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From ‘Staring’ to ‘Not Caring’: Development of Psychological Growth and Wellbeing among Adults with Cleft Lip and Palate

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According to Goffman’s typology of stigma, cleft lip and palate (CLP) registers as an example of stigma of the body, a mark of difference that is physical in nature and immediately apparent on meeting. The social and psychological burden of living with this ‘discredited identity’ has been well documented within the academic record, and in turn has served to maintain the stigmatizing effects of CLP.¹ However, there have been recent calls from some clinicians and academics challenging the negative conceptualisation of CLP. One way to counter the hegemony of stigma in CLP studies is through qualitative research and exploring the self-representation of adults with CLP. This chapter discusses qualitative findings from face to face interviews with adults with CLP. These data acknowledge that living with CLP registers as an experience of feeling different and that the experience is negotiated through a number of key transitional periods as people grow into adulthood. Progression through each of stage can be either helped or hindered by the actions of some key institutional players –the immediate family, peer group and the school and work settings. Overall, this chapter contends that CLP can be a life affirming experience, albeit with challenging moments at times.

It is widely agreed that we live in a society with an aesthetic preference for facial symmetry and regularity. Conformity to this societal ideal resonates as a particular potent social process and any one whose bodily traits differ from this ‘ideal’ are rendered different and atypical as a result. For those born with some degree of facial difference we can expect

¹ Erving Goffman, *Stigma: Notes on the management of Spoiled Identity* (Harmondsworth: Penguin, 1963), 14.

their lives to be shaped by an active process of ‘othering’, an experience that undermines their sense of self and self-identity as well as singling them out for a life long struggle against the forces of stigma, social exclusion and discrimination. Many theorists, from Goffman to Garland Thompson have documented the phases and stages of this corrosive social process.² As a result, the life experiences of all people with facial difference are assumed to fall in, uncontested, with these theoretical observations.

However, it is worth noting that stigma is a ‘negatively defined condition’ and so using it as a conceptual tool to analyse and interpret the lived experiences of people with facial difference may adversely bias the nature of the research, priming researchers to attend to instances of self-blame and negative self-concept.³ This tendency of stigma and difference research to foreground the pathological is an inherent limitation of facial difference research, one that is not often reflected upon in the literature. As researchers working with adults with cleft lip and palate we are acutely aware of how current scholarship is skewed in its negative conceptualisation of CLP. Moreover, our experience of working with people with CLP and listening to their life experiences and testimonies reminds us that an alternative, more constructive discourse about living with CLP also exists, though underreported.

² Goffman, *Stigma*; Rosemarie Garland-Thomson, ‘The Politics of Staring: Visual rhetorics of Disability in Popular Photography’, in *Disability Studies: Enabling the Humanities*, ed. Sharon L. Snyder *et al.* (New York: Modern Language Association of America, 2002), **PAGES**; Rosemarie Garland-Thomson, *Staring: How we Look* (Oxford/New York: Oxford University Press, 2009).

³ Lee F. Monaghan and Simon J Williams, ‘Stigma’, in *Key Concepts in Medical Sociology*, ed. Jonathan Gabe and Lee F. Monaghan (London: Sage, 2013), 58

The aim of this chapter is to challenge the long-held assumption that all people with facial difference are perpetually perplexed by the ‘otherness’ of their lives, that the effects of facial stigma impose very real limits on their life and that the label of ‘difference’ is the constant medium through which they experience and encounter the social world. We plan to contest this by attending to the life experience of adults with CLP through a qualitative lens. We do not deny that a mechanism of difference and stigmatisation is experienced by people with cleft, lip and palate. Indeed the pathological effect of being different in a society that values the ‘norm’ is well documented. However, we contend that by pursuing an interpretative approach to understanding people with CLP, inviting and listening to their personal testimonies, an alternative discourse based on their first person experience will emerge. By enabling people with CLP to share their own biographical narratives we create the possibility for an understanding about facial difference to be informed by self-authority and self-representation rather than the self-perpetuating cycle of stigma and difference. In this way we strive to circuit break the stigmatizing effect of CLP.

