

# Young Person and Parent Perspectives on the Impact of Cleft Lip and/or Palate within an Educational Setting

## Abstract

*Background:* During the school years, a cleft of the lip and/or the palate (CL/P) may pose a risk to educational achievement. To further understand this multifaceted association, and to offer suggestions as to how young people's educational experiences might be improved, qualitative investigation is warranted.

*Design:* Semi-structured telephone interviews were conducted with young people born with CL/P ( $n = 10$ ; aged 10-16 years) and their parents ( $n = 10$ ). The resulting data was subjected to inductive thematic analysis.

*Results:* Negative social interactions, cleft-related treatment, the presence of an additional condition and a lack of appropriate support from teachers was found to influence young people's educational experience. Methods for promoting diversity, support from clinical teams, facilitation of positive school transitions, implementation of training for teachers, and a holistic approach to the measurement of 'success' were suggested by participants as potential ways of improving this experience.

*Conclusions:* The findings of this study point to a need for a range of school-focused interventions, as well as the inclusion of a number of potentially impactful variables within future quantitative research.

*Key words:* cleft lip and palate, education, school, bullying, treatment, transition

## Introduction

Educational experiences contribute significantly to a young person's development (Tuckman and Monetti, 2010). In the longer term, academic achievement is strongly associated with physical health, psychological wellbeing, employability and higher earnings (OECD, 2006), and has implications which play out on an individual, institutional and population level (Needham et al., 2004). One of the risks to academic achievement during childhood and adolescence is the presence of a condition requiring long-term management and intervention (Taras and Potts-Datema, 2005). Although many young people with such conditions cope well with the associated medical, social and emotional challenges, at least one third are likely to experience difficulties, such as absences from school and poor attainment, as well as low self-esteem, social withdrawal, anxiety and depression (Mukherjee et al., 2000; Kaffenberger, 2006).

One condition posing a variety of ongoing challenges for those affected and their families is cleft lip and/or palate (CL/P; see Stock and Feragen, 2016; Nelson et al., 2012 for a review). In recent years, research into the impacts of CL/P has identified a concerning trend in relation to educational outcomes. Specifically, individuals born with CL/P appear to perform more poorly in school than their unaffected peers, both in terms of actual achievement (Snyder and Pope, 2010; Persson et al., 2012; Wehby et al., 2014; Knight et al., 2015; Aravena et al., 2017), and in relation to their confidence in their own academic abilities (Gussy and Kilpatrick, 2006; Broder et al., 2012). According to some studies, young people with CL/P are more likely to be engaged in special educational services and to repeat a grade than their peers who were born without a cleft (Damiano et al., 2006; Collett et al., 2010; Hentges et al., 2011; Wehby et al., 2014; Lorot-Marchand et al., 2015). Further, research has identified a high incidence of difficulties related to expressive language and verbal memory among

individuals born with CL/P, which may impact upon learning (see Richman et al., 2012 for a review).

Interestingly, other studies have found scores of academic ability and perceived scholastic competence to be similar to or better than unaffected comparison groups. For example, no statistically significant group differences were found between participants with and without CL/P in either academic performance or academic self-esteem in two studies (Cheung et al., 2007; van der Plas et al., 2013). When compared to their unaffected siblings, children with CL/P performed similarly on various tests of academic achievement, including reading, language, math and science (Collett et al., 2014). In two further studies, 16-year-olds with CL/P reported comparable scholastic competence scores to an age-matched reference group (Feragen et al., 2015), and both patients and their parents reported the impact of CL/P on school/professional life to be minor (Gkantidis et al., 2015).

Taken together, these findings suggest that the association between conditions such as CL/P and academic achievement is likely to be multifaceted. While these questions may therefore be best addressed through comprehensive longitudinal studies (see Stock et al., 2016 for an example), qualitative research may also shed light on some of the intricacies of this relationship, by delving deeper into patients' and parents' experiences in context. Despite the widespread acknowledgement that qualitative investigation can make a significant and complementary contribution to knowledge, particularly in an area where quantitative findings have produced conflicting accounts, relatively few studies in the field of CL/P have taken this approach (Nelson, 2009; Stock and Feragen, 2016). This paucity of qualitative research is particularly evident in relation to young people with CL/P (Sharif et al., 2013), and even more so when compared to other fields of healthcare. Further, previous research exploring the views of patients and parents has tended to focus on the early years, resulting in little knowledge of the potential challenges faced by parents and young people who are further

along the treatment pathway (Nelson et al., 2012). Crucially, as well as identifying potential risk factors for poor educational outcomes, there is a need to investigate possible protective factors, and to offer clear suggestions for how young people's educational experience might be improved.

