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**PATIENTS WITH CLEFT; EXPERIENCES, UNDERSTANDING AND INFORMATION PROVISION DURING TREATMENT**

## Abstract

**Objective:** To explore the knowledge of late adolescent's and adults' affected with cleft lip and/or palate (CL/P) about their condition and their experiences in relation to information about treatment options and outcomes within the cleft care pathway.

**Setting and Sample Population:** Twenty eight people with CL/P who had recently finished or were about to finish their definitive orthodontic/orthognathic(OGN) treatment. Participants were purposively recruited from two cleft centres in the UK.

**Materials and Methods:** Qualitative, semi-structured interviews were conducted and all interviews were recorded and transcribed verbatim. Thematic analysis was undertaken using the framework method.

**Result:** There are a broad range of interpretations and explanations for both the causes and implications of CL/P amongst those living with the condition. This resulted in confusion and left participants vulnerable to misinformation and unable to combat stigma. In addition, there was some confusion about the implication of different treatment options. Participants felt that they did not receive enough information about the nature of the treatment that they would be undergoing and the length and implications of recovery post treatment. This was a source of concern for the participants?.

**Conclusion:** The findings of this study suggest that there is a mismatch between the information provided to the families of people with CL/P and the levels of knowledge they have, both about their condition and the treatment options available to them. It is essential that clear, accessible information is provided at the right times in the care pathway to ensure that patients are able to make informed decisions about their care.

**Keywords:** *cleft lip and palate, qualitative, information*

## Introduction

Cleft lip and/or palate (CL/P) are common deformities that are known to occur in less than one per cent (0.014%) 0.14% of newborn babies. CL/P can affect both males and females with a prevalence that varies according to parental ethnicity, gender and the socio-economic status of the family. Cleft lip and palate is more common in boys while cleft palate is more common in girls.<sup>1</sup> Together they are the most common congenital anomaly to affect the craniofacial region in humans.<sup>2</sup> The causes can be genetic and/or environmental. Cleft treatment starts from birth and continues into adulthood and prenatal diagnosis means that most babies with CL/P in the UK are born into the CL/P care pathway. The management of patients with CL/P requires a multidisciplinary team approach reflecting the complexity of treatment.<sup>3,4</sup> This is the context in which the parents/carers of babies born with CL/P, and later on, the person with CL/P themselves, need to make informed decisions about the care that they wish to receive. If the care is complex and multidisciplinary, the information about the care is also likely to be complex and coming from multiple different expert sources. People with CL/P need to navigate their way through this in order to make informed decisions about their care.

Research on the experiences of people living with a range of different long term conditions suggests that information is key to relationships with clinicians and that people with long

term conditions are generally less satisfied with their relationship with doctors<sup>5,6</sup> and with the amount of information provided by their doctors.<sup>5</sup> Although there is a paucity of research on the experiences of people with CL/P and their families, existing studies suggest similar issues. A study focusing on diagnosis and the first few months post birth, for example, found that a lack of information at diagnosis was reported by many parents.<sup>7</sup> Parents felt that they had insufficient information about the condition itself but also lacked information about the practicalities of caring for a baby with CL/P, particularly related to feeding and recognizing illness.<sup>7</sup> Where information was available, it was often not clearly presented.<sup>8</sup> This ties in with the wider literature on long term conditions where a lack of information can lead to uncertainty, both about the condition itself and how it has developed, but also about the treatment options available, what they entail and how effective they are likely to be.<sup>9</sup> This has implications not just for informed decision making, but also for the ability of young people with CL/P to respond to questions and combat bullying and stigma based on a lack of understanding about the condition and its causes.<sup>9</sup>

Shahrif et al. (2013) carried out a study to highlight the lack of qualitative evidence in relation to the experience of people living with CL/P including in relation to their experiences of treatment and the CL/P care pathway.<sup>10</sup> Exploring the perspectives of people living with CL/P using qualitative methodology may help us to better understand issues related to their experiences of and participation in the care pathway, facilitating patient centred cleft care.

The aim of this research was to undertake a qualitative study to explore late adolescent's and adults' with CLP knowledge about their condition and their experiences in relation to information about treatment options and outcomes.