In this chapter we will begin by defining what is meant by cleft lip and / or palate. Next we will outline the current scholarship on CLP and the centrality of the notion of stigma found there. From this we will present our argument for the merits of an alternative paradigm to researching CLP through the interpretivist approach. Qualitative research with 15 adults with CLP will be presented revealing an alternative, strengths based narrative which will challenge existing cannon as well as our own preconceptions about people living with facial difference.

What is CLP?

Cleft lip and palate (CLP) is a congenital condition affecting a child’s facial structures which also has functional consequences for feeding, chewing, breathing and impaired dental, facial,

speech and language development.⁴ CLP occurs due to fusion failure in the structures forming the different parts of the mouth during the first trimester of pregnancy and is among the most common congenital malformations. The global incidence of CLP is approximately 1 /700 live births.⁵ Cleft lip and/or palate is generally categorized 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 affected children.

Visible scarring, an under-developed maxilla or a flat asymmetric nose may characterize the look of a person born with CLP and thus have significant implications for appearance. A child born with CLP may also experience functional difficulties when feeding, chewing and breathing as well as having impaired dental, facial, speech and language development.⁶ Typical speech deviations in CLP are hypernasality, audible nasal air leakage, decreased pressure on consonants and deviant articulation patterns. For these reasons, a child with CLP is likely to begin corrective surgery within the first few months of life. The cleft of the lip is the most visible part of the cleft and is usually closed in the first year of life. In the

⁴ Orlagh Hunt, Donald Burden, Peter Hepper and Chris Johnston, 'The Psychosocial Effects of Cleft Lip and Palate: a Systematic Review', *European Journal of Orthodontics* 27 (2005): 274-285.

⁵ Peter A. Mossey, Julian Little, Ron G. Munger, Mike J. Dixon, and William C. Shaw, 'Cleft Lip and Palate', *The Lancet*, 379 (9703) (Nov 9, 2009): 1173-1178.

⁶ Orlagh Hunt, Donald Burden, Peter Hepper, Mike Stevenson and Chris Johnston, 'Self-reports of Psychosocial Functioning among Children and Young Adults with Cleft Lip and Palate', *Cleft Palate-Craniofacial Journal* 43 (2006): 598-605.

UK lip closure surgery is usually undertaken at about 3 months with palate closure following at about 6 months, and additional surgery and intervention may continue into early adulthood. In most western countries, **patient person** with CLP is cared for by a multi-disciplinary cleft team, usually including a plastic surgeon, orthodontist, speech and language therapist and audiologist. Increasingly, psychological services are being included in cleft care teams in the UK in response to a body of evidence re: difficulties faced by children who are visibly different and who may have communication deficits.⁷ Most cleft teams follow their patients routinely until their late teens. Clearly, CLP is an intense medicalized process for children and families alike until their early adulthood in which they face ongoing involvement with multi-disciplinary healthcare teams to ensure the child's optimal physical and psychosocial development.

Stigma and CLP: a literature review

It has been long assumed that living with facial difference has a psychosocial impact for children born with CLP. According to Goffman's 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. Though all stigma gives rise to 'a sense of undesired differentness', the 'hare' or cleft lip does register as a 'stigma symbol', something that 'break(s) up an otherwise coherent picture' of a human face. In this way people born with CLP may acquire a 'discredited identity'.⁸ There are three consequences for being 'visibly conspicuous' in society.⁹ First is the perception that one is different from the majority in

⁷ Elaine Lockhart, 'Mental Health Needs of Children and Adolescents with Cleft Lip and/or Palate', *Clinical Child Psychology and Psychiatry* 8 (2003): 7-16.

⁸ Goffman, *Stigma*, 14, 15, 59, 60, 14 respectively.