The present study aimed to explore the impact of CL/P during the school years, and any support needs, from the perspectives of young people born with CL/P and their parents. Specifically, this study aimed to address two key research questions:

- 1) What factors might influence academic outcomes in the context of CL/P?
- 2) What methods of support could improve young people's educational experience?

## **Materials and Methods**

### ***Ethical Considerations***

Ethical approval was granted by the Faculty Research Ethics Committee at (*university*). The ethical guidelines of the British Psychological Society were followed at all times.

### ***Design***

This study utilised an inductive, qualitative approach. Drawing upon current knowledge from the immediate and broader health fields, a semi-structured interview schedule was created by the first author, and discussed with various colleagues. Interview questions for both parents and young people encompassed a broad range of topics, focused on the school setting. This included: interactions with peers, satisfaction with appearance and speech, cleft-related treatment, perceptions of educational achievement, relationships with teachers, vocational aspirations, and the availability of and satisfaction with any support received. Individual interviews were conducted with young people and their parents over the telephone.

Participants were asked open-ended questions, and were prompted to provide more details where appropriate.

### ***Participants***

Participants in this study included young people ( $n = 10$ ; aged 10-16 years, mean age = 13 years) and their parents ( $n = 10$ ; seven mothers and three fathers; aged 38-47 years, mean age = 42 years). All of the young people who participated in the study attended a state primary or secondary school. Six young people were female, while four were male. The majority of the young people who took part had been born with a unilateral cleft lip and palate (UCLP;  $n = 7$ ), while three had been born with a bilateral cleft lip and palate (BCLP). As reported by the participants themselves, five young people had some level of hearing difficulty, while speech was of some concern for four young people. Five of the ten parents had achieved a bachelor's degree or equivalent, one parent had achieved a doctoral qualification, and four parents had received post-secondary tertiary education. Eight parents were in employment at the time of interview, while two mothers stated their occupation as 'housewife'. Of the ten participating families, five had a history of CL/P in the immediate or extended family, while five had no known history of CL/P. Nine of the ten families stated that they were White British, while one family reported their ethnicity to be Indian (Hindu).

### ***Procedure***

Potential participants were approached via advertisements published on relevant websites and social media, such as that belonging to the UK-based charity, the Cleft Lip and Palate Association. A press release calling for participants was also disseminated through the (*university*), and the study was subsequently advertised via national and local media. Potential participants who expressed an interest in the study were sent a Participant Information Sheet, containing further details about what participation in the study would

entail, and key ethical information such as confidentiality and their right to withdraw. Those choosing to take part were asked to provide some basic demographic information and a handwritten, signed consent form. In the case of young people (all under the age of 18), consent from a parent/caregiver was also sought.

Telephone interviews were conducted by both authors, who are trained in qualitative methods. On average, interviews with parents lasted approximately 53 minutes, while interviews with young people were 38 minutes in length. Following the guidance provided by Braun and Clarke (2006), inductive thematic analysis was carried out by both authors independently, and discussed until agreement upon the key themes was reached.

## **Results**

In regard to potential factors influencing academic outcomes, four themes were identified: Social Experiences; Cleft-Related Treatment; Additional Conditions; and Support from Teachers. Five further themes were identified in relation to possible methods of support: Dealing with ‘Difference’ and Promoting Diversity; Support from the Clinical Team; Facilitating School Transitions; Teacher Training; and Assessing Achievement Holistically. Each theme is described in further detail and illustrated using exemplar quotes below (also see Figure 1). All participants have been assigned pseudonyms to preserve anonymity.

### ***What factors might influence academic outcomes in the context of CL/P?***

#### Social Experiences

Young people who participated in this study described a feeling of being ‘different’ to their peers, which in turn had a detrimental effect on their ability to ‘fit in’.

*“At school there are different levels of popularity...people don’t really accept anyone with a difference, so I am basically at the bottom of the pile”* – Katie (15-year-old with UCLP).

Participants also described instances of teasing and bullying related to their/their child’s condition.

*“I get bullied quite a lot...people ask questions, make fun of me, start mimicking me...you get used to it after a time and learn to ignore it, but it can be very hard”* – James (12-year-old with BCLP).

*“[The kids] were taking close-up pictures of [my son’s] face and putting them on Snapchat to send around the school”* – Ralph (father).

Challenging social experiences were most likely to occur following the transition from primary school to secondary school.

*“When I went to [secondary school], straight away there were 50 or 60 new people that I had to explain [my condition] to...sometimes you don’t want to talk about it and it can just get frustrating”* – Amy (13-year-old with UCLP).

