors of behaviour in 5-year-old children with non-syndromic unilateral cleft lip: The Cleft Care UK study. Part 5. *Orthodontics & Craniofacial Research*. 2017;20(S2):40–7.

[2] Cleft lip and palate [Internet]. nhs.uk. 2017 [cited 2019 Apr 2]. Available from: <https://www.nhs.uk/conditions/cleft-lip-and-palate/>

[3] Hunt O, Burden D, Hepper P, Johnston C. The psychosocial effects of cleft lip and palate: a systematic review. *Eur J Orthod*. 2005 Jun;27(3):274–85.

[4] Bjerke SM, Feragen KB, Bergvik S. Strengths and Difficulties Questionnaire (SDQ): Informant Agreement Between Children Born With Cleft Lip and/or Palate and Their Parents. *Cleft Palate Craniofac J*. 2018;55(2):204–12.