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Psychological growth and well-being in individuals born with cleft

Psychological growth and well-being in individuals born with cleft: an application of self-determination theory

Abstract

Objective

Many studies of individuals born with cleft lip and / or palate (CLP) address the psychological impact of CLP in terms of stigma and/or 'resilience'. The present study challenges the usefulness of resilience in CLP research with the application of Self-Determination Theory (SDT). It is proposed that SDT can serve to better understand how individuals born with CLP can achieve psychological growth and wellbeing.

Design

Interviews were conducted with 15 individuals born with CLP in the U.K.

Results

A thematic analysis was conducted and four main themes emerged: 1. Personal challenges, 2. Support and strategies for social interaction, 3. Experience of treatment and outcomes, 4. Personal development. The thematic analysis and the interpretation in the context of SDT leads to a greater understanding of the development of psychological growth and well-being in individuals born with CLP.

Conclusion

Interpreting the life experiences of individuals with CLP through the theoretical lens of SDT allows the conceptualisation of individuals with CLP as a positive psychological resource when faced with the exclusionary practice of stigma. This resourcefulness is primarily nurtured by a supportive family and social environment that leads to the development of

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positive psychological growth and well-being. A new direction in CLP research is proposed that seeks to inform and implement change in professional practice to support individuals with CLP and their families.

Key words: Cleft Lip and / or Palate, Stigma, Resilience, Self-Determination Theory

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Introduction

Cleft lip and palate (CLP) is a congenital condition that occurs due to fusion failure in the structures forming the different parts of the mouth during the first trimester of pregnancy. It is among the most common of congenital malformations with a global incidence of approximately 1 /700 live births (Mossey & Castillia, 2003). CLP is generally categorised into three types: 1. unilateral or bilateral cleft lip and / or alveolus (approximately 25% of CLP cases) 2. unilateral or bilateral cleft lip, alveolus and palate (approximately 25% of CLP cases) and 3. isolated cleft palate which is the most common form of CLP accounting for approximately 40% of all cases (Sommerlad, 1994). In each instance, the diagnosis of CLP presents with various degrees of facial difference and functional impairment. Visible scarring, an under-developed maxilla or a flat asymmetric nose may characterize the look of a person born with CLP (Mossey, Little, & Munger et al, 2009).

A child born with CLP may also experience functional difficulties when breathing, feeding and chewing as well as having impaired dental, speech and language development (Hunt, Burden, & Hepper, et al, 2006). Typical speech deviations in CLP are hypernasality, audible nasal air leakage, decreased pressure on consonants, and deviant articulation patterns.

Individuals born with CLP in the U.K. undergo ‘corrective’ surgery in infancy and engagement with the ‘cleft treatment pathway’ is facilitated by a child’s family. Thus, lip repair is usually performed at about 3 months, with cleft palate repair following at about 6 months. Further cosmetic and functional intervention may continue into early adulthood. Estimates indicate that about two-thirds of children with CLP receive speech and language therapy in the U.K (Hardin-Jones & Jones 2005). Many individuals born with CLP have

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impaired hearing due to a propensity for ‘glue ear’ in childhood and may require grommets in infancy and hearing aids in later child and adulthood (CLAPA, 2016)

Increasingly, psychological services are also being included in cleft care teams in the U.K. in response to a body of evidence regarding difficulties faced by individuals who are visibly different and may have communication deficits (Lockhart, 2003). Specific features associated with CLP such as the nose and teeth are likely to be considered less than satisfactory and further treatment requested to improve appearance (Marcusson, Paulin & Ostrup, 2002). It has also been shown that some children born with CLP feel dissatisfied by their appearance and/or speech as adults (Feragen, Kvaem, & Rumsey et al, 2010; Havstam, Laakso & Ringsberg et al., 2011). Speech has been defined as a key marker of identity and speaking in a way that deviates from the adult norm can also threaten social acceptance (Havstam, Laakso & Ringsberg et al, 2011). Consequently, many studies attend to the potentially negative psychological impact that CLP has on an individuals’ self-concept, self-esteem and relationships throughout the lifespan.

Stigma and CLP

Numerous studies note that the effects of facial difference among children and adolescents born with CLP, including being stared at, being talked about by others as well as being teased about their appearance, can be stigmatising (e.g. Strauss, Ramsey & Edwards et al, 2007; Masnari, Landolt, Rosler et al, 2012; Masnari, Schiestl, Rossler et al, 2013). In addition, concerns about the educational attainment and performance of children with CLP

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have been confirmed by more recent population-based school performance studies (e.g. Bell, Raynes-Greenow, & Turner et al., 2016, Persson, Becker & Svennson, 2012). There is also limited evidence suggesting that children and young adults born with CLP have fewer friends than non-cleft peers (Noar, 1991), and may also marry less often, later and be childless (Ramstad, Ottem, & Shaw, 1995).

Stigma is defined as an individual attribute that is discredited by society and leads to rejection by peers and society, exposing the individual to a lifelong journey of difference and reactions from others (Goffman, 1963). According to Goffman's (1963) typology of stigma, cleft lip and palate registers as an example of stigma of the body, a mark of difference that is physical in nature and immediately apparent on meeting. Individuals who possess any stigma, including stigma of the body, are argued to be acutely aware of the fact that they differ from societal norms of (facial) appearance and attractiveness. Consequently individuals can be treated differently and struggle throughout their life to come to terms with their 'spoiled identity' (Goffman, 1963). Individuals born with CLP may experience stigma because of their different facial appearance and impaired speech and this may lead to social avoidance and experiences of appearance related teasing (Adachi, Kochi & Yamaguchi, 2003).

However, people with a visible difference themselves may, in part, be responsible for the problems encountered during social encounters. Indeed, people with a visible difference may become preoccupied with their appearance and the possible effect that it may have on others. Many become convinced (often with justification) that they are the object of unwelcome attention from other people. In anticipating negative reactions from others they can behave defensively, in an aggressive or shy manner (Rumsey, Bull & Gahagan, 1996).