In turn, negative social experiences appeared to impact upon young people’s self-confidence.

*“[My daughter] definitely lacks self-confidence... I don’t think she feels she is as good as everybody else. And that can definitely show in her school work”* – Debbie (mother).

### Cleft-Related Treatment

Participants described ongoing CL/P-related treatment to be distressing at times.

*“Sometimes you just wake up and think ‘well what’s going to be next? When am I going to be told I need another operation? When is it going to stop?’”* – Amy (13-year-old with UCLP).

*“In the lead up to the operation [my daughter] didn’t want to speak about it [bone graft surgery] ...She would slam the door and cry whenever it was mentioned” – Nadia (mother).*

Taking time out of school for cleft-related treatment could also be seen as a burden.

*“Going to hospital appointments is annoying, because I miss most of the school day and have to catch up” – James (12-year-old with BCLP).*

*“[The schools] go on about attendance which is a worry...they need to have a certain percentage otherwise someone will come knocking at your door” – Nadia (mother).*

### Additional Conditions

Participants highlighted the potential impact of additional conditions (including hearing problems, speech difficulties and learning disabilities) known to be related to CL/P. The most common additional condition to cause problems in the school environment among participating families was hearing difficulties.

*“Her hearing has been the biggest issue...when you’re in a class environment and there’s lots of noise it must be very difficult” – Megan (mother).*

Speech difficulties were also thought to impact upon some aspects of academic life, such as in the case of oral examinations.

*“My oral tests is where I drop marks because of my speech...it does make me think that actually I haven’t done well...and why am I bothering? I’m failing, I’m a failure” – Amy (13-year-old with UCLP).*

Two families also alluded to the possible presence of additional learning needs, although this had not been formally assessed in either case.



*“We did think [our daughter] might be dyslexic...she often gets her opposites confused...if you got her to describe a picture she would just come out with the bare basics, those little things”* – Nadia (mother).

*“I would say [my daughter] generally struggles with comprehension and spelling...apart from a few extra lessons in Year 4 [age 8]...there’s never been anything done”* – Simon (father).

### Support from Teachers

Although some teachers were seen to be supportive, participants believed that teachers’ understanding of CL/P could be improved.

*“Teachers might know what [a cleft] is, they might see it on the surface, but I don’t think they understand the intricacies of it”* – Max (16-year-old with UCLP).

As a result, parents had actively sought to raise awareness of their child’s condition within the school.

*“I’ve always gone in to the school and explained what a cleft is, what it means...I think it’s important to make [teachers] aware”* – Debbie (mother).

Nonetheless, parents had found communication with the school to be a challenge at times.

*“We were constantly calling, sending emails...and thinking ‘how many more times do we have to do this?’ Teachers come and go, so you have to repeat yourself...it was all very hit and miss”* – Sandra (mother).

Four parents also perceived teachers’ responses to bullying to be unsatisfactory.

*“They’ve got all these anti-bullying policies in place but I don’t think they really work to be honest with you”* – Ralph (father).

### ***What methods of support could improve young people's educational experience?***

#### Dealing with 'Difference' and Promoting Diversity

Participants felt there was a need for strategies to help young people address comments and questions surrounding CL/P and its treatment.

*"The first time someone asked [my daughter] about her lip, it came as a complete shock...she obviously had no idea what to say...something around that, either for the children themselves or for the parents so that we can pass that information down would be good"* – Debbie (mother).

Three young people had been encouraged to give a presentation in a school assembly, to talk about their cleft and any upcoming operations.

*"I had my operation coming up and I was scared what everyone would think, so my teacher said I could give a presentation to my school... These girls came up to me afterwards and said how brave I was...that made me feel really good"* – Emily (14-year-old with UCLP).

However, participants felt that striking a balance between providing appropriate support, while not overly drawing attention to 'differences' was important.

*"If [my son] is having difficulties with anything his teachers will help him out...but it's subtle...he's not outwardly treated differently from anyone else at the school"* – Michael (father).

#### Support from the Clinical Team

Participants felt that increased input from the clinical teams would help to tackle school-based issues more effectively.

*“I often think it would be nice for the cleft team to communicate more with the school...everyone would be better informed...it wouldn't be us trying to manage everything on our own” – Megan (mother).*

*“The Psychologist in the cleft team wrote the school a letter to explain that [my daughter] might need extra support because of her cleft...we now get the most amazing pastoral care...that's all thanks to the Psychologist getting involved” – Simon (father).*

Participants also believed that the clinical teams could do more to support the identification of additional conditions which may affect learning.

