

Risks associated with delays to cleft lip & palate surgery - lip revision surgery, rhinoplasty and orthognathic surgery

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Background

With the pressure on surgical capacity across the NHS, because of the coronavirus pandemic, the case has been made elsewhere (e.g. Royal College of Paediatrics and Child Health) for the importance of ensuring that children and young people (CYP) and children's services are not impacted. This paper makes the case specifically for prioritisation of surgery for patients born with a cleft lip and/or palate (CLP) who are requiring surgery, which may in part be for appearance reasons, including lip revision, rhinoplasty and orthognathic surgery. The case is supported by published, peer reviewed evidence and the professional consensus of the specialist clinical psychologists working in regional cleft centres across the UK.

As a professional group, the cleft clinical psychology CEN are very concerned about delays to these surgeries and uncertainties around plans for the re-introduction of these surgeries, and believe they should be considered for prioritisation alongside other time sensitive surgery, as appropriate. The concerns detailed below are organised into three categories: the specific impact of appearance factors and concerns on children and young people born with a cleft; harmful or risk factors specific to adolescents and younger children; and the disproportionate impact of the pandemic on this group of people. There is an additional section relating specifically to orthognathic surgery.

Factors specific to children and young people born with a cleft

Although the surgeries highlighted may primarily aim to address appearance concerns, these are not cosmetic procedures. Lip revision surgery, rhinoplasty and orthognathic surgery are part of a 20+ year treatment pathway, required as a result of a congenital craniofacial anomaly. There is national consensus about these surgeries being part of a complete treatment pathway, as described in the National Service Specification for Cleft Units.

Appearance factors specific to cleft

Recent research confirms and highlights a number of concerning issues, demonstrating the importance of being able to offer CYP the appearance based surgery as indicated, at the earliest appropriate time, in order to normalise appearance as much as possible:

- Shockingly, Bous et al (2021) found that a sample of 130 participants, which included health care providers and lay people, showed significant levels of implicit bias against people with a repaired cleft lip. The study involved viewing images of people, so judgements were based on appearance factors alone, and replicates similar, older

findings. This is important in considering the negative societal impact that being born with a cleft lip/palate can create. Stigma and negative social reactions are known to be associated with psychological distress including social anxiety and shame.

- A systematic review in 2020 by van Dalen found that adolescents with a visible difference experience increased levels of anxiety. Adolescence can be viewed as a critical time, filled with other stressors and pressures, and therefore alleviating anxiety wherever possible is important.
- Satisfaction with appearance for CYP born with a cleft reduces significantly between the ages of 10 and 15 and there is a significant negative association for this group between appearance satisfaction and both emotional and social difficulties (Kelly 2020).
- Adolescents born with CLP are known to be at higher risk of psychosocial problems than their peers (Bous 2020). Surgeries that may assist in alleviating psychosocial problems are therefore vital.
- Bullying in relation to appearance is an experience commonly reported to psychologists in cleft MDT clinics, particularly from age 8 and above. This often leads to discussions about lip revision and rhinoplasty surgery. The experience of bullying for CYP born with a cleft is known to predict increased difficulties and abnormal psychosocial adjustment (e.g. Bous 2020).

Treatment pathways

When a baby is born with CLP, the parents will be told about the patient pathway, from birth to the child's early 20s. This includes opportunities for lip revision, rhinoplasty and orthognathic surgery. Furthermore, reference will frequently be made in cleft MDT clinics from age 5 onwards, about the option for these surgeries, as needed, in future. For rhinoplasty and orthognathic surgery in particular, patients are usually told this will be considered once they stop growing, which may be from age 15 for girls but later for boys. As a result, patients will often have waited many years being told they can be considered for surgery at a particular age, only for this plan now to have been changed. In many cleft teams, there is no replacement plan since there is no current option to restart these types of surgery. Lip revision surgery could be indicated at any age whilst rhinoplasties and orthognathic surgery will usually be indicated in adolescence.

The reliable and predictable treatment pathway, which until 2020 was consistent nationally, provides psychological safety and containment for CYP and families, thereby reducing anxiety through clear expectation management and reassurance. We know that adolescents are at particular risk of developing anxiety and other mental health conditions as detailed below, and we know that parental anxiety is associated with poor outcomes for children including child anxiety and other mental health disorders (Lawrence 2019). The current situation risks increasing anxiety for parents and CYP through a number of mechanisms:

- There is ongoing uncertainty about when surgery can be arranged.

- There is inconsistency between cleft centres, which CYP and parents are aware of through national forums (e.g. CLAPA), resulting in increased anxiety, reduced confidence in the local cleft unit and a 'postcode lottery'. In a specialised commissioned service that aims to promote consistency across the UK this is concerning.
- Families have an ongoing relationship with their cleft team, based on at least 20 years of involvement and treatment, and this facilitates trust and confidence through often very difficult treatment decisions and events. This relationship risks being undermined through the cleft team's inability to deliver treatment at timings that have been publicly stated and agreed.

These factors are important because anxiety for CYP and for parents has implications for the experience of surgery and all future treatments, being known to be associated with levels of distress, cooperation and perceived pain (e.g. Liossi et al 2007, Frank et al 1994, Rocha et al 2009).