Goffman (1963) proposes that individuals respond to having a 'spoiled identity' in a number of ways: in the context of CLP they may seek to directly change their status and correct it via

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surgery or treatment or they may opt to correct it via more indirect means. For example, due to the impact that CLP can have on speech and audiology individuals may seek speech and language therapy or source invisible hearing aids to enhance their communication with others. Alternatively, they can choose to reinterpret their stigma as a 'blessing', something to learn from, that can enrich their lives and facilitate insight into others (Goffman, 1963). Though Goffman is theoretically open to these three options; the concealment, correction or conversion of stigma, the framing of CLP as a 'blessing' is rarely found in the literature.

Resilience and CLP

The well documented stigmatising effect of CLP has resulted in popularising the notion that CLP resonates as a negative social experience and significant psychological burden for individuals. However, there have been regular calls from some clinicians and academics challenging this negative conceptualisation of CLP (e.g. Omiya, Ito & Yamazaki, 2011; Strauss, 2001). For example, Strauss (2001) posits that resilience could offer a new theoretical avenue for CLP studies, but that an evidence base would be needed to test this proposition. Since then, the field of CLP studies has opened up to the idea of pursuing research documenting the positive and adaptive qualities of CLP (Strauss, 2001). Some researchers have addressed this by undertaking a critical appraisal of the psychological research exploring self-concept and self-esteem in children with CLP. Many psychological studies on CLP were found to be cross-sectional, of a small sample size and often deal with different age groupings (Broder, Wilson-Genderson & Sischo, 2014). Following appraisal of these methodological issues, it has been found that children and adolescents born with CLP undergo periods of psychological adjustment, especially during adolescence (Strauss, Ramsey & Edwards et al, 2007), and are generally found to have a 'normal' self-concept

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(Landolt, Grubenmann & Meuli, 2000, Sheerin, MacLeod & Kusumaker, 1995, Masnari et al, 2013). This theme of psychological adjustment has also emerged from recent qualitative research with people with CLP (e.g. Havstam, Laakso & Ringsberg, 2011, Omiya, Ito & Yamazaki, 2012; Nelson, 2008). Together these empirical and methodological developments have made a positive contribution to CLP scholarship. Despite this, there has been little development with regards to how best to theoretically interpret this data.

Since its first introduction to the field of CLP in the early 2000s, the concept of resilience has come to adopt taken-for-granted status, with many researchers announcing that the discovery of positive adjustment is itself a sign of resilience, without any critical interrogation of the concept and its associated theory (e.g. Baker, Owens, & Stern, et al, 2009; Hamlet & Harcourt, 2015). Though some individual studies try to introduce other theories into the discussion, such as Roberts and Shute's (2010) brief consideration of the utility of the theory of chronic childhood illness and positive psychology to explain the psychosocial changes of children with CLP, these are the exception. The uncritical acceptance of the concept and theory of resilience to explain the psychosocial development of people with CLP is problematic on a number of grounds.

First, the resilience literature is based on the experiences of 'at-risk' children and those who have experienced childhood neglect, abuse and deprivation (Ong, Bergeman & Boker, 2009, Zolkoski & Bullock, 2012). As a result, resilience research is strongly linked to the study of psychopathology (Marsten, 2011, Zolkoski & Bullock, 2012). However, CLP is not associated with psychopathology and it is not considered a clear risk to child development (Masten & Coatsworth, 1998, Zolkoski & Bullock, 2012). Second, the model of psychological growth proposed in resilience theory posits that environmental factors play an important part in the development of resilience. Although positive adjustment has been demonstrated in individuals born with CLP it is unclear which aspects of an individuals'

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environment promote the development of a resilient identity in child or adulthood. Indeed, most resilience research considers the impact of external risks like poverty, abuse and neglect on child development (Rutter, 2007). Finally, resilience theory has paid little or no attention to the role that intrinsic factors, such as personality, may play in helping people adapt to challenging circumstances (Rutter, 2007). As a result, how individuals appraise, internalise and respond to external events is missing from the theoretical framework (Rutter, 2007). Such an omission detracts from the value of the theory since it fails to acknowledge that life experiences and their meanings are forged iteratively and dialectically, through the continual interchange between our external and internal worlds. For these reasons, the concept of resilience may not be appropriate in the context of understanding individuals' experiences and their response to CLP as they develop into adulthood.

Caution should be taken when incorporating a theoretical concept from another field of inquiry into the discourse of a discipline without first critically examining its epistemological assumptions. Yet this is what has happened with resilience theory and CLP. We have outlined three reasons why the employment of the concept of resilience in CLP studies may be failing our understanding of psychological growth in individuals born with CLP.

This critique of resilience theory as applied to CLP studies forces us to look for a different theoretical model for how to interpret the affirmed life narratives of people with CLP. To this end, it is contended that the application of Self-Determination Theory (SDT) offers an alternative theoretical perspective from which to explore psychological growth and well-being among individuals born with CLP.

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Self-Determination Theory

Self-Determination Theory (SDT) is ‘a broad theory of human motivation’ (Silva, Marques & Teixeira, 2014) that elaborates on how the interplay of three basic human needs - autonomy, competence and relatedness might help the attainment of good psychological health (Ng, Ntoumanis, & Thogerson-Ntoumani et al, 2012). The three key psychological needs of *autonomy*, *competence* and *relatedness* are considered to be essential to ‘ongoing psychological growth, integrity and well-being’ (Deci & Ryan, 2000 in Silva, et al, 2014). Autonomy refers to intrinsic actions that are self-initiated and regulated. Competence may be intrinsically motivated but extrinsically regulated and refers to the experience of mastery and challenge and is witnessed in curiosity, exploration and stretching of ones’ capacities (White, 1959). Relatedness refers to the feeling of belonging and being significant in the eyes of others (Ryan & Deci, 2000) because of “who they are” essentially, rather than because of their behaviour, appearance, or status and is an interplay between internal and external factors. Relatedness is the universal want to interact, be connected to, and experience caring for others (Baumeister & Leary, 1995) These needs do not function in isolation but are part of an integrated theoretical framework that can enhance autonomy, competence, and relatedness, through the provision of an ‘autonomy-supportive environment’ (See Figure 1.).