*“[The school] now thinks that [my daughter] might have dyslexia...she's 14 now and we're still waiting to get an assessment...I get quite upset when I think what difference it could have made to her learning if it had been picked up earlier [by the clinical team]” – Nadia (mother).*

### Facilitating School Transitions

Parents commented on the challenge of choosing a school that would best meet their child's additional needs.

*“I don't regard [cleft] as a disability per se, but it does come with its challenges... As a parent it is difficult to know what to do for the best. There are so many schools but they are all different and all have a different feel” – Jenny (mother).*

Participants believed that young people could be much better supported to make the transition from primary to secondary school.

*“There wasn't much dialogue between the two schools...they didn't think of organising a visit. There was nothing written down either, no information that I can remember” – Max (16-year-old with UCLP).*

## Teacher Training

Participants expressed their appreciation for the support that some teachers had provided.

*“[The school] has been exceptionally positive...the teachers have been very proactive in getting hold of all sorts of information...to find out what they can do to support [my son] and us as a family”* – Michael (father).

This was particularly the case in regard to upcoming operations.

*“When [my son] went in for his operation, the teacher rallied round and got everyone in the class to send ‘get well’ cards... [My son] got a lot of positive attention as a result of that”* – Jenny (mother).

*“My head teacher was really nice...after my operation she gave me some homework and some time to catch up on what I missed”* – Leo (10-year-old with UCLP).

Nonetheless, all participants felt that teachers could benefit from training in relation to CL/P, its effects and its treatment.

*“It would be good if my teachers understood what all my appointments are for, and understand why I have to miss lessons”* – James (12-year-old with BCLP).

*“There would be definitely be benefits to teachers knowing more about cleft...they are important figures in the children’s lives and could have a key role in supporting them with day-to-day issues”* – Nadia (mother).

## Assessing Achievement Holistically

Due to the potential impacts of CL/P and its associated conditions, parents believed that traditional methods of assessing academic achievement (i.e. written examinations in core

subjects, including English, mathematics and science) did not capture young people's skills and learning holistically.

*"[My daughter] does OK in tests, but it's not her strength... She is a great ideas person...she's very sharp and bright, but not academically bright, which is different"* – Debbie (mother).

*"We do have a very traditional education system...it's Maths, English and Science and that's what all the grades and statistics are based on...not education in a broader sense"* – Sandra (mother).

Young people in this study also believed that education should be approached in a more holistic way.

*"I'm much more than a grade on a piece of paper...but at school it can feel a bit like that's all that counts"* – Amy (13-year-old with UCLP).

*"Outside of school I do lots of sports...in the summer I go to a drama club...it would be good if these things were part of school though because that's the stuff I'm really good at"* – Leo (10-year-old with UCLP).

Participants did not believe that having a cleft should impact in any way on young people's aspirations for the future.

*"I don't think I'm better than anyone, but I'm no worse either...I have the same aspirations as everyone else... Just because you've got a cleft you shouldn't be told you can't do stuff. I think that if you want something, you should go for it"* – Amy (13-year-old with UCLP).

## **Discussion**

This study is one of the first to qualitatively explore the impact of CL/P within the school setting, and potential methods of support, from the perspective of both young people and their

parents. Participants highlighted a range of challenges related to social experiences, cleft-related treatment, and the presence of an additional condition. Participants felt that the promotion of diversity within schools, improved communication between schools and clinical teams, the provision of cleft-specific training for teachers, and the adoption of a more holistic approach to the measurement of 'success' could all help to improve young people's educational experiences. The findings of the present study offer suggestions for a range of school-focused interventions, and future research in this area.

### Promoting Diversity

Questions, comments, teasing and social exclusion appeared to be a common challenge for participants in this study, and resulted in some young people feeling 'different' to their peers. This finding corroborates the insights of previous qualitative work with adolescents and adults with CL/P (Alansari et al., 2014; Chetpakdechit et al., 2009; Havstam et al., 2011; Tiemens et al., 2013), and contributes the suggestion that negative social experiences associated with CL/P may impact upon education. A better awareness of the condition and its treatment among school pupils may help to increase young people's feelings of social acceptance. One example of how this could be achieved is through a school assembly, as highlighted by the findings of this study. Alternatively, and so as not to draw unwanted attention to the condition, schools could consider running lessons or workshops which tackle issues of 'difference' but that apply to the class as a whole. Examples of this include school-based interventions which promote diversity, challenge societal perceptions of beauty, and tackle issues of bullying (*see* Diedrichs and Halliwell, 2013). In addition, clinical interventions which help young people to cope with unwanted attention due to their 'difference' may be beneficial. Examples include clinical guides such as those developed by Clarke and colleagues (2013), online intervention programmes such as YP Face IT

(Williamson et al., 2015), and materials provided by charitable organisations such as Changing Faces ([www.changingfaces.org.uk](http://www.changingfaces.org.uk)).