## Methods

This qualitative explorative study used semi-structured interviews to collect data about patients experiences of information provision within the cleft care pathway. A purposive sampling strategy was adopted in which the sample criteria were prescribed. This was deliberate non-random sampling, which aimed to identify a group of people with particular characteristics, where respondents were selected because they have knowledge that is valuable to the research questions. Table 1 presents the inclusion/exclusion criteria. Patients were recruited using two CLP hospital service centres. The CLP services were managed under one unit. The data collection period extended over 18 months. To reflect on the diversity of the possible experiences and to explore the range of perspectives, the sample included patients of different genders, ages, ethnicity and different types of CLP. People who recently finished their orthodontic/orthognathic treatment or were about to finish were invited to participate and subsequent interviewees were chosen to allow exploration and refinement of concepts and themes until data saturation occurred.<sup>11</sup> The definitive orthodontic/ orthognathic treatment is placed at the end or near the end of the CLP care pathway; participants at that stage will have experienced the majority of the CLP care pathway and will be able to comment on the whole pathway. A phenomenological approach was taken in this study with the aim of describing the lived, contextualised experience of the CL/P care pathway as described by participants.<sup>12</sup> Semi-structured interviews were conducted . The interviews followed an interview schedule (topic guide) which ensured the key areas were covered but had the flexibility to allow participants to explore and explain their experiences in their own words. It was generated after considering the research questions and incorporating the opinions of professionals working at the CLP centres?. It was flexible to adjust to the new themes that were raised during the interviews. All

interviews were recorded, transcribed verbatim and analysed using thematic content analysis, the 'rigorous and systematic analysis of data that results in the development of concepts and categories that emerge from the words of informants, culminating in the development of explanatory models'.<sup>13</sup> Double blind coding was undertaken by four researchers (authors) independently who then met to refine the analytical framework and agree the final themes. Ethical approval was obtained (12/LO/1022) and all participants gave written informed consent.

Table 1: Inclusion and Exclusion criteria

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>-Participants having any form of CLP</li> <li>-Participants who have recently finished their definitive orthodontic/orthognathic treatment (Maximum 18 months post treatment) or were about to finish</li> <li>-Minimum age 15 years but any age after that as long as other criteria were met</li> <li>-Equal number of male and female participants</li> <li>-English speakers and non-English speakers</li> </ul>	<ul style="list-style-type: none"> <li>-Patients with other significant medical condition or a declared learning disability or any associated craniofacial syndromes</li> </ul>

## Results

In total twenty eight (14 male, 14 female) people participated. All participants had experienced orthodontic treatment and twelve had also undergone orthognathic treatment (Table 2).

Table 2: Participants details at the time of the interview

Interview Number	Gender	Age	Interview length	Ethnicity	Cleft Type	OGN
1	M	23.1	77 min	Afro Caribbean	BCLP	Yes
2	F	16.8	48 min	Caucasian	CPO	No

3	F	17.5	58 min	Caucasian	UCLP	Yes
4	F	15.8	36 min	Caucasian	CLO	No
5	M	21.5	57 min	Caucasian	BCL	No
6	M	19.11	55 min	Caucasian	UCLP	Yes
7	F	27	62 min	Caucasian	UCLP	Yes
8	F	17.5	64 min	Caucasian	UCLP	No
9	F	18	46 min	Caucasian	BCLP	Yes
10	F	23.9	64 min	Caucasian	UCLP	Yes
11	M	22.2	54 min	Caucasian	UCLP	No
12	F	45	60 min	Caucasian	UCLP	Yes
13	F	20.1	49 min	Caucasian	UCLP	No
14	M	18	30 min	Afro Caribbean	UCLP-Van der Woude left	Awaiting
15	F	17	19 min	Caucasian	CPO-Isolated alveolar cleft	No
16	M	22.6	24 min	Caucasian	UCLP	No
17	M	23	108 min	Caucasian	BCLP	Yes
18	M	16.2	34 min	Caucasian	CPO	No
19	M	18.5	26 min	Caucasian	UCLP	No
20	F	20.4	40 min	Indian	UCLP	No
21	F	18.9	64 min	Caucasian	BCLP	Awaiting
22	M	17	32 min	Caucasian	CPO	No
23	M	20	52 min	Chinese	UCLP	Yes
24	M	18	33 min	Caucasian	CPO	No
25	F	17.11	24 min	Caucasian	CPO	No
26	M	21	73 min	Caucasian	UCLP	Yes
27	F	21	65 min	Caucasian	UCLP	Yes
28	M	20	81 min	Caucasian	UCLP	Yes

Participants were asked a series of questions about their understanding of CL/P and their understanding of the treatment options available to them. Each of these areas are presented below with sub themes related to experiences of, and attitudes towards, information and informed choice. Themes and sub themes are illustrated with quotes from the interviews, all of which are identified by interview number and the gender of the participant.