Insert Figure 1 about Here

SDT also proposes to aid an understanding of how social and cultural factors facilitate or undermine an individuals’ own sense of volition and initiative. Accordingly, SDT categorises the social context of individuals in terms of its ability to be either ‘needs supportive’ or ‘needs thwarting’ (Vansteenkiste & Ryan, 2013). The key difference between a needs supporting and a needs thwarting environment is the extent to which an individual’s

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needs are satisfied. If a person's need for autonomy, competence or relatedness is satisfied then this context is needs supportive and conducive to the development of positive psychological growth and wellbeing. For instance, if an individual and their opinions are shown respect from others this can be a sign of the environment supporting their autonomy (Silva, Marques & Teixeira, 2014). When individuals are given clear and useful feedback on their behaviour or actions in a non-judgemental way, then their social context is supporting their need for competence. Moreover, if individuals in their immediate social environment display genuine affection and concern for the person then their need of relatedness is being satisfied in that context (Silva, et al, 2014). These examples demonstrate some of the ways an individuals' social context can be 'needs supporting'. However, if an environment frustrates needs satisfaction, or purposely strives to prevent an individual from having their needs satisfied, then it is considered that this environment is needs thwarting. Exposure to a needs thwarting environment will pose a significant risk for negative psychological development (Vansteenkiste & Ryan, 2013). A common example of needs frustration is the experience of being rejected or excluded by peers. However, should this experience escalate into a sustained and purposeful campaign of bullying, or if a child is exposed to a physically abusive parent (Cicchetti, 2006; Vasteenkiste & Ryan, 2013), then there is an increased likelihood that the individual will develop fewer psychological resources and, potentially, a malfunctioning identity. SDT has both broad and behaviour-specific implications for understanding practices and structures that can enhance or diminish need satisfaction and optimal functioning.

The foregoing suggests that individuals born with CLP may be compromised in experiencing needs supportive environments. For example, Marcusson et al, (2001) reported a negative impact of CLP on individuals' social life, and Berk, Cooper & Liu et al (2001) concluded that

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adults with CLP receive less social support and higher levels of social anxiety compared with siblings without CLP. Thus it is proposed that the ‘strength-orientated’ (Vansteenkiste & Ryan, 2013) focus of SDT offers us an alternative way of evaluating the experiences of individuals born with CLP through acknowledging ‘potentials’ and ‘vulnerabilities’ of these individuals and their life opportunities and experiences (Vansteenkiste & Ryan, 2013). Indeed, SDT may provide a more realistic and holistic world view of the lives of individuals born with CLP to avoid perpetuating the stigmatising experience of individuals with CLP which past CLP research inadvertently condones.

Method

This qualitative study was conceived following research undertaken in the development of the Cleft Lip and Palate module for Healthtalk.org (<http://www.healthtalk.org/about/overview>). The data on www. Healthtalk.org is based on the narrative experience of individuals living with health conditions and is presented in video, audio and text format. However, the data that forms the basis of this study is an additional thematic analysis of the original audio dataset.

Participants

Individuals born with CLP were recruited through a variety of methods including personal networking, social media including the Facebook pages of organisations such as CLAPA (Cleft Lip and Palate Association), Healthtalk.org and Adult Voices (An online forum for adults born with CLP). All potential participants were sent an information sheet via email by AS. Participants were given a period of 1-2 weeks before they were re-contacted by AS to

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consent for either a video or audio only interview. Those agreeing to participate signed a consent form prior to interview.

Interviews

A combination of two approaches were used to interview individuals born with CLP in accordance with the methods of www.healthtalk.org. Following initial rapport building exchange individuals were invited to tell their story of living as an individual born with CLP and its impact on their life. Second, a topic guide was used to further probe and prompt individuals, to generate specific data about their experiences (see Appendix 1). The topic guides covered aspects pertinent to living with a cleft lip and / or palate, engaging with cleft services in the U.K. and life for young adults and older adults after leaving the cleft treatment pathway in the U.K. The topic guide was developed in collaboration with an advisory panel of lay people born with CLP, cleft care health professionals and academics that were assembled to guide the development of the cleft lip and palate module for www.healthtalk.org.

The interviews were conducted across the U.K. by AS between April 2013 and April 2014 with 15 individuals aged 17- 62 years who had been born with CLP (9 Female, 6 Male). All were of White-British origin although one male was born in Canada and one female was born and living in Northern Ireland. All 15 individuals were born with CLP except one female who was born with an isolated cleft palate. Three individuals interviewed had children born with CLP. Further details of these individuals can be found in Table 1. Twelve face to face interviews were conducted in individuals' homes and video-recorded and 3 interviews were

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audio-recorded via telephone. The interviews ranged from 22 minutes to 66 minutes in length and the mean was 55 minutes.

[Insert Table 1 about here]

Ethical approval

Ethical approval for the study was granted to Healthtalk.org / Health Experiences Research Group, University of Oxford by Berkshire Research Ethics Committee for health research.

Analysis

All transcripts of the audio data from the interviews with 15 individuals born with CLP were transcribed verbatim. A thematic analysis was then undertaken following the guidelines for thematic analysis stipulated by Braun & Clarke (2006). Thematic analysis is described as a flexible and useful research tool for psychological research, which can potentially provide a rich and detailed, yet complex account of data (Braun & Clarke, 2006).

First, the analysts AS and PN read and reread the transcripts to familiarise themselves with the dataset. Second, initial codes were identified and an initial coding frame was developed on a sub-sample of 4 interviews by AS and PN. Discrepancies in codes were discussed by the analysts until consensus was achieved and a definitive coding frame was generated comprising 17 codes. All transcripts were then coded using N.Vivo, Version 9. Third, once all the transcripts had been coded AS and PN searched for emerging themes. Fourth, the emerging themes were reviewed and discrepancies were discussed until consensus was achieved. Fifth, four main themes were defined and a thematic map of the process was

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generated: 1. Personal challenges 2. Support and strategies for social interaction, 3.