⁹ Garland-Thomson, 'The Politics of Staring', 576.

society manifests. This is called felt stigma. Second, is enacted stigma, or being explicitly treated differently from the majority of society (either in the form of discrimination or ostracisation). Last, self-stigma, or where ‘internalised feelings of guilt, shame, inferiority’ overwhelm the internal dialogue of the person.¹⁰

Stigma theorists posit that the experience of being stigmatized is an incredibly painful process and an untenable state. This position has been confirmed by some CLP studies. In quantitative studies differences have been established between young people born with CLP and non-cleft peers that may support this position. For example, those with CLP are reported to drop out of school more frequently and be less likely to belong to clubs and societies.¹¹ In addition, young adults with CLP are less likely to aspire to further education compared with their non-cleft peers, and are more frequently unemployed and have a lower income than

¹⁰ Ann Jacoby, ‘Felt versus Enacted Stigma: A Concept Revisited: Evidence from a Study of People with Epilepsy in Remission’, *Social Science and Medicine* 38.2 (1994): 269-274; R. G. Block, “‘Is It Just Me?’ Experiences of HIV-Related Stigma’, *Journal of HIV/AIDS and Social Services* 8 (2009): 1-19; Debbie Patterson, Alex Barnes and Chloe Duncan, *Fighting Shadows. Self-stigma and Mental Illness* (Auckland: Mental Health Foundation of New Zealand, 2009), 14.

¹¹ John Peter and Rosalie R. Chinsky, ‘Sociological Aspects of Cleft Lip and Palate Adults. 1. Marriage’, *Cleft Palate Journal* 11 (1974): 295-309; John Peter and Rosalie R. Chinsky, ‘Sociological Aspects of Cleft Lip and Palate Adults. 2. Social Integration’, *Cleft Palate Journal* 11 (1974): 304-310; John Peter and Rosalie R. Chinsky, ‘Sociological Aspects of Cleft Lip and Palate Adults. 3. Education’, *Cleft Palate Journal* 11 (1974):443-449.

their non-cleft peers.¹² More recent research suggests that children and young adults with CLP have fewer friends than non-cleft peers.¹³ Children with CLP are also believed to marry less often and later and childless marriages are more likely to occur.¹⁴

Other studies confirm instances of felt stigma and enacted stigma among children with CLP. Hunt *et al.* conducted a cross-sectional study of 160 children (8-21 years) to determine the psychosocial effects of living with CLP.¹⁵ The study also included a comparison group of children without CLP. Children born with CLP reported greater behavioural problems, greater depression and teasing and were less satisfied with their facial appearance than controls. Teasing was a significant predictor of poorer social functioning and it was concluded that children with CLP require psychological assessment as part of routine cleft care. Hunt *et al.* conducted a further study with 129 parents of children with CLP to determine the level of agreement of perceived teasing between children with born with CLP

¹² John Peter, Rosalie R. Chinsky and Mary J. Fisher, 'Sociological Aspects of Cleft Lip and Palate Adults. 4. Vocational and Economic Aspects', *Cleft Palate Journal* 12 (1975): 193-199.

¹³ Joe Noar, 'Questionnaire Survey of Attitudes and Concerns of Patients with Cleft Lip and Palate and their Parents', *Cleft Palate-Craniofacial Journal* 28 (1991):279-284.

¹⁴ Tore Ramstad, Ernst Ottem and William C. Shaw, 'Psychosocial Adjustment in Norwegian Adults who had undergone Standardised Treatment of Complete Cleft Lip and Palate. Part I. Education, Employment and Marriage', *Scandinavian Journal of Reconstructive Surgery and Hand Surgery* 29 (1995): 251-257.

¹⁵ Hunt *et al.*, 'Self-reports of Psychosocial Functioning'.

and their parents.¹⁶ Their experiences were compared to those of 96 parents of children without CLP. Parents of children born with CLP reported that their child was teased more often than their non-CLP peers and parents were less satisfied with their child's speech. Children who had been teased were more anxious, less happy with their appearance and had greater behavioural problems.