## Understanding of Cleft Lip and/or Palate

The first part of the results explores participants understanding about their CL/P. Two major groups were identified: those who able to give some explanation about the condition including aetiology, timescales and effects, and those who were unsure about the cause of CL/P and felt unable to explain how and why the condition developed.

### *CL/P Informed Patients*

Participants in the first group demonstrated a wide range of knowledge about the condition and it's implications. Descriptions given ranged from detailed explanations of CL/P, its aetiology and its effects on the individual to experiential accounts that focused on the care pathway and treatment options. Descriptions included both personal (presentation of the CL/P) and more generalised, biomedical information about the condition (prevalence and process).

General descriptions incorporated both the process that had occurred, or failed to occur, and the timescale within which it had happened:

*"It ... a cleft occurs when in the womb the bones don't fuse together as they ought to. That just leaves a gap in your palate and your lip."(3.F)*

This was combined with information about the incidence of cleft:

*"I know that it's fairly common, something is it 1 in 700, something like that" (10.F)*

Personal accounts contained broadly similar information. Descriptions included CL/P presentation in addition to a timescale although there seemed to be some confusion over whether the condition developed within the womb or at the point of birth.

*"Well as much as I know about it is that just after I was born I had a hole in the roof of my mouth ..."(24.M)*

When asked about the causes of CL/P opinions were divided and there was some confusion about whether and to what extent, genetics played a role in the development of the condition:

*"I know it's not genetics, it's a condition where basically when you're a baby, your body is not, it's supposed to be fused right in the middle so I didn't get that fusion..." (23.M)*

Alternative explanations based on environmental factors were also provided. One participant, for example, talked about his mother's explanation for his CL/P:

*"It can be caused by the environment, like my Mum always thinks, she was scared by a dog when I was early development in her tummy, she was knocked over by a dog or something, she's always said it must be that, but obviously that's just a story..." (11.M)*

Whilst he dismissed this as a 'story', he was unable to provide an alternative account for how or why his CL/P developed.

A small number of participants talked about the different types of CL/P that people could have:

*“I know that there are different stages of cleft lip and palate, or just the palate, deformity. So, in my case I got both, the cleft lip and the palate” (17.M)*

In each case the descriptions were explicitly linked back to the type of CL/P that the participant was living with. This can be seen throughout the accounts, general information was repeatedly linked back to personal experience. This is particularly apparent in descriptions of CL/P provided by a small number of participants who focused on the effects of the condition rather than the process by which it develops or the potential causes.

*“Yes, the only thing I know about it you end up with bent teeth (laughing).” (16.M)*

This suggests that understanding of the condition may not easily be separated from individual/personal experiences of it, and again highlights the importance of qualitative research in this area.

### ***CL/P Uninformed Patients***

The second group were participants who self-reported that they did not know much about CL/P. with reports ranging from knowing ‘nothing’ to only being aware of ‘limited details’. This group could be further divided into two smaller sub-groups. The first sub-group were those who do not know much about CLP but would like to know more about it (information seekers) whilst the second sub-group were those that did not want, or feel the need, to have more information (information avoiders).

#### ***Information Seekers***

Information seekers provided two linked reasons to explain their need for a better understanding of the condition. Both explanations involved the ability to provide information to ‘others’ in social situations, whether this was by way of a general explanation about the condition and its causes to broaden understanding or a specific attempt to combat misinformation and potential stigmatisation or bullying. One participant explained the feelings of insecurity they experienced because they were unable to explain their condition to others:

*“... when I was younger I didn’t really know about cleft lip and palate and it would have been nice to know about it ...because ...you have a lot of young people that also don’t know about it and obviously I didn’t really know a lot about it so I couldn’t really tell them about it ...” (14.M)*

Information about the condition had been provided to parents when the affected children were very young and so they were reliant on their parents for information and explanations. This not only left some people with CL/P unable to explain their condition to others, it also left them vulnerable to, and unable to combat, misinformation:

*“The main issue is growing up with something and not being able to fully understand it yourself ... Which means when other people tell you something about it you then*



*believe that because you don't know yourself and you are too young to understand it anyway so you become very susceptible" (28.M)*

In both of these examples a lack of information was identified as making the participants feel vulnerable in social situations. Participants in this group saw information as a tool to combat a lack of awareness and/or misinformation. A specific problem was identified in the way and times that information was provided and the lack of age specific information targeted at younger children in particular.

