

# **Falling through the gap: Dental treatment experiences of patients affected by cleft lip and/or palate**

## **Abstract**

*Introduction:* In the UK, one in 600-700 infants are born with a cleft lip and/or palate (CL/P). Previous research has identified patients with CL/P to be at high risk of long-term oral health issues. Yet, few of these patients are currently accessing community dental care.

*Aims:* To assess patients' dental treatment experiences and their suggestions for improving services.

*Materials and methods:* Five focus groups were conducted with 24 adults with CL/P. Thematic analysis was performed on the data.

*Results:* Participants perceived local dental practitioners to lack knowledge about CL/P and its treatment. Consequently, some participants had stopped visiting a dental practice altogether. Participants were also largely unaware of the specialist CL/P services they are entitled to.

*Discussion:* Suggestions are made for the integration of improved training and resources for local dental practitioners. Closer communication between specialist cleft teams and local dental practitioners could also help to bridge the gap in knowledge and improve patients' engagement with dental services. The tertiary sector has a crucial role to play in empowering patients to take more control of their oral health and dental treatment.

*Key words:* cleft lip and palate; oral health; treatment; training

## **In brief:**

- Poor oral health is a key concern among patients born with a cleft lip and/or palate (CL/P), yet few are accessing community dental care.
- Community dental practitioners may lack knowledge of CL/P and its treatment and how to refer patients to specialist services, while patients lack an understanding of the treatment they are entitled to.
- Improved training and resources for local dental practitioners, as well as closer collaboration between specialist cleft teams and local professionals could help to bridge the gap in knowledge and improve patients' engagement with dental services.

## **Introduction**

In the UK, one in every 600-700 children are born with a cleft lip and/or palate (CL/P) each year<sup>1</sup>. While the primary surgical repair usually takes place during the child's first year of life, individuals born with CL/P will be expected to engage in a long-term multidisciplinary treatment pathway<sup>2</sup>. NHS services for CL/P were centralised following a report commissioned by the Clinical Standards Advisory Group (CSAG) in 1998<sup>3</sup>, and specialist care is now provided across seventeen surgical sites. These specialist cleft teams are each responsible for providing treatment across a wide geographical area.

As well as engaging with the specialist cleft teams, children may also attend appointments with local, non-cleft specialist health professionals. One of the most frequently sought health professionals is the local dentist, yet children with CL/P can find it difficult to access NHS primary dental care<sup>4</sup>. Further, local dentists may only see one or two children with CL/P every two years<sup>5</sup>, reducing the opportunity for them to acquire clinical experience with this population. This is particularly concerning given the high prevalence of dental caries among individuals with CL/P<sup>6-10</sup>. This remains true in the UK many years after the centralisation of CL/P services<sup>11</sup>, indicating that more frequent dental check-ups may be necessary. Additionally, poor oral health is known to impact on patients' quality of life<sup>12</sup>.

Although routine specialist CL/P treatment often ends between the ages of sixteen to eighteen years, some patients require additional aesthetic or functional treatment during adulthood<sup>13</sup>. Yet, many adults treated prior to the centralisation of CL/P services may be unaware of the specialist services now available to them<sup>13</sup>. Although the patients' local dentist could be ideally placed to provide treatment information and/or a referral to the specialist cleft team, this has not been the case in some adults' experience<sup>14</sup>. This could be due in part to the suggestion raised by previous research that non-cleft specialist health professionals, including dentists, may lack knowledge of CL/P, the associated challenges, and the routine treatment pathway<sup>13-14</sup>.

## **Aims**

The aim of the present study was to assess the dental treatment experiences of adults born with CL/P, as well as their suggestions for how community dental services could be improved.

## **Materials and methods**

### *Ethical considerations*

Ethical approval was granted by the Faculty Research Ethics Committee at the University of the West of England, Bristol. The ethical guidelines issued in the Declaration of Helsinki and by 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 co-authors. Interview questions encompassed a range of topics, including treatment history with both the cleft team and the local dentist, positive and negative experiences in relation to dental treatment, and views relating to how the service might be improved (Table 1). Participants were asked open-ended questions in a focus group setting, and were prompted to provide more details where appropriate.