Experience of treatment and outcomes, 4. Personal development.

An additional step was taken to further explore the data set and axial coding was conducted to identify relationships among the open codes and the relationships among the codes in relation to psychological growth and wellbeing (see Figure 2.). Axial coding is defined as the disaggregation of core themes in the process of relating codes to each other, via a combination of inductive and deductive thinking (Strauss & Corbin, 1990). The main principles and concepts of SDT theory guided the deductive analysis of the data.

[Insert Figure 2 about here]

Results

The four main themes emerging from the analysis are presented with regard to their relationship with the development of psychological growth and wellbeing and illustrated with quotes taken verbatim from individuals' interview transcripts below;

1. Personal challenges

Common to individuals' experience of living with CLP was the role primary school played in the acquisition of a sense of difference about having CLP. The experience of going to primary school was where individuals first acquired a sense of difference, through their interactions with their peers. As a result, the notion of difference was extrinsic in origin, a consequence of their new social context:

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I remember kind of thinking, “Oh I’ve got a cleft.” But it was more probably around primary school age, which probably about 6-ish kind of was first kind of memories. And it wasn’t so much school wasn’t so much of an issue as in like bullying and kind of name calling. I just remember like going to school and people saying, “Crikey, what a difference from us,” or, “Crikey, you speak funny,” or, “What’s wrong with your face?” it was quite a lot of that. (Female, 19 years, born with cleft lip and palate)

Individuals’ awareness of their visible difference was exacerbated by peers and other people in their environment making reference to it continued into adolescence. In addition, the extent of medical appointments and treatment of CLP was a further challenge that made this self-awareness more poignant.

As a youngster or as a child, I think one is only aware of I think any difference, I suppose, because other children point it out, I guess, or other people point it out and that makes you aware of it. I think also because obviously one is quite regularly going to kind of outpatients and orthodontics and operations and so on, I think that obviously makes one aware that that you have, well in this case a cleft, but whatever it might be. In terms of age, the awareness, I couldn’t really pinpoint it, but I guess certainly I remember being perfectly aware of it sort of sort of primary, late primary school, so probably between 7 and 13. (Male, 36 years, born with cleft lip and palate)

The challenges faced by individuals born with CLP were not only associated with having a visible differences. Indeed, individuals born with a cleft palate often experienced problems with being understood due to having impaired speech:

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Sometimes you just got so frustrated and you would just say it. But and then speech-wise my speech has never been great. It's getting there are times it's good and times it's bad. And sometimes that people just wouldn't have a clue what you were saying, and they'll be saying, "Sorry can you repeat that?" People would screw up their faces, and a lot of people's reactions, that would kind of, that made you kind of step back a wee bit, because you didn't want people to make those reactions. So you just kind of when you're out it can be quite hard. (Female, 19 years, born with cleft lip and palate)

Finally, individuals born with CLP could also feel challenged in the context of dating such that they could be uncertain how comfortable potential partners were with their visible difference:

Probably the single most traumatic thing was beginning to date with it. Yeah, it's just because you're forced then to confront the physicality of it, and ask: is it who you are, is it what other people see, can people see past it? These types of typical questions. (Male, 41 years, born with cleft lip and palate)

2. Support and strategies for social interaction

Although the primary school environment invoked a sense of difference as individuals grew older they did not passively succumb to these negative experiences. Buoyed by a needs supportive family environment, individuals born with CLP developed a repertoire of strategies for coping with public awareness and social interaction. These strategies enabled individuals to take these negative experiences and turn them into opportunities for positive self-growth.

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Individuals recalled turning to their parents for advice and support to help them understand and cope with responses from peers and others in their environment. Individuals said that their family background was an overwhelmingly positive experience where having CLP didn't single them out for differential treatment. As a result, the family context emerged as a 'needs supportive' environment, one that nurtured the whole child, rather than dwelling on their CLP. In this respect, the family context provided the building blocks for the development of psychological growth and wellbeing in individuals born with CLP.

I wasn't really aware that I had a visible difference until I went to school. And then I started to notice that people were staring at me, and then that, that is really when I became aware that I, I have this. But before that I was quite sheltered at home so you know, I wasn't made to feel any different than anyone else. So that has kind of been one of my values, you know, to get me through school and everything else, that you know, I don't, it doesn't make me a different person; it's just I look different. (Female, 20 years, born with cleft lip and palate)

While the experience of attending primary school confronted children with CLP with a sense of their visible difference on a regular basis, this difficult social context also challenged their parents as well.

I don't actually recollect much about being made aware that I was different until I actually went to school. I started, you know, at about age 4. I remember little comments from the other kids. Kids are naturally quite curious: if they see something different they want to know. And my mum remembers after the first day, my first day of school coming back and I said, "Mummy, what's wrong with my face?" And that

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was her first sort of experience of what was... to come basically, all the questions and everything like that. (Female, 25 years, born with cleft lip and palate)

However, many individuals described how their parents' values had helped to create a strong family unit despite experiencing difficulties themselves.

My father was very ill from the [interviewee's] age of 10 and so as a family we financially struggled a lot. But our values were strong, so the values were right and my parents did the best they could and that's, you know, that's all you can hope for, isn't it? So I think as a family we were very, we were a very strong unit. Yeah I have no qualms over my childhood. I mean every family has its problems and skeletons in the cupboard. But, no, my father did his best, as my mother did. (Female, 47 years, born with cleft lip and palate)

Some individuals were actively encouraged by their parents to confront perpetrators of bullying. Rather than parents confronting other children or their parents it was considered that these individuals had to learn to deal with bullying themselves;

.....throughout all of it my parents were supportive. They certainly never talked down or you know, made me feel stupid, not at all. And my dad made me defend myself. It sounds problematic, but what I mean is if I was being bullied he would talk to me and give me advice but he would never go and confront the kids or the kids' parents. He thought I had to learn how to sort of navigate those situations for myself. (Male, 41 years, born with cleft lip and palate)

Individuals reported that their parents felt secure and were comfortable with the visible appearance of their child and were not overwhelmed by the extent of medical intervention.