### Improving School Transitions

The transition to secondary school is a key event during middle childhood. As indicated by the findings of the current study, young people with CL/P and their parents may feel anxious and unprepared for this change. While these concerns may be similar to the apprehension experienced by all children during this time (Zeedyk et al., 2003), the cleft and its treatment may serve to heighten fears of social rejection (Marshman et al., 2009). In addition to routine psychological assessments, ‘school change days’ which provide strategies for dealing with the transition, such as those hosted by some of the UK clinical teams, may be of considerable benefit to both young people with CL/P and their parents (e.g. Holman and Keen, 2012). In addition, schools could provide written information about the school setting, and offer opportunities for pupils to visit, in order to ease the transition for all pupils; particularly those who may be most vulnerable.

### Managing Medical Issues

For some young people with CL/P, cleft-related treatment will form a significant part of their childhood. According to the findings of this study, schools may need to be appreciative of necessary school absences, and be aware that treatment may provoke emotional distress. On the other hand, an upcoming surgical procedure may present an opportunity for the school and its pupils to learn more about CL/P, as well as for the young person themselves to speak openly about their condition and to receive positive attention from teachers and peers. Additional support may be required following surgical procedures, such as helping the young person catch up on any missed learning objectives, and offering a phased return to school. Further, schools may need to provide additional support to young people with additional

conditions, such as hearing difficulties (*see* [www.NDCS.org.uk](http://www.NDCS.org.uk)) and any additional learning needs. A high prevalence of additional conditions (such as hearing difficulties, speech and language impairments, and developmental delay) has been found among young people with CL/P (Feragen et al., 2014); conditions which have been demonstrated to impact upon several areas of psychological functioning (Feragen and Stock, 2014). It is therefore necessary for both the school and the cleft team to play a role in identifying and managing such conditions. Routine screening may pick up any areas of concern from a young age, allowing for early intervention and the establishment of appropriate school-based support, such as classroom hearing aids, local speech and language therapy, and additional learning opportunities. Research with young people with more severe learning difficulties in addition to the cleft, and how to support them within the school setting is also needed (Bates, 2012).

#### Training Provision for Teachers

Although there were instances of young people and their parents receiving positive support from schools in this study, all participants felt that teachers' knowledge of and approach to cleft-related issues could be improved. Previous texts have also discussed the need for school staff to be aware of the issues around visible (and invisible) health conditions such as CL/P (Frances, 2004; Venville et al., 2016). Although CL/P is one condition among many, a recent study specifically investigating teachers' views of CL/P found that teachers may also appreciate a level of training in this area (paper in press, 2017). Further investigation of the preferred content of such training materials, as well as an evaluation of their acceptability and effectiveness, is warranted. In addition, providing schools with evidence-based, standardised information packs about CL/P, as well as establishing good communication between schools and the health professionals involved in young people's care (Mukherjee et al., 2002) could be beneficial.



### Conceptualising 'Success'

Interestingly, many participants in this study commented on the way in which school 'success' is conceptualised and measured. Specifically, participants believed that academic ability, as measured by traditional examination methods, is valued above other skills and achievements, such as sports and the arts. Given the growing importance of school pastoral services, which provide emotional and practical support and guidance to children with additional needs (O'Higgins et al., 2014) and the emphasis on the development of each child's personalities and talents to the fullest (UNICEF, 2012), school-based research could consider whether a more holistic approach to the measurement of 'success' and 'achievement' might be informative in the future.

### Methodological Considerations

This study used semi-structured interviews which were conducted over the telephone. This is an established and flexible method of investigation with adults, allowing for in-depth exploration of a topic without geographical limitations and the costs associated with travel (see Burke and Miller, 2001). However, in the future, alternative methods may be more appropriate in understanding the experiences of young people. This could include interviews via Skype, as well as more novel methods, such as photography, drawing, videos, or keeping a journal (see Harcourt, 2013).

The sample size of this study, even in the case of qualitative research, is relatively small. While the sample size is predominantly based upon theoretical saturation, this study was also limited by funding and time restraints. The findings of this study should therefore be considered to be an important but exploratory step in understanding more about the education experiences of young people with CL/P, to be corroborated by further research.