Interestingly, family members are not impartial bystanders to the stigmatisation that people with cleft lip and palate feel and experience. Goffman contends that family members assume a 'courtesy stigma' by virtue of having a family member with a stigma.¹⁷ Research with parents of children with CLP attest to the psycho-social impact of having a child with a 'visible difference'. For instance, research shows that both the ante-natal diagnosis of cleft and the months following diagnosis may be a traumatic period for parents and their family.¹⁸ While most of the research on children with CLP and their families documents this unsettling time as a reaction to their movement through the cleft treatment pathway, a recurrent theme in this literature is the role that perceptions of facial appearance and difference plays in the decision-making process of families. Forth recognized that coping with a CLP diagnosis has

¹⁶ Orlagh Hunt, Donald Burden, Peter Hepper, Mike Stevenson and Chris Johnston, 'Parents' Reports of Psychosocial Functioning in Children with Cleft Lip and/or Palate', *Cleft Palate-Craniofacial Journal* 44.3 (2007): 304-311.

¹⁷ Goffman, *Stigma*, 44.

¹⁸ F.-J. Kramer, C. Baethge, B. Sinikovic, and H. Schliephake, 'An Analysis of Quality of Life in 130 Families having Small Children with Cleft Lip/palate using the Impact on Family Scale', *International Journal of Oral and Maxillofacial Surgery* 36.12 (2007): 1146-1152.

similarities to the process of grieving due to the loss of a ‘perfect’ child.¹⁹ Farrimond and Morris also discovered that parents’ primary motivation for CLP repair was to make their baby acceptable to others even though they themselves loved their babies as they were.²⁰ It has been suggested that the mechanics of this desire for ‘normalizing’ surgeries is also driven by a moralistic component. Nelson *et al.*’s research into the beliefs and motivations in relation to treatment decision-making of families of children born with CLP reported the fulfilment of a moral obligation to be ‘good’ parents by pursuing ‘normalizing’ treatments. Thirty-five in-depth interviews were conducted with parents of children with CLP between the ages of 20 weeks to 21 years to explore experiences across the treatment programme.²¹ Findings showed that, throughout the child’s childhood and adolescence, parents experienced conflicting emotions about their child’s treatment and the stigmatizing attitudes of others. Uncertainty about treatment / interventions was a potential source of conflict for parents. At diagnosis, either pre-natally or at birth, parents sometimes reported a simultaneous mixture of

¹⁹ S. Forth, ‘Antenatal Diagnosis of a Cleft Lip and Palate: Supporting the Parents’, *Journal of Neonatal Nursing* 9 (2003): 57-61.

²⁰ J. Farrimond and M. Morris, ‘Knowing or not Knowing before Birth: Parents' Experiences of having a Baby with a Cleft Lip, with or without Cleft Palate’ (Unpublished BSc. Diss., University of the West of England, Bristol, UK, 2004).

²¹ Pauline A Nelson, Anne Louise Caress, Anne Marie Glennly and Sue A. Kirk, “Doing the Right Thing”: How Parents Experience and Manage Decision-making for Children's “Normalising” Surgeries’, *Social Science and Medicine* 74 (2012): 796-804; Pauline A Nelson, Susan A. Kirk, Anne Louise Caress and Anne Marie Glennly, ‘Parents’ Emotional and Social Experiences of Caring for a Child through Cleft Treatment’, *Qualitative Health Research* 22.3 (2012): 346-359.

grief about the impairment and delight about having a newborn. There was confusion around simplistic categorizations of ‘normality’ and ‘difference’ and there was some ambivalence about labelling a child as ‘normal’ or ‘abnormal’. Conflicting emotions were particularly evident with regard to parents’ views of surgery. As much as parents believed in the possibility of surgery to improve a child’s function or ‘normalize’ his or her appearance there was a strong emotional urge to protect their child from discomfort and distress in relation to ‘surrendering’ the child to the surgical team. Experiences of treatment were sometimes reported to become more arduous for both children and their parents as children grew older. Post-surgery discomfort such as bleeding, swelling, infection and nausea was also challenging for parents pursuing repeated surgical treatments. It was reported to bring about a profound sense of guilt and **the way** to resolve such guilt was to place their trust in the specialist clinicians involved in cleft care. Such treatments were viewed as a way of facilitating their child’s social inclusion and helping them reach their full potential.