### **Information Avoiders**

In contrast, a small number of participants were happy with a minimal amount of information and/or showed no interest in finding out more. A variety of reasons for avoiding, or not actively seeking, information was given.

A number of participants explained that CL/P was just something that was there and had to be accepted and dealt with as part of normal life. In this case no information was needed because CL/P was not perceived as an issue but rather accepted as 'what is'.

*"I think, I didn't think of it as anything very special that I felt like I had to go and then know about it like why did it happen to me, I think like me and my family we accepted it and it was like normal for us"(20.F)*

For some this was an acceptance based on the responses of those around them. For a small number of participants, however, this was because CL/P ran in the family and so information was passed down and the condition was normalised:

*"...and because my mum had it, I just followed in her footsteps in a way, because she was telling me her experiences through having it, so I never really thought of looking it up." (13.F)*

For others, the CL/P was seen as peripheral, causing no functional or aesthetics issues, one participant explained that treatment for his 'cleft lip only' had left a barely visible scar as his only sign.

One participant explained that he does not have much information about his CL/P because scientists do not actually seem to know much about the condition. The perception was that the lack of certainty renders the information that is available suspect, incomplete and of little use.

*"...until they know why people are born with cleft palates that is the only question I've ever had. And they don't know why, they know how it happened, they don't know why. So there's nothing really."INT28.M*

Interestingly this participant was not uninterested in gaining more information but frustrated by the quality of what was currently available.

What is clear is that the level of understanding of their own condition and its causes varied significantly amongst participants. Not only were some people lacking a basic understanding of even the type of cleft that they had, there was a lack of understanding, or even misunderstanding, about the causes of the condition. This led to some participants expressing the inability to protect themselves from misinformation and the associated stigma and/or bullying. Conversely, some participants saw information as unnecessary

because CL/P was accepted as a routine part of daily life. For all participants, however, at least in the early years, people with CL/P are entirely reliant on others as sources of information. Whilst information about cleft, its causes and the implications is provided, it is aimed at parents/carers, and provided at a time when the affected children are too young to understand it. This leaves them reliant on the explanations provided by parents and carers and vulnerable to their interpretations of the information.

### ***Information related to cleft care***

After establishing understanding of the condition itself, participants were asked about the treatment options available to them and their implications and outcomes. In general participants were happy about the amount and quality of information they received, however, specific gaps were highlighted in relation to the organisation of treatment and aftercare and variations in communication skills of different team members were highlighted.

Some participants were aware of a lack of information and the need for more explanation:

*“I got loads of information in one go and then I would come back in four weeks and that information has gone because of school. I think I would have liked a few more little random appointments in-between those times to discuss how things were going...” (2.F)*

This suggests the need to ensure not just that information is provided but that it is understood and that patients have the time and space to absorb it and ask questions. In some cases, however, participants were unaware of missing information and this only became apparent when issues were raised which demonstrated this lack of information. One participant, for example talked about the inconvenience of having to wait in between orthodontic appointments:

*“...if I change my brace and it only takes me a week before I have to come back I would like to be seen in a week as opposed to 3 weeks because that would mean the rate of the progress is quicker...” (1.M)*

It is clear here that the participant has either not been made aware of the need to leave time for movement to occur in between appointments, or their understanding has not been checked after information has been provided. This has led to avoidable dissatisfaction. The same was seen in participants who were unaware of the complex and drawn out recovery process following orthognathic surgery, or the length of aftercare required:

*“we didn’t really know the whole of what the recovery would be before I had the operation, we didn’t realise how long, how hard it would be, because we never really got told” (9.F)*

Even where information was provided it is unclear whether understanding had been checked and whether information had been provided in clear and accessible language in a variety of formats.

Previous accounts suggest a lack of understanding about information that was provided, but some participants also highlighted receiving conflicting information from different clinicians. This is a particular problem in a care pathway where a large multidisciplinary team is involved and can cause confusion and uncertainty.

*“I’ve been to the hospital with my mum quite a lot over the last couple of years we keep finding that we’re going to consultation, and we come out being told something different. It has been a bit challenging for us” (3.F)*

One suggestion about how to overcome issues with poor or conflicting information was to use appointments with the CL/P psychologist in conjunction with the clinicians to ensure information was both consistent and understood.