Unlike in the present study, it is relatively rare within CL/P research for qualitative studies to seek more than one perspective. Although the views of parents and young people were found to be similar overall, some minor discrepancies, such as the frequency of teasing (with young people reporting a higher incidence of teasing than their parents), and how well the young people were doing academically (with young people rating their achievements more highly than their parents), were noted in three of the ten cases. Incongruities in the views of patients, parents and health professionals have previously been acknowledged within the field (e.g. Nelson and Kirk, 2013), and future studies could therefore consider including different perspectives where possible. Further, data collection could potentially be expanded to include a third source, so that data can be triangulated.

## **Conclusions**

In addition to existing successful school-based approaches, the findings of this study highlight a number of school-based challenges with the potential to impact upon young people's educational experiences. These findings point to a need for a range of school-focused interventions. In particular, the development of training materials for teachers, an emphasis on routine clinical screening for additional conditions, and practical and psychological support around the time of important school transitions is warranted. Future research into the impact of CL/P in an educational context could consider the inclusion of a number of potentially impactful variables: perceptions of negative and positive social experiences, self-confidence, burden of treatment, school absences, the presence of an additional condition, perceived support from teachers and members of the clinical team, satisfaction with school transitions, attainment in a broad range of subjects, and the impact of CL/P on future aspirations. This study also illustrates the value of incorporating qualitative approaches when addressing complex and multifaceted research questions.

## Declaration of Interest Statement

No financial interests or benefits have arisen from the direct applications of this research.

## References

- Alansari R, Bedos C, Allison P. Living with cleft lip and palate: The treatment journey. *Cleft Palate Craniofac J.* 2014;51:222-229.
- Aravena PC, Gonzalez T, Oyarzun T, Coronado C. Oral health-related quality of life in children in Chile treated for cleft lip and palate: A case-control approach. *Cleft Palate Craniofac J.* 2017;54:e15-e20.
- Bates A. Intellectual disability and cleft lip/palate: Young people's appearance self-perceptions and psychosocial experiences. Presented at the IASSID World Congress; July 2012; Halifax, Canada.
- Berger ZE, Dalton LJ. Coping with a cleft: Psychosocial adjustment of adolescents with a cleft lip and palate and their parents. *Cleft Palate Craniofac J.* 2009;46:435-443.
- Berkowitz S. *Cleft Lip and Palate: Diagnosis and Management (3rd ed.)*. Berlin Heidelberg: Springer-Verlag, 2013.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research Psychol.* 2006;3:77-101.
- Broder HL, Wilson-Genderson M, Sisco L. Health disparities among children with cleft. *Am J Pub Health.* 2012;102:828-830.

- Burke LA, Miller MK. Phone interviewing as a means of data collection: Lessons learned and practical recommendations. *Qualitative Social Research*. 2001;2:Article 7. Accessed on 2<sup>nd</sup> December 2016 at: <http://www.qualitative-research.net/index.php/fqs/article/%20view/959/2094>.
- Cadogan J, Bennun I. Face value: An exploration of the psychological impact of orthognathic surgery. *Br J Oral Maxillofac Surg*. 2011;49:376-380.
- Chetpakdeechit W, Hallberg U, Hagberg C, Mohlin B. Social life aspects of young adults with cleft lip and palate: Grounded Theory approach. *Acta Odontologica Scandinavia*, 2009;67:122–128.
- Cheung LK, Loh JSP, Ho SMY. The early psychological adjustment of cleft patients after maxillary distraction osteogenesis and conventional orthognathic surgery: A preliminary study. *J Oral Maxillofac Surg*. 2006;64:1743–1750.
- Clarke A, Thompson AR, Jenkinson E, Rumsey N, Newell R. *CBT for appearance anxiety: Psychosocial interventions for anxiety due to visible difference*. Chichester: John Wiley & Sons, 2013.
- Collett BR, Leroux B, Speltz ML. Language and early reading among children with orofacial clefts. *Cleft Palate Craniofac J*. 2010;47:284–292.
- Collett BR, Wehby GL, Barron S, Romitti PA, Ansley TN, Speltz ML. Academic achievement in children with oral clefts versus unaffected siblings. *J Pediat Psychol*. 2014;39:743-751.
- Damiano PC, Tyler MC, Romitti PA, Momany ET, Canady JW, Karnell MP, Murray JC. Type of oral cleft and mothers' perceptions of care, health status and outcomes for preadolescent children. *Cleft Palate Craniofac J*. 2006;43:715–721.