The ambivalence experienced by parents of infants and children with CLP towards their child’s changing face is an important finding often underreported in the literature. However, the parental discourses produced by those whose children were born with CLP serve as a potent reminder of the hegemony of facial appearance and of a parent’s ardent desire to protect their child from the social and psychological consequences of being visibly different. Here, we find evidence of people ‘opting out’ of the process of stigmatisation and creating their own terms of reference for how they engage with facial difference. Social expectations of ‘normal’ and ‘difference’ are re-written as inversions of each other and a new, alternative ideological space is created for the family to inhabit and maintain through their interactions with their child. Though operating at a micro level, this interrogation and negotiation of social norms and pressures is encouraging as a localized response against the process of stigmatisation. This confirms Goffman’s claim that **the family offers** ‘a protective

capsule for its young' as a key site where the negative stereotypes and ideologies associated with the stigma are not allowed to penetrate or influence their home life.²²

Proposing a new paradigm for CLP

The stigma associated with CLP appears to popularize the notion that CLP resonates as a negative social experience and significant psychological burden. However, there have been regular calls from some clinicians and academics challenging this negative conceptualisation of CLP.²³ Advocates of this paradigm shift have been inspired by a critical appraisal of the psychological research conducted on the self-concept and self-esteem of people with CLP, a reassessment of the role that families play in the dealing with stigmatisation, the emerging literature on resilience and health and a resurgence in qualitative research with people with CLP.²⁴ Together, these methodological reflections and empirical studies point to the possibility of an alternative paradigm in conceptualizing the CLP experience that doesn't take stigma as its starting point.

The exploration of the psychological impact of living with CLP brings into question the methodology of many of the studies which pronounce CLP as a negative experience. In part, this is because there are methodological differences between these studies, and some are

²² Goffman, *Stigma*, 46.

²³ Tomoko Omiya, Mikko Ito and Yoshihiko Yamzaki, 'The Process Leading to Affirmation of Life with Cleft Lip and Cleft Palate: The Importance of Acquiring Coherence', *Japan Journal of Nursing Science* 9 (2012): 127-135; Ronald P. Strauss, "'Only Skin Deep": Health, Resilience and Craniofacial Care', *Cleft Palate-Craniofacial Journal* 38.30 (2001): 226-230.

²⁴ Strauss, "'Only Skin Deep".

cross-sectional, based on a small sample size and often deal with different age groupings.²⁵ It should also be noted that previous research has used a wide variety of quantitative assessment methods. For the most part, parental self-report questionnaires have been utilized and there is a possibility of poor agreement between child and parent pairs. In addition, many studies neglect to document the age of infants or children and findings are based at one time-point. There appears to be conflicting evidence as to whether children born with CLP experience major psychological problems throughout adolescence and into adulthood. For instance, while children and adolescences with CLP undergo periods of psychological adjustment, especially during adolescence, they generally have been found to have a normal self-concept.²⁶ There is also evidence that those with acquired rather than congenital facial difference (e.g. changes due to trauma or accident) experience more difficult psychological adjustment.²⁷ In their study of the stigma experiences of 11-18 year olds with facial

²⁵ Hilary L. Broder, Maureen Wilson-Genderson and Lacey Sischo, 'Examination of a Theoretical Model for Oral Health Related Quality of Life Among Youths with Cleft', *American Journal of Public Health* 104.5 (2014): 865.