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Through the provision of a need supportive environment individuals born with CLP became more confident.

.....my parents were very secure in the fact that I was no different to my siblings or you know, I was still a, a person inside, and that was more important to them than the way that I looked. So, I think because they were comfortable with it, I was comfortable with it. So, you know, it's like all the operations and stuff, it never seemed to overwhelm them. It was just, "We'll do what we have to do," and, you know, for me that was a really strong upbringing. So you know, right now I owe everything to my parents, you know, bringing me up to be confident. (Female, 25 years, born with cleft lip and palate)

The presence of 'needs supportive' family environment may positively impact on psychological growth and wellbeing. Indeed, those who had experienced adverse responses to being visibly different believed that family support in early years had served to make them more determined individuals;

. . . kids can be very cruel, especially when they don't understand it and they can be very, very cruel. So, yeah, I got bullied, I got teased. But that kind of spurred me on to... basically be the person that I am today, you know, I am very determined, and if someone says, "You can't do this because of this, that and the other," I try and set out to prove that I can. So it's made me the person I am. I think my parents definitely helped with that, because they're both very, very driven, very determined people anyway, and they kind of made me... the sort of saying of 'don't let them get you down' sort of was very well... very, that basically summed up what they stood for, and

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what I stand for is the same: don't let them get you down. (Female, 25 years, born with cleft lip and palate)

In addition to family support individuals developed strategies for coping with social interaction with others in their environment lacking awareness of CLP. One strategy was to re-frame the negative social interactions, and re-categorise them into 'standard' bullying and 'CLP specific' bullying.

.....mainly it was just kind of teasing and sort of... snide comments, I guess. But actually there was always a level of bullying which I think actually quite a lot of which wasn't related to having a cleft; a lot of it was just... it happened to everyone as well. So I guess one has, you know, one has to pick apart the stuff that was cleft related and the stuff that was just teenage boys being nasty to each other [laughs]. I reckon there was probably more of the latter than the former actually. I think the cleft, as I say, might occasionally have been a catalyst, might have set you apart.

(Male, 36 years, born with cleft lip and palate)

Another strategy was being open about the condition and prepared to talk to others which served to increase *relatedness*. Individuals were often proactive in seeking out and creating support networks and registers as an act of *autonomy* and *competence*.

I personally found people that I could talk to, whether it be people at school or family and you just kind of learn to accept that you're born with a cleft, and that's not going to change. And over time you learn to think, "That is what makes me different and that's actually a good thing." But until you reach that point, you need to find a good like support network to kind of talk over what you're thinking because if you don't

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voice what you're thinking, nothing's going to get done. I feel it's quite important to talk about it. Yeah, positive things just having a good support network and helping the helping you to come to terms with, as I said, helping you to come to terms with the fact that having a cleft is a good thing. (Female, 19 years, born with cleft lip and palate)

On leaving the school environment many individuals born with CLP engaged in further or higher education choices of their own volition. This autonomous decision was often a liberating experience as individuals benefitted from more accepting attitudes of their peers. Thus this educational environment can be considered as needs supportive and served to enhance competence and relatedness.

I found it (college) was a lot more enjoyable for me. I was studying something I really enjoyed (public services). I found the whole attitude in college was a lot more mature than school, I'd say, especially the course I was on. I don't think you really get too many time wasters or people who bully people on the course. Yeah, you're at the place you want to be because you chose to do that, rather than school where everything's just a bit of a laugh with your mates and you study in the meantime. College for me was a great experience because I think when I got to college I was very self-conscious and not very confident at all, and then the course was very confidence boosting. (Male, 20 years, born with cleft lip and palate)

3. Experience of treatment and outcomes

Individuals born with CLP often recalled past experiences of treatment with unease due to physical and emotional trauma and unmet expectations with regard to outcome. There were also instances where individuals had declined offers of appearance altering surgery in young

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adulthood having reached a stage of physical and emotional maturity in which they were relatively comfortable with their appearance. Although such decisions were difficult to make many individuals were reluctant to undergo the trauma and disruption of further surgery.

I was maybe 12, 13, 14, perhaps when it mattered most to me how I looked. But I wasn't prepared with the pay-off, you know, I'd had other surgeries, and some of them were quite enormous and had been not so great, and I just thought, "No I'm not prepared to go this way." And when I was at university, there were times I thought, "Maybe I should have opted to have my nose changed," and it was probably a notion maybe in a moment when maybe socially I didn't feel as confident as I had at other times. But it passed and I certainly never felt that the need for you know, my fear of surgery and my unwillingness to undertake the surgery far outweighed my need or willingness to change my face. (Female, 39 years, born with cleft lip and palate)

Furthermore, there were individuals that experienced disappointment following surgical procedures. Feelings of disappointment were due to the aesthetic outcome of surgery perceived as not being consistent with their own expectations but rather the expectations of health professionals. Furthermore, some older individuals reported that they did not have the opportunity to directly discuss with health professionals,

I was always really disappointed with the outcome because I'd think I was going to be this, you know, perfect nose or perfect lip or perfect teeth and in reality I if I'd had the opportunity to discuss it, I'm sure they would have told me, "Well actually, no, we're, we're giving you the best outcome not necessarily how you may view it or want it." So I really feel that it was something that was discussed between my parents and the doctors, and my parents went along with everything that the doctors and professionals suggested, and for the best of reasons, I'm sure, but I wasn't part of that process at all; it was just done to me. (Female, 53 years, born with cleft lip and palate)

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Individuals born with CLP had also experienced uncertainty with regard to the extent they were autonomous in the decisions for appearance altering or functionally related surgical intervention. Some individuals felt that health professionals disregarded their feelings when offering appearance altering intervention focusing on the external features. It was considered more important to feel comfortable with the inner self as a treatment goal than finessing external features.