- Diedrichs PC, Halliwell E. School-based interventions to promote positive body image and the acceptance of diversity in appearance. In: N Rumsey, D Harcourt, eds. *The Oxford Handbook of the Psychology of Appearance*. Oxford: Oxford University Press, 2013: 531-550.
- Feragen KJB, Stock NM. When there is more than a cleft: Psychological adjustment when a cleft is associated with an additional condition. *Cleft Palate Craniofac J*. 2014;51:5-14.
- Feragen KJB, Stock NM, Rumsey N. Toward a reconsideration of inclusion and exclusion criteria in cleft lip and palate: Implications for psychological research. *Cleft Palate-Craniofacial Journal*. 2014;51:569-578.
- Feragen, KJB, Stock NM, Kvalem I. Risk and protective factors at age 16: Psychological adjustment in children with a cleft lip and/or palate. *Cleft Palate Craniofac J*. 2015;52:555-573.
- Frances J. *Educating children with facial disfigurement: Creating inclusive school communities*. London: Routledge Falmer, 2004.
- Gkantidis N, Papamanou DA, Karamolegkou M, Dorotheou D. Esthetic, functional and everyday life assessment of individuals with cleft lip and/or palate. *BioMed Research Int*. 2015;510395:e1-8.
- Gussy M, Kilpatrick N. The self-concept of adolescents with cleft lip and palate: A pilot study using a multidimensional/hierarchical measurement instrument. *Int J Pediatr Dentistry*. 2006;16:335-341.
- Harcourt D. Using novel methods in appearance research. In: N Rumsey, D Harcourt, eds. *The Oxford Handbook of the Psychology of Appearance*. Oxford: Oxford University Press, 2013: 645-657.

- Havstam C, Laakso K, Ringsberg KC. Making sense of the cleft: Young adults' accounts of growing up with a cleft and deviant speech. *J Health Psychol.* 2011;16:22-30.
- Hearst D, Middleton JA, Owen T, Zefferett A. *Teasing and bullying in children with clefts: A framework for formulation.* United Kingdom: Cleft Special Interest Group, 2008.
- Hentges F, Hill J, Bishop DVM, Goodacre T, Moss T, Murray L. The effect of cleft lip on cognitive development in school-aged children: A paradigm for examining sensitive period effects. *J Child Psychol Psychiatry.* 2011;52:704–712.
- Holman N, Keen C. School Change Day. Presented at the North West England, the Isle of Man and North Wales Cleft Lip and Palate Network meeting; June 2012; Manchester, United Kingdom.
- Hunt O, Burden D, Hepper P, Johnston C. The psychosocial effects of cleft lip and palate: A systematic review. *European J Orthod.* 2005;27:274-285.
- Kaffenberger CJ. School re-entry for students with a chronic illness: A role for professional school counsellors. *Professional School Counselling,* 2006;9:223-230. Accessed on 27<sup>th</sup> November 2016 at: <http://eric.ed.gov/?id=EJ743335>.
- Knight J, Cassell CH, Meyer RE, Strauss RP. Academic outcomes of children with isolated orofacial clefts compared with children without a major birth defect. *Cleft Palate Craniofac J.* 2015;52:259-268.
- Lorot-Marchand A, Guerreschi P, Pellerin P, Martinot V, Gbaguidi CC, Neiva C., Devauchelle B, Frochisse C, Poli-Merol ML, Francois-Fiquet C. Frequency and socio-psychological impact of taunting in school-age patients with cleft lip-palate surgical repair. *Int J Pediatr Otorhinolaryngol.* 2015;79:1041–1048.

- Marshman Z, Baker SR, Bradbury J, Hall MJ, Rodd HD. The psychosocial impact of oral conditions during transition to secondary education. *European J Pediatr Dentistry*. 2009;10:176-180. Accessed on 27<sup>th</sup> November 2016 at: <http://admin.ejpd.eu/download/2009-04-03.pdf>.
- Mukherjee S, Lightfoot J, Sloper P. The inclusion of pupils with a chronic health condition in mainstream school: What does it mean for teachers? *Educational Research*. 2000;42:59-72.
- Mukherjee S, Lightfoot J, Sloper P. Communicating about pupils in mainstream school with special health needs: The NHS perspective. *Child Care Health Dev*. 2002;28:21-27.
- Needham BL, Crosnoe R, Muller C. Academic failure in secondary school: The inter-related role of health problems and educational context. *Social Problems*. 2004;51:569-586.
- Nelson P. Qualitative approaches in craniofacial research. *Cleft Palate Craniofac J*. 2009;46:245–251.
- Nelson P, Glenny A-M, Kirk S, Caress A-L. Parents' experiences of caring for a child with a cleft lip and/or palate: A review of the literature. *Child Care Health Dev*. 2012;38:6-20.
- Nelson P, Kirk SA. Parents' perspectives of cleft lip and/or palate services: A qualitative interview. *Cleft Palate Craniofac J*. 2013;50:275-285.
- O'Higgins Norman J, Martin M, Lewis CA, Pimlott N. *Education matters: Readings in pastoral care for school chaplains, guidance counsellors and teachers*. Ireland: Veritas Publications, 2014.
- OECD. *Measuring the effects of education on health and civic engagement: Proceedings of the Copenhagen symposium*. 2006. Accessed on 15<sup>th</sup> November 2016 at: <https://www.oecd.org/edu/innovation-education/37437718.pdf>.