²⁶ Ronald P. Strauss, Barry L. Ramsey, Todd C. Edwards, Tari D. Topolski, Kathy A. Kapp-Simon, Christopher D. Thomas, Carla Fenson and Donald I. Patrick, 'Stigma Experiences in Youth with Facial Differences: a Multi-site Study of Adolescents and their Mothers', *Orthodontic Craniofacial Research* 10 (2007): 96-103; Strauss, "'Only Skin Deep'", 227; Ornella Masnari, Clemens Schiestl, Jochen Rossler, Stefanie K. Gutlein, Katrin Neuhaus, Lisa Weibel, Martin Meuli and Markus A. Landolt, 'Stigmatization Predicts Psychological Adjustment and Quality of Life in Children and Adolescents With a Facial Difference', *Journal of Pediatric Psychology* 38.2 (2013): 162-172.

²⁷ Masnari *et al.*, 'Stigmatization', 163.

difference, Strauss *et al.* found that young people with congenital conditions reported fewer instances of being stared at and were less likely to talk about their appearance to others than those with an acquired facial difference. This finding led them to conclude that young people with congenital conditions have better coping strategies than those with acquired facial difference because they have lived with the condition longer than others and so have become less vulnerable to the opinions of others.²⁸ Moreover, as surgical techniques for the repair of CLP have become more refined the potentially visible ‘deformity’ may not be as pronounced as it has been in the past and may help to explain why adults with CLP seem relatively satisfied with their body image.²⁹

Affective influence of families

Previously, it was reported how families struggle with the CLP diagnosis with many fearful about the social rejection of their infants. However, this parent research has also revealed an interesting contradiction. Farrimond and Morris⁴⁴ suggest that parents had adjusted their ‘internal’ picture of their baby so well during the initial weeks following birth that they did not want to change their child’s facial appearance by the time the surgery was scheduled.³⁰ This finding was most salient when the ‘defect’ was less severe. Furthermore, in their evaluation of specialized cleft counselling, Ray-Bellett and Hohfield reported that some mothers expressed distress following lip closure as they had to re-adapt to the baby’s new

²⁸ Strauss *et al.*, ‘Stigma Experiences in Youth’, 100-101.

²⁹ Tore Ramstad, Ernst Ottem and William C. Shaw, ‘Psychosocial Adjustment in Norwegian Adults who had undergone Standardised Treatment of Complete Cleft Lip and Palate. Part II. Self-reported Problems and Concerns with Appearance’, *Scandinavian Journal of Reconstructive Surgery and Hand Surgery* 29 (1995): 329-326.

³⁰ Farrimond and Harris, ‘Knowing or not Knowing before Birth’.

facial features and expressions.³¹ This phenomenon was also described by Hammond *et al.* They reported that some parents adjust well to the appearance of their baby and the cleft raising doubts about the perceived pressures from society to conform to the idea of ‘perfection’.³² However, the initial joy of a safe delivery may be quickly replaced by a parental concern for the infant to be healthy and perceptions about the management of the facial difference through corrective surgery. However, the research suggests that the path to achieving a ‘normal’ appearance for the infant is more complicated than initially implied. Clearly, the mechanics of stigmatisation can be challenged and resisted within the family context and through the transition from childhood to adulthood. Indeed, parents and siblings can potentially be powerful agents against stigmatisation and can act as catalysts in the development of emotional resilience in individuals born with CLP.

Resilience and CLP

Emotional resilience refers to one’s ability to adapt to stressful situations or crises. In an effort to shift the focus away from the potentially negative effects of CLP, the concept of emotional ‘resilience’ has been introduced to determine why some individuals with CLP do

³¹ Celine Ray-Bellett and Judith Hohfield, ‘Parental Diagnosis of Facial Clefts: Evaluation of Specialised Counselling’, *Swiss Medical Weekly* 134 (2004): 640-644.