I think doctors and surgeons want to do everything that they can to help, but it doesn't necessarily mean that it's right for you. And I think it's important to focus on the person inside than the person outside. And if you're comfortable with the person inside then it doesn't, you know, matter to have great big implants in your face or... but yeah, just taking it slow, that's what I would say. (Female, 22 years, born with cleft lip and palate)

However, some younger individuals born with CLP reported feeling involved in decision-making prior to surgical intervention. These individuals reiterated the value of talking to both parents and the individual concerned to ensure the rationale and expected outcomes of treatment are well understood by all parties;

.....yeah don't kind of just discuss things with their parents: make sure they're involved in those conversations as well. I was always there for the conversations and kind of knew everything as they knew it, which was good. But if I hadn't known those things I'd be a lot more uncertain about it. (Male, 17 years, born with cleft lip and palate)

4. Personal development

Engagement in creative pursuits and physical activities suggests that individuals with CLP act themselves as agents within their needs supportive environments. Individuals reported experimenting with new behaviours and habits and did not let their CLP set the limits of their

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abilities. Through these group or individual activities, individuals expanded their existing needs supportive environment to accommodate their developing psychological growth and wellbeing and gained a sense of *relatedness* with others despite their CLP.

When I was younger I managed to get quite a lot of rock climbing outdoors through that, so yeah. It's not your average sport. It's not like you don't think of it as exercise so that's quite good, so it's more of a hobby rather than like forcing myself to go and thinking of it as exercise. It's really good because often you go and you can't often do it alone so you need someone to be a partner with it. So when you go it's quite good to meet other people (Female, 19 years, born with cleft lip and palate).

This relatedness also extends to feeling comfortable with socialising in environments such as nightclubs where there may be more emphasis on physical appearance than regular day time environments:

I have been clubbing once or twice, and you do meet people that look at you a bit strangely because you look different from what, you know, normal people would look like without a cleft palate. But when you're out people don't really look and think of me any different. I mean they might look at me and give me a few strange looks, but they won't treat me any differently. (Female, 18 years, born with cleft lip and palate)

It was also apparent that both physical and creative activities can act as an outlet for self-expression which served in the development of positive psychological growth and wellbeing;

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...what's shaped me is a supportive family, good friends and you know, the influence of music and the space to be creative and to allow yourself to express yourself. And I think that's so important, and anything creative is, is going to get that out of you. And I think if I didn't have that I can't imagine what [laughs] I'd be like: probably clinically insane. But yeah, I'd definitely say the music is the core thing that brought me out of my shell. (Female, 22 years, born with cleft lip and palate)

All individuals were either employed or if still in education had experience of employment. Many individuals found the working environment to be needs supportive and a transformative experience. These individuals also accrued social skills through interacting with members of the public allowing them to further develop competence and relatedness in the 'real world'.

....it was just kind of just a regular job in a restaurant, nothing it was definitely beneficial and it was in terms of kind of coming out your shell a wee bit more, kind of going from school where everything about school was remembering about being bullied, and not being happy as I was meant to be, and to then kind of going somewhere new and meeting new people, and nobody knows anything about that, and you don't really have any memories of, like any bad memories, no. It was it was good to go somewhere where people didn't point and ask questions. (Female, 19 years, born with cleft lip and palate)

Career paths taken by individuals included education and caring professions. Indeed, these career pathways require good interpersonal skills and where communication plays a key role.

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Taking career paths such as these emphasised individuals' sense of *autonomy*, *competence* and *relatedness* and led to the development of psychological growth and wellbeing.

I do have to be very open and very talkative to new people I don't know, because we're always going to have new parents come in to visit, to look at [school name], and new children come in. So I guess part of what's made me very confident is working where I do, because I have had to come out of my shell, I have had to meet new people and... Yeah, yeah I think that's been the best thing for me that I've ever done really, is going there. Because it's, it's really helped me in, in my personality and it's helped me grow a lot more. I've developed that confidence to just get out there and do what I want. (Female, 20 years, born with cleft lip and palate)

Discussion

This qualitative study explored the dataset from in-depth interviews with individuals born with CLP using thematic analysis. The dataset identified 4 main themes that are implicated in the development of psychological growth and wellbeing: 1. Personal challenges, 2. Support and strategies for social interaction, 3. Experience of treatment and outcomes, 4. Personal development. These themes have implications for living with CLP, challenging stigma and understanding the development of psychological growth and wellbeing in the context of Self-Determination Theory (STD).

Firstly, the findings suggest that there were key periods when individuals were liberated from the 'spoiled identities' of earlier years (Goffman, 1963) and enhanced their relatedness with

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others (Bartley, Blane & Montgomery, 1997). With regard to stigma theory, many individuals found that school can be a context where individuals encounter their first and sustained instances of ‘stigma learning’, being taunted and treated differently by their peers (Goffman, 1963). Other key points for stigma learning are believed to emerge in adolescence, and when entering the employment market in adulthood (Goffman, 1963). Goffman refers to these key points as ‘occasions of stigma learning’ (Goffman, 1963) that can be incidental in nature as well as systematic or planned. However, the forgoing data suggested that entering further education or employment was a key point with regard to overcoming stigma learned in early life, particularly school. According to Goffman (1963) families offer ‘a protective capsule for its young’ where negative stereotypes and ideologies associated with stigma are resisted by a process of ‘normalization’ and instruction on how people should interact with a stigmatised individual. Thus it was apparent that the family and social background of individuals in this study had provided the foundations for overcoming stigma in early adulthood. However, it should be borne in mind that at the time of this study there may be a culture of greater awareness of and acceptance of individuals born with a visible difference. Furthermore, the value of the family in overcoming of stigma also resonates with the underlying tenets of Self-Determination Theory (SDT). Indeed, the provision of an *autonomy supportive environment* may be present in domains outside of the family unit (i.e., higher education and employment) and their role in the development of psychological growth and well-being in individuals born with CLP are discussed hereon.