### *Participants*

Twenty-four adults born with CL/P (10 male, 14 female) participated in one of five focus groups. Participants were aged between eighteen and 68 years, with a mean age of 38 years. Twelve participants were born with a unilateral cleft lip and palate, seven were born with a cleft palate only, and five were born with a bilateral cleft lip and palate. Nineteen participants identified as 'White British', two as 'Indian', two as 'White European' and one as 'mixed'. At the time of interview, seventeen participants were employed, three were self-employed, and four were unemployed (housewife/disabled/student/retired). Twelve participants were single, nine were married and three were divorced. Twenty participants reported having no associated conditions, while four reported conditions such as van der Woude syndrome and Pierre Robin sequence. Participants were predominantly from the South East of England (most likely due to the location of the focus groups). However, five other regions across the UK were also represented.

### *Procedure*

Participants were approached opportunistically via the UK-based charity, the Cleft Lip and Palate Association (CLAPA) at a series of relevant events, e.g. at a CLAPA conference aimed at adults born with CL/P. Potential participants were given a verbal and a written description of what the study would entail, and key ethical information such as confidentiality and the right to withdraw. Those choosing to participate were asked to provide demographic information and a handwritten, signed consent form. No adults declined to participate in the study. All five focus groups were held in London, UK, and were led by four independent facilitators. Each focus group included between

three and six participants, and lasted approximately 49 minutes on average. All interviews were subsequently transcribed verbatim. In accordance with the guidelines provided by Braun and Clarke<sup>15</sup>, the following steps were taken: (1) becoming familiar with the data; (2) identifying interesting features of the data; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) producing the report. Analysis was seen as a recursive process, and detailed notes were written throughout. Themes were subsequently chosen for their prevalence and/or their importance (or “keyness”) in relation to the research question. Inductive thematic analysis was carried out by the first three authors independently, and then discussed until consensus upon the key themes was reached. Original data are available upon request.

## Results

Three themes were identified from the data: 1) Dentists’ lack of understanding of CL/P; 2) Patients’ limited understanding of dental treatment; and 3) Bridging the gap in cleft care. Each theme is outlined below alongside representative quotes. Key findings are also illustrated in Figure 1. All participants have been given pseudonyms to preserve anonymity.

### **THEME 1: Dentists’ lack of understanding of CL/P**

Participants perceived local dentists and hygienists to be lacking in knowledge and experience in relation to CL/P.

*“Each time I go, the dental staff examine all the plights that I have in my mouth rather cautiously... it’s something they haven’t seen before and they’re curious” – Georgia.*

*“I did find with the hygienists...they really didn’t understand that actually my mouth is more sensitive than other people’s - that it hurts in different places than other people’s, and that some of the normal techniques...don’t really work for me, and can actually just makes things worse. I think they were learning that at the same time as I was experiencing that” – Matthew.*

As a result, participants felt that dentists could be reluctant to treat patients with CL/P.

*“I wouldn’t see an issue...if I had a filling, or needed work done...for the dentist to do it...but when I was last in there, she was just like, ‘no, I can’t do anything because of your cleft’” – Anna.*

*“I think they’re quite scared to do anything...scared of damaging it or something” – Lisa.*

Some participants had had unfortunate experiences, whereby their dentist had carried out work that ultimately did more harm than good.

*“At the time they said, ‘there’s too many teeth, we’ll take some out’, which down the line is actually something that caused more problems, because I had to go into [hospital] and have more operations... What a local dentist does could positively or negatively impact the pathway of treatment that’s happening elsewhere, either that is currently happening...or might happen in the future” – Matthew.*

Participants described feeling uneasy when they visited their local dentist, and some had stopped visiting their dentist and/or hygienist altogether.

*“It makes you feel very...not safe in their hands” – Claire*

*“I actually no longer go to the hygienist...I found it to be very intrusive, very harsh...and painful, and in fact...I didn’t trust they knew what they were doing” – Stephen.*

## **THEME 2: Patients’ limited understanding of dental treatment**

Participants discussed their own lack of knowledge regarding how to maintain good oral hygiene.

*“I didn’t know how to look after my teeth. I was never really taught that as a child... I have a lot of caries, and my teeth get stained... but there isn’t really much help with trying to keep them clean... I’ve had to be proactive and learn a lot of that stuff by myself” – Matthew.*

Participants who were receiving specialist treatment from their cleft teams were unaware of the need to also attend regular appointments with the local dentist.

*“No one actually told me I was supposed to have my own dentist. I thought that being with the hospital orthodontist - that was my dental care. It was only when someone at the hospital asked me, ‘who’s your dentist?’ that I realised. But by then...it had been eleven years!” – Daniel.*

Equally, patients receiving dental treatment in the community were unaware of their entitlement to specialist cleft care.