Adolescent factors

Beginning at age 10, there is growing consensus that adolescence continues through a person's early 20s, particularly in terms of brain development (e.g. Sawyer et al, 2018). This range straddles the time period where the majority of appearance based surgery would optimally be offered. A number of factors associated with adolescence highlight the importance of prioritising these surgeries in order to continue to offer surgery at the optimal time:

- Key developmental tasks for adolescence are to establish lasting aspects of identity and to integrate socially with peers (Simpson 2001). Both of these tasks may be negatively impacted by delays to appearance based surgery.
- Linked to this, for many CYP, the salience of appearance increases during adolescence (Rumsey and Harcourt 2005). Negative views of the CYPs own appearance will impact on their emerging self-esteem and identity. Furthermore, negative interactions and judgements from peers will impact on multiple mental health and wellbeing factors including depression, anxiety, self-esteem, social avoidance and loneliness (e.g. Faith et al 2008, Feragen and Stock 2016, Hawker and Boulton 2000).
- The multiple physical, emotional and social changes experienced in adolescence make adolescents vulnerable to mental health problems (WHO 2020). Adolescents with anxiety disorders are at increased risk of subsequent anxiety, depression and educational underachievement (e.g. Woodward and Fergusson 2001). Any treatment that could halt this negative trajectory should be prioritised.

Impact of pandemic on adolescents

CYP have been disproportionately impacted by the pandemic, through disruption to their health care and treatment alongside education, social lives and key developmental milestones and tasks. This has been highlighted by the World Health Organisation (WHO) who report that for some young people this impact will be lifelong (www.euro.who.int/en/health-topics/Life-stages/child-and-adolescent-health/covid-19-and-children). Furthermore, it has been highlighted by a number of

Health Board and Trust's ethical committees that it is unethical for children and young people's healthcare to be unduly impacted by the COVID-19 pandemic, where COVID-19 primarily effects adults. It will also be important to consider the different impacts on male and female young people. Where surgery is ideally timed when a young person stops growing, this is likely to mean that a greater number of females are able to access paediatric surgical lists, whereas a greater number of males will need to be included on adult surgical lists. It will be important to ensure there is no unintentional discrimination for CYP born with a cleft requiring surgery in adolescence.

Orthognathic surgery

Orthognathic surgery for young people born with a cleft has a specific treatment protocol requiring a psychology assessment at different time points through the treatment. The option for orthognathic surgery at the point at which the young person stops growing, is often discussed as an option from age 5, when there may be early indicators of suboptimal mid-face growth. The aetiology of this suboptimal midface growth is thought to be due in part to the underlying congenital deformity and in part to the primary cleft lip and palate surgery carried out in the first year of life.

For those young people who are not able to start on the orthodontic phase of treatment, this will be a complete change to the expectations of the treatment journey, as discussed earlier in the paper. This risks a breakdown in trust and relationship with the team, along with increased anxiety and uncertainty for the young person and family. Often, as cleft psychologists, we hear from young people who have had difficult experiences through early adolescence related to concerns about appearance, teasing and bullying and functional difficulties, who have used the knowledge that they will be considered for orthognathic treatment at the point at which they stop growing as a coping strategy. Delays and uncertainty about when they will be able to commence this treatment will undermine this as a coping strategy and risks a loss of hope and deterioration in their mental health.

Part of the psychological assessment pre-treatment for this group is careful consideration of the young person's wellbeing and mental health and their ability to manage the treatment process, expected to last approximately 2 – 2½ years. For those young people who have had the initial phases of treatment involving orthodontic work, delays to surgery will impact on and extend this treatment time. The young person and family will not have factored in additional significant delay, often of unknown duration, when they planned for and consented to treatment. This may subsequently interfere with important areas of development and plans (e.g., further education, employment). During the orthodontic phase of treatment, the teeth are aligned within each jaw, in preparation for surgery, which corrects the jaw relationships. This is likely to have exacerbated the young person's concerns and difficulties, whether they be appearance or function based, in relation to their bite. In effect, they have undergone partial treatment with the cleft team, which may have made their situation worse, and there is no certainty about when this treatment can be completed. Following surgery there is a post-operative phase of orthodontic treatment which usually lasts around 3-6 months. Capacity issues in orthodontics also have the potential to elongate this phase of treatment.

Orthognathic surgery is a major operation and involves lengthy treatment. One of the responsibilities of the cleft psychologist is to encourage and support young people to think carefully about their decision to proceed with treatment and their motivation and expectations of treatment. Frequently therefore, it is young people with very significant concerns at the outset of treatment

who embark on the process. It is the consensus of the cleft psychology CEN that delays to surgery for this patient group are risking the wellbeing and mental health of an already vulnerable group of young people, with anecdotal evidence of significant detrimental effects on mood.

Completing the orthognathic treatment process, including surgery, has been shown to significantly increase quality of life (e.g. Abdullah 2015), to increase satisfaction with facial appearance, self-confidence, self-esteem and to positively impact on anxiety and social functioning (e.g. Takatsuji et al 2015) and to increase social confidence (e.g. Schwitzer et al 2015). Similar findings have been found by our national cleft clinical psychology CEN study where orthognathic surgery was found to result in increased satisfaction with appearance and increased quality of life (presented by LeMarechal in the Utrecht International Cleft Congress 2019).

The case has been made earlier in this paper about the importance of carrying out cleft surgery, including orthognathic surgery, in a timely way for adolescents in order to normalise appearance as much as possible during a particularly sensitive phase of development and to reduce the risk of a negative impact on mental health and wellbeing. This section highlights the particular relevance of this to any delays to orthognathic treatment, whether this is delays to commencing the orthodontic phase of treatment or delays to surgery.

Summary

In summary, there is a clear case for prioritising cleft lip revision surgery, rhinoplasty and orthognathic treatment for CYP born with a cleft, in order that the surgery can be undertaken at the appropriate time for individual patients. Many factors, including cleft specific factors and factors relating to the CYP's developmental stage, have been highlighted, within the context of the COVID-19 pandemic. Failure to prioritise these surgeries may have a long-term, life-long, deleterious impact on physical and psychological outcomes for the young person.

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