- Persson M, Becker M, Svensson H. Academic achievement in individuals with cleft: A population-based register study. *Cleft Palate Craniofac J.* 2012;49:153-159.
- Richman LC, McCoy TE, Conrad AL, Nopoulos PC. Neuropsychological, behavioural and academic sequelae of cleft: Early developmental, school age and adolescent/young adult outcomes. *Cleft Palate Craniofac J.* 2012;49:387-396.
- Sharif MO, Callery P, Tierney S. The perspectives of children and young people with cleft lip and palate: A review of qualitative literature. *Cleft Palate Craniofac J.* 2013;50:297-304.
- Shavel-Jessop S, Shearer J, McDowell E, Hearst D. Managing teasing and bullying. In: S Berkowitz, ed. *Cleft Lip and Palate: Diagnosis and Management (3rd edition)*. New York: Springer Heidelberg, 2013: 917-926.
- Snyder H, Pope AW. Psychosocial adjustment in children and adolescents with a craniofacial anomaly: Diagnosis-specific patterns. *Cleft Palate Craniofac J.* 2010;47:264–272.
- Stock NM, Feragen KJB. Psychological adjustment to cleft lip and/or palate: A narrative review of the literature. *Psychol & Health.* 2016;31:777-813.
- Stock NM, Humphries K, St Pourcain B, Bailey M, Persson M, Ho KM, Ring S, Marsh C, Albery L, Rumsey N, Sandy J. Opportunities and challenges in establishing a cohort study: An example from cleft lip/palate research in the United Kingdom. *Cleft Palate Craniofac J.* 2016;53:317-325.
- Taras H, Potts-Datema W. Chronic health conditions and student performance at school. *J School Health.* 2005;75:255-266.
- Tiemens K, Nicholas D, Forrest CR. Living with difference: Experiences of adolescent girls with cleft lip and palate. *Cleft Palate Craniofac J.* 2013;50:e27-e34.



Tuckman B, Monetti D. *Educational Psychol*. Belmont, USA: Wadsworth, 2010.

UNICEF *Fact sheet: A summary of the rights under the Convention on the Rights of the Child*, 2012. Accessed on 13<sup>th</sup> November 2016 at: [http://www.unicef.org/crc/files/Rights\\_overview.pdf](http://www.unicef.org/crc/files/Rights_overview.pdf).

van der Plas E, Conrad A, Canady J, Richman L, Nopoulos P. Effects of unilateral clefts on brain structure. *Arc Pediatr Adol Med*. 2010;164:763–768.

Venville A, Mealings M, Ennals P, Oates J, Fossey E, Douglas J, Bigby C. Supporting students with invisible disabilities: A scoping review of postsecondary education for students with mental illness or an acquired brain injury. *Int J Disability Dev Education*. 2016;63:571-592.

Watterson T, Macini MC, Brancamp TU, Lewis KE. Relationship between the perception of hypernasality and social judgments in school-aged children. *Cleft Palate Craniofac J*. 2013;50:498-502.

Wehby GL, Collett B, Barron S, Romitti PA, Ansley TN, Speltz M. Academic achievement of children and adolescents with oral clefts. *PEDIATRICS*. 2014;133:785-792.

Williamson H, Griffiths C, Harcourt D. Developing Young Person's Face IT: Online psychosocial support for adolescents struggling with conditions or injuries affecting their appearance. *Health Psychol Open*. 2015;2: 2055102915619092.

World Health Organization. *Oral Health (Fact Sheet No. 318)*, 2012. Accessed on 13<sup>th</sup> November at: <http://www.who.int/mediacentre/factsheets/fs318/en>.

Zeedyk MS, Gallacher J, Henderson M, Hope G, Husband B, Lindsay K. Negotiating the transition from primary to secondary school: Perceptions of pupils, parents and teachers. *School Psychol Int*. 2003;24,67-79.

NB. One reference has been removed for the purpose of maintaining author anonymity.

**Figure 1:** A thematic map of the identified themes and subthemes