*“I didn’t know about the [cleft teams], or their partnership with dentistry. I didn’t know I could get things done...that the cleft services were a part of that” – Maria.*

As a result, participants were concerned that patients with CL/P may not feel in control of their dental treatment.

*“If you don’t know what’s out there, what can you do?... I wasn’t really in control of the stuff [the dentists] did. They might have had a grand plan, but I didn’t know what it was” – Teresa.*

*“There’s a lot of responsibility on you to really understand your condition... I guess there’s a lot of people who aren’t confident enough to say something...even those with learning difficulties...those are the ones you need to worry about” – Daniel.*

In the worst cases, participants felt that patients with CL/P could be vulnerable to financial exploitation.

*“[The dentist] proposed a course of treatment...and I think the cost was about £4,500... Private practices especially...could be prone to seeing money opportunities” – Stephen.*

### **THEME 3: Bridging the gap in cleft care**

Participants believed that, especially given the commonality of CL/P, there is a need for dentists and hygienists to possess a basic level of knowledge about the condition.

*“One child in every 600-700 is born with a cleft...that’s a big proportion of people that are highly likely to turn up at a dental surgery” – Matthew.*

*“Anything that affects our mouth or our teeth, I think a dentist should know about that. I think it would help in the long run, for them and for us” – Maria.*

Nonetheless, patients did not expect dentists or hygienists to be cleft specialists, and noted the importance of distinguishing between the remit of the local dentist and that of the cleft team.

*“There’s definitely a training need [for dentists], but how much training and how in-depth you can go is something else altogether, because I’m assuming dentists have a whole load of other ailments and conditions that they’ve got to deal with” – Daniel.*

*“Some of [the treatment] falls outside dentists’ remit, and I’m kind of happy that those parts are dealt with by people that are a bit more specialist” – Claire.*

Participants themselves stated their uncertainty about which parts of treatment are within the local dentist’s remit.

*“I’m currently in a predicament of ‘do I trust my dentist with a root canal?’ - knowing full well that [my mouth] might not be what he’s used to seeing - or do I go to my cleft team?” – Daniel.*

Consequently, participants believed it was crucial for dentists to be aware of the routine treatment pathway for CL/P, and how to refer a patient to the cleft team when necessary.

*“I don’t think [my dentist] would have known that restorative dentistry was an option, and to refer me to the cleft team. I think that I’ve been quite lucky...that I’ve not fallen through the gap” – Fiona.*

*“I was told I was too old to see a cleft team, so I just left it... Now I know that’s not true...so maybe if dentists knew the basics...then a lot of people won’t be turned away” – Lisa.*

Participants discussed their perceived lack of communication and information-sharing between local dentists and cleft teams.

*“Each [dental] practice has their own notes, and the hospital notes are completely separate from general practice...so if I go to see one, they have no clue what’s happened at the other, and it’s quite frustrating” – Joanne.*

Participants felt that improved communication between health professionals, wherever possible, would result in benefits for all parties.

*“I think the dentist and the cleft team both knowing what kind of treatment you’re having...would make everything a bit more integrated” – Hannah.*

*“It would be great if [your dentist] could work with your orthodontist in some way to improve your outcome...be that cosmetic or functional...I think it would be better for everyone if the [local dentist] could have more direct input” – Claire.*

Participants also thought that patients could be empowered to take more control of their dental treatment.

*“I think it would be helpful for us to think about, not just [materials] to inform dentists, but also information for patients...if the cleft teams and [patient organisations] had literature that they could give to patients and say, ‘take this to your dentist’, whether it’s something that is tailored to you or something more generic, you give that to your dentist and it’s written in a language that they would be familiar with” – Bella.*

Finally, participants believed that patients with CL/P should have priority access to dental treatment within the National Health Service.

*“People with clefts and related conditions, and other oral conditions as well, should be given an NHS dentist... I think there are lots of people out there that aren’t registered...and don’t get the care they need... People who are more likely to have dental issues should get priority” – Daniel.*

## **Discussion**

The present study set out to assess the dental treatment experiences of adults born with CL/P, as well as their suggestions for how community dental services might be improved. The findings provide important insight into current service provision from the patient perspective. Specifically, participants perceived local dentists and other dental professionals, including hygienists, to lack knowledge about CL/P and its treatment. As a consequence, participants felt dentists could be reluctant to treat them, resulting in treatment access issues. Alternatively, participants felt dentists could carry out treatment which ultimately did more harm than good, resulting in patients experiencing anxiety upon visiting their dentist, or ceasing to visit a dental practice altogether. Despite being considered a high priority group due to their complex medical and dental requirements, previous research has suggested that children with CL/P may find it difficult to access NHS primary dental care, either from being unable to find a dentist, the dentist not being able to provide appropriate treatment, or for other reasons, including dental anxiety<sup>4,16</sup>. The challenges facing NHS dental care are not limited to CL/P and have been highlighted by a number of government initiatives<sup>17-18</sup>. Reducing the variability of patient outcomes and addressing the problem of tooth decay in young people are key priorities for the future of the field<sup>18</sup>. The current study offers further evidence to this effect, and implies that additional efforts may be necessary among patient groups with enhanced dental needs.