1. *Personal challenges*

Individuals born with CLP experienced challenges in response to having a visible difference and most notably during the school years. However, individuals’ peers and families provided

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autonomy supportive environments that served to temper these external challenges. As individuals progressed through school into further education or employment they became more autonomous in their actions and this promoted the development of psychological growth and well-being in these individuals.

The family emerges as a pivotal developmental setting where children feel valued and cherished as “children” and not as “children with CLP”. The role of the family in the early and teenage years can support the development of a positive self-identity (La Guardia, 2009). Furthermore, families can provide ‘*autonomy supportive environments*’ by attempting to grasp, acknowledge and convey understanding of the individuals’ wishes and encourage individuals to initiate and explore new activities, interests or roles (La Guardia, 2009). Furthermore, the role of the family in the early and teenage years can support the development of a positive self-identity (La Guardia, 2009).

This provision of structure can support competence, as families, peers, and health professionals create opportunities for the individual to optimise their skills in a challenging way and provide clear feedback and guidance in order to help them mobilize and organise actions. The family can act as a protective buffer for individuals born with CLP potentially reducing the impact of negative interactions beyond this intimate circle (Baker et al, 2009) and help to build inner resources that contribute to subsequent coping (Vansteenkiste & Ryan, 2013).

2. Support and strategies for social interaction

The school environment posed a particular threat to individuals born with CLP with regard to their development of psychological growth and wellbeing. However, while the family context and the schooling context are independent of each other, they do converge, with events

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happening in the school environment being mitigated by the family and vice versa.

Individuals in this study encouraged questions and embraced 'open' dialogues with others in their communities. This dialogue served in the development of psychological growth and well-being helping them to cope with environmental challenges.

It is also proposed that SDT can serve to map how the internal psychological world of people born with CLP react to and operate alongside external forces. It is these interactions across these contexts that shape the trajectory of psychological growth and well-being in individuals born with CLP. The present findings suggest that psychological growth and wellbeing appear to be a function of how individuals internalise the influence and extrinsic response of family and peers, as well as those of the wider social and institutional contexts. Finally, relationships with parents, peers, schools and employers remain important at times of transition and in future-orientated domains such as education and career. However, it is also not clear to what extent families are implicated in *autonomy supportive environments* once an individual with CLP has left the family home. Indeed, over time most teenagers come to prefer the companionship of peers to that of their family (Larson et al, 1996) as peers are less likely than parents to coerce, criticise, and lecture and are more willing to give each other personal validity, social status and shared interests.

3. *Experience of treatment and outcomes*

With regard to fostering autonomy within individuals born with CLP it would appear that for some it is important for individuals to experience internal satisfaction with themselves and this cannot necessarily be achieved through external manipulation such as surgery. Thus the motivation for engaging with treatment may not be intrinsically driven but rather through external forces.

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Acknowledging how the interplay of intrinsic and extrinsic factors shape the development of psychological growth and wellbeing for individuals with CLP may also be facilitated by the approach of healthcare professionals who work in CLP services. However, many individuals had experienced situations in which they had felt that they had not been adequately consulted or made aware of the emotional cost of appearance altering surgical intervention.

In the context of SDT, it is understood that intrinsic factors such as autonomy, competence, and relatedness may contribute to pro-activity, integration, and well-being whereas the frustration of these same psychological needs, particularly with regard to significant others and caregivers (e.g. family, health professionals) can leave individuals at risk of passivity, fragmentation and ill-being (Vansteenkiste & Ryan, 2013).

4. Personal development

With regard to the theme of personal development individuals emphasised the importance of engaging in creative and physical activities. For many individuals such activities were a counter-point to the challenges of living with CLP and served in the development of their own needs supportive environments. It would appear that individuals engaging in these pursuits enhanced their sense of *autonomy*, *competence*, and *relatedness* and sought new ways of dealing or challenging the negative peer interactions. However, it should also be considered that these individuals are motivated to engage in these pursuits through external rewards such as approval from others. This is supported by Deci (1971) who found that giving people unexpected positive feedback on a task increases people's intrinsic motivation to do it, meaning that this was because the positive feedback was fulfilling people's need for competence.

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Families can provide ‘*autonomy supportive environments*’ by attempting to grasp, acknowledge and convey understanding of the individuals’ wishes and encourage individuals to initiate and explore new activities, interests or roles (La Guardia, 2009). Indeed, the individuals in this study had not let CLP define them, rather many had taken ownership of their CLP and attributed their strength of character to being born with CLP. Individuals were also able to consider their own interests and emotions which in turn fostered volition with engaging in educational, occupational, and personal lifestyle choices.

Implications and conclusions

There is a growing body of SDT-based research focused on the role of parents as they support their children’s psychological needs in a variety of domains, including academic achievement (Roth, et al, 2009) involvement in sports (Assor, 2009), emotion regulation (Roth, 2010), identity development (Soenens & Vansteenkiste, 2010) and mental health (Ryan, Deci & Grolnick, et al, 2006). Thus, it may be useful to extend this current focus of SDT research in CLP to the context of psychological need support, parenting styles and practices. The present findings indicate that an individual’s autonomy can be enhanced and supported by parents and significant others including health professionals. Previous studies have shown that SDT based interventions can be both well received and efficacious. For example, one SDT based intervention facilitated engagement in physical activity in individuals with depression (Searle, Haase, & Chalder et al, 2014). Furthermore, the centrality of peers in adolescents’ social lives means that there is scope to introduce peer-based autonomy- supportive environments through school pupil-mentoring programmes: such peer-led support could enhance the development of psychological growth and well-being at school instead of the

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transition to school being one in which individuals encounter their first and sustained instances of ‘stigma learning’ (Goffman, 1963).