*“I think that the psychiatrist would be a bit more relaxed. It would be one to one, it wouldn’t be a panel of doctors talking to me, it would be one person talking to me, making sure that I understand” (2.F)*

This highlights the importance of the multidisciplinary team in cleft care with different, but complimentary, skills.

A final issue raised highlighted changing information needs over time. The need to know about treatment tended to grow with time and develop as the individual became older and was expected to take a more active role in treatment decision making.

*“ I don’t know a lot about it actually because as a child...we were just put in hospital and not really told what we were having done so I just grew up to accept it and we weren’t sort of given counselling or explained a lot really...” (12.F)*

In childhood, information was predominantly provided to the parents rather than the child. This meant that by the time the young people reached the age where they were expected to take an active part in decision making they often had little, or only a sketchy, understanding of their condition, the treatment that they had received so far and the options available to them going forward.

## **Discussion**

The results of this study suggest that there are a broad range of interpretations and explanations of CL/P amongst those living with the condition, with explanations ranging from the failure of the palate to close prior to birth, to the mother being bitten by a dog during pregnancy. What is clear is that there is no consistent, shared understanding of the condition and how it came about amongst people living with it. One possible explanation for this is that information is provided to parents when the children are very young and it is left to them to explain to their children. The children are then reliant on what parents have understood, remember, or choose to tell them. This supports work carried out by Chapados and Patel and Ross<sup>14,15</sup> who emphasise the importance of giving appropriate information to people with CL/P. Adopting a more systematic approach to providing information with facilitated information sessions or giving leaflets supported with explanations would be a potential way forward. Information should also be tailored to different age groups including children.<sup>9,16</sup> Customising information to individual needs would ensure that information was provided in the right format at the right stage to maximise the chances of patients within the pathway having the information they need at the point at which they need it and facilitating informed decision making. This reiterates the findings of a study by Hall et al.<sup>16</sup> who highlighted the important of providing targeted, age appropriate information throughout the pathway, including to very young children.

Some participants did not want more information about CL/P, however. Some felt that they had sufficient information and that the condition was simply something that they lived with and did not need to think about – particularly those with milder cases of CL/P where there was little aesthetic or functional impact. A small number felt that the lack of scientific certainty, either on aetiology or the potential outcomes of treatments, meant that there was little point in trying to find out more until such a time as some definitive answers were available.

General information on CL/P itself was variable, but there were also issues with information on treatment options and implications. In early to mid-teens children with CL/P are expected to begin taking an active role in treatment decision making. Some participants in this study felt that they were asked to make treatment decisions without sufficient information either about the technicalities of the treatment itself or the timeframe or recovery times involved. One participant was not aware, for example, prior to starting orthodontic treatment, that they would be required to attend the clinic every 6 weeks for clinical/biological reasons (giving teeth time to move) and not due to a lack of appointment availability for shorter recalls. Clearly it is essential that patients understand not only what their treatment entails but also the longer term implications.

The findings of this study suggest a number of recommendations in relation to the provision of information:

- Age appropriate information should be provided throughout the care pathway
- Information initially provided to parents/carers on the aetiology and trajectory of CL/P should be provided in an age appropriate format to young people at key stages in the lifecourse – such as when first attending school, moving to secondary school etc.
- Members of the cleft care team should ensure that information provided is consistent.
- Age appropriate, comprehensive, personalized information should be provided about different aspects of treatment (treatment choices, processes, risks and outcomes) to parents and affected children/adults at different points in the care pathway.
- People with CL/P and their carers should know where to get information from as and when needed.

This study has its limitation, due to the comparatively small sample size of this qualitative study and the retrospective nature of the study as it explores participant experience which hinges on memory recall. That said, the sample size is in line with other similar studies<sup>10,11,14,15,16</sup>; and the findings have important implications for the provision of patient centred cleft care where patients are enabled to make informed decisions about their care, and empowered to raise awareness of CL/P and combat misinformation wherever encountered.

## **Conclusion**

The results of this study suggest that whilst a significant amount of information is provided to people with CL/P and their parents and carers, the information may not currently be targeted to maximise the understanding of young people born in to and growing up within the CL/P care pathway. It is essential that the care, support and information provided

reflects this, both in relation to the ageing of the patient and their changing relationship with both their parents/carers and the healthcare team, but also in relation to the need to target information at specific times in the life-course – such as when starting a new school – where particular issues may arise. The data presented here highlight potential problems with information currently provided. This has implications for people’s ability to manage social situations and combat misinformation, stigma and bullying as well as for their ability to make informed choices about the treatment options available to them.

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