A key starting point in improving dental outcomes for patients with CL/P is the improved education of undergraduate students working in the fields of dental and allied health. In addition, resources containing an overview of CL/P and its treatment could be made accessible to trainee and qualified dental professionals, and could direct them toward appropriate websites and contacts, such as CLAPA and the nearest specialist cleft team. As a more intensive option, Continuing Professional Development training could be offered. This could take the form of a formal training workshop led by a health professional and/or a charitable organisation, with the added benefit of meeting individuals affected by CL/P. Alternatively, an online training module could be developed, which could be accessed and completed by dental staff as and when required. Continued learning for all health professionals is strongly recommended in the UK<sup>19</sup>, and the benefits of such learning have already been demonstrated<sup>20</sup>. Yet, practitioners often report difficulty in accessing information and



training programmes<sup>21</sup>. Further research is needed to identify and overcome the barriers to accessing training in this context. One further suggestion is for closer partnership working with the tertiary sector, to enhance the quality and accessibility of all education provision<sup>19</sup> and to empower patients to bring key resources to the attention of their dental practitioner, as also identified in the current study.

However, the present study also identified patients with CL/P to lack general knowledge about their oral health, and the dental services they could and should be accessing. As a result, participants struggled to maintain their oral hygiene, lacked a feeling of control over their dental treatment, and felt patients could be open to financial exploitation. Patients with CL/P and their families are likely to benefit from oral health education from an early age<sup>9,21</sup>. General information and advice could be provided by the family's local dentist, with more specialist guidance being offered by the cleft team. **However, the challenge for parents and patients in coordinating and attending numerous multidisciplinary appointments should not be underestimated<sup>22</sup>. Community oral disease prevention and oral health promotion programmes are therefore also necessary in educating the public. Several initiatives have made significant progress in recent years<sup>23-24</sup> and may help to address some of the issues raised in the current paper, as well as enabling CL/P patients to take more control of their oral health.**

Adults with CL/P, who received their cleft treatment prior to the centralisation of CL/P services are most likely to be unaware of their entitlement to treatment, and are most difficult for patient organisations to reach<sup>13-14</sup>. The patients' local dentist is one health professional who is ideally placed to provide this information to patients, and referrals to the specialist cleft team when appropriate. Participants in the current study felt that communication and collaboration between community dental practitioners and networks and specialist cleft teams could be improved, for the benefit of all parties. At its most rudimentary, this could include the sharing of treatment updates and recommendations, delivered by letter or telephone. Where permitted, medical notes could also be shared, although participants recognised that opportunities for this were often restricted by issues of confidentiality. A more integrated approach to dental care for those with additional dental needs could help to bridge the gap in knowledge, prevent incompatible treatment from being carried out, and improve patients' engagement with dental services. Finally, cleft-specialist clinical psychologists may be able to offer support for those patients struggling with dental anxiety.

A number of limitations of the present study should be acknowledged. First, participants were recruited opportunistically through a patient organisation, and may therefore not be wholly representative of the target population. Second, the focus groups were conducted by four independent facilitators. Although a semi-structured interview format was followed, the manner of

delivery, as well as the presence of CLAPA staff and volunteers, may have affected the data collected. Finally, only adults (aged 18+ years) born with CL/P were recruited to this study. Public healthcare is continually improving, evidenced not least by some of the initiatives highlighted in this paper, and the older age of some of the participants may therefore have affected a proportion of their experiences. Nonetheless, findings were common across all focus groups, and the study provides unique insight into how to address a complex problem known to be prevalent within this understudied population in both research and practice.

## **Conclusion**

While not without challenges, there is a need for improved training for local dental practitioners, and closer communication and collaboration between community-based and specialist dental professionals, in order to effectively tackle the increased prevalence of dental caries and poor oral hygiene among individuals with CL/P. The tertiary sector also has a crucial role to play in empowering patients to take more control of their oral health and dental treatment.

## **Declaration of interests**

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