The present findings also imply a need to support and facilitate *autonomy-supportive environments* for individuals born with CLP and their families. By attending to the intrinsic (autonomy, competence and relatedness) and extrinsic factors (needs supportive and needs thwarting environments) that shape and determine psychological coherence a new direction in CLP research is proposed that seeks to inform and implement change in professional practice around the support of individuals with CLP and their families. Indeed, clinical psychologists working in cleft services could provide education and training for families, educationalists, employers as well as fellow health professionals involved in the cleft treatment pathway based on the principles of SDT. Health professionals, parents, peers and colleagues may struggle with knowing how to support individuals born with CLP. Thus an understanding of how SDT can support psychological growth and wellbeing may offer a more inclusive and holistic way of working with people with CLP and their families. Finally, there is also a need for both specialist and non-specialist professionals to be more aware of individuals born with CLP expectations of appearance and speech altering treatment. Indeed, individuals may require psychological and emotional support both prior to making decisions about surgery and adaptation post-surgery. .

Strengths and limitations

The present findings are supported through having interviewed individuals representing a wide age range and living in geographically diverse regions of the U.K. These individuals responded with great candour during the interviews and disclosed experiences from living

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with CLP that could be considered to be implicated in the development of ‘stigmatised identities’. However, there was also the potential for self-selection in that individuals may have participated to voice particular negative social experiences or interactions with health care professionals and services.

Due to the wide age range of individuals regarding psychological growth and wellbeing may be restricted to experiences up to and including adulthood. Since individuals were predominately young (under 25 years) the findings may not reflect the experience of older individuals living with CLP who may have grown up in an era less accepting of visible differences. Finally, with regard to the theoretical perspectives of understanding the experience of living with CLP it is acknowledged that interpreting data in the context of theories such as SDT where the gaze is on the response of the affected individual rather than how society responds to visible or audible differences may also serve to perpetuate the negative experiences of individuals born with CLP.

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Psychological growth and well-being in individuals born with cleft

Table 1. Individuals born with cleft lip and /or palate (N=15)

Individual Gender / Age	Cleft type	Marital Status	Occupation	Ethnicity	Location of interview
Male, 62 years	Cleft lip, son and grandson also born with cleft	Single	Docker	White British	Hull
Male, 23 years	Cleft lip and palate, Son born with cleft lip and palate	Cohabiting	Lifeguard	White British	Hull
Female, 25 years	Cleft lip and palate	Married	Graduate / Call centre worker	White British	Fareham
Female, 24 years	Cleft palate	Single	Teacher	White British	Wokingham
Female, 22 years	Cleft lip and palate	Single	HE Student	White British	Shoreham By Sea
Male, 41 years	Cleft lip and palate	Married	Lecturer	Canadian	Bristol
Female, 47 years	Cleft lip and palate	Married	Self- employed /Street Pastor	White British	Kettering
Male, 38 years	Cleft lip and palate	Single	Self- employed Arts promoter	White British	Edinburgh (Telephone)
Female, 19 years	Cleft lip and palate	Single	Nursing student	White British	Glasgow
Female, 39 years	Cleft lip and palate	Single	Teacher	White Irish	Belfast (Telephone)

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Male, 17 years	Cleft lip and palate	Single	FE Student	White - British	Bristol
Female, 19 Years	Cleft lip and palate	Single	HE Student	White British	Coventry
Female, 53 years	Cleft lip and palate. Daughter born with cleft lip and palate	Single	Teacher	White British	London
Female, 18 years	Born with cleft lip and palate	Single	Student /Childcare worker	White British	Plymouth
Male, 20 years	Cleft lip and palate	Single	Retail Manager	White British	Bristol

Figure 1: Self Determination Theory (adapted from Vansteenkiste and Ryan 2013)

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Figure 2. Four main themes and codes (in quarters) from thematic analysis

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Appendix. 1.

Experience of Cleft Lip and Palate Topic Guide: Individuals

Background

To start, how would you describe yourself to someone who hadn't met you?

Do you live alone or with others?

What are your interests – what do you do in your spare time?

Could you tell me about your earliest experiences as a child:

School experience

Can you tell me about your school years?

What sort of challenges did you face at school?

PROMPT:

- Emotional
- Educational attainment
- Identity
- Relationships with other pupils and teachers
- Satisfaction with appearance
- Awareness of others
- Social and cultural differences
- Parental guidance / family life

Everyday life

Can you tell me about your life outside of school?

Are you studying or Employed?

- Emotional
- Identity and relationships with others
- Satisfaction with appearance
- Awareness of others
- Social and cultural norms/differences
- Parental guidance

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Cleft treatment

What can you remember about your past treatment for cleft – what are your earliest memories?

To what extent have you felt / do you now feel satisfied with treatment?

What impact did it have on your life in school?

What particular aspect of treatment has had the biggest impact?

- On your schooling?
- On your social experience?
- On your employment prospects and (if appropriate) professional role?

PROMPT:

- Lip repair and facial surgery
- Palate / gum repair surgery
- Orthodontics
- Speech therapy / audiology
- Psychological services
- Other

Social experience – post school

Can you tell me about your social experience since leaving school?

PROMPT:

- Emotional aspects
- Identity and relationship with others
- Romantic relationships
- Satisfaction with appearance
- Awareness of others treating you differently
- Social and cultural differences
- Parental guidance / family life

Post school experience and employment

What have you done since leaving school?

Are you currently employed?

If so, can you tell me about your experiences of finding employment?

- If still in education, can you tell me about your future employment plans?

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Can you tell me about your opportunities for employment and progression within the workplace?

What plans do you have for the future?

Strategies for overcoming cleft related difficulties

In what ways have you been able to overcome any social difficulties relating to having cleft?

Are there any issues relating to being born with a cleft that could have been addressed differently?

What advice do you have for other young people who have a cleft lip and /or palate?

How do you feel about the possibility that a future child of yours may be born with a cleft lip and / or palate?

Do you have any thoughts regarding the cause/s of clefts?

Summary

How would you summarise your experience of living with a cleft lip and/or palate?

Is there anything we haven't covered that you want to talk about?