³² V. Hammond, Amy Fletcher, Jenny Hunt, Sue Channon, ‘Mothers’ Experiences of Cleft Repair Surgery for their Babies born with a Cleft Lip and/or Palate’, paper presented at the Cranio-Facial Society of Great Britain and Ireland, Annual Conference, Bristol, 25-27 April, 2012.

better than others in the context of psycho-social development and functioning.³³ Resilience was initially presented as a useful way to interpret this formational aspect of CLP because it is concerned with positive human development in spite of identifiable risks.³⁴ However, there is much debate as to how to define resilience: at its most basic, resilience refers to a dynamic process of adaptation within the context of severe adversity.³⁵ Since the 1970s a growing body of literature has identified other protective factors and competencies necessary to respond positively to adversity.³⁶ These include the impact that a sense of self, self-determination and prosocial attitude can have in protecting against adversity.³⁷ Although resilience has contributed to our understanding of child development some theoretical issues raise doubts about its applicability to the study of individuals born with CLP. Firstly, the resilience literature is based on the experiences of ‘at-risk’ children and those who have

³³ Kirsten B. Feragen, Ingela L. Kvaalem, Nicola Rumsey and Anne I. H. Borge, ‘Adolescents with and without a Facial Difference: The Role of Friendships and Social Acceptance in Perceptions of Appearance and Emotional Resilience’, *Body Image* 7 (2010): 271-9.

³⁴ Staci M. Zolkowski and Lyndal M. Bullock, ‘Resilience in Children and Youth: A Review’, *Children and Youth Services Review* 34.12 (2012): 2295-2303.

³⁵ Michael Rutter, ‘Resilience, Competence and Coping’, *Child Abuse and Neglect* 31.3 (2007): 205; Janice G. Dyer and Teena Minton McGuinness, ‘Resilience: Analysis of the Concept’, *Archives of Psychiatric Nursing* 5 (1996): 276-282; Suniya S. Luthar, Dante Cicchetti and Bronwyn Becker, ‘The Construct of Resilience: A Critical Evaluation and Guidelines for Future Work’, *Child Development* 71.3 (2000): 543-562.

³⁶ Dyer and Minton McGuinness, ‘Resilience: Analysis of a Concept’; Zolkowski and Bullock, ‘Resilience in Children and Youth’.

³⁷ Dyer and Minton McGuinness, ‘Resilience: Analysis of a Concept’.

experienced childhood neglect, abuse and deprivation.³⁸ As a result, resilience research is linked to the study of psychopathology.³⁹ Secondly, the model of psychological growth proposed in resilience theory posits that environmental factors play an important part in the development of resilience. Although resilience has been demonstrated in individuals born with CLP it is unclear which aspects of an individuals' environment promote the development of a resilient identity. Indeed, most resilience research considers the impact of external risks like poverty, abuse and neglect on child development.⁴⁰ However, CLP is not associated with psychopathology and it is not considered a clear risk to child development.⁴¹ 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. As a result, how individuals appraise, internalize and respond to external events is missing from the framework.⁴² 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

³⁸ Zolkowski and Bullock, 'Resilience in Children and Youth'.

³⁹ *Ibid.*

⁴⁰ Rutter, 'Resilience, Competence and Coping'.

⁴¹ Zolkowski and Bullock, 'Resilience in Children and Youth'.

⁴² Rutter, 'Resilience, Competence and Coping'.

individuals' experiences and their response to CLP. However, this raises the issue of the need for a new theoretical framework that can explain their experiences with CLP.⁴³

Qualitative research and CLP

Despite this critique of resilience theory, there is value in putting forward a theory that promotes a positive understanding of living with CLP. While living with a 'spoiled identity' does come with challenges, being born with CLP may also provide opportunities for self-growth that go beyond the terms of the negative label.⁴⁴ A growing number of qualitative research studies with people with CLP confirm this.⁴⁵

Nelson has postulated that qualitative research could make a contribution to understanding the factors that influence adjustment in young people and adults born with CLP and their satisfaction and adherence with treatment.⁴⁶ Recent research studies show a growing interest in the application of qualitative research methods to help in this.⁴⁷ In

⁴³ For further discussion of this issue Aidan Searle, Patricia Neville and Andrea Waylen, 'Psychological Growth and Well-being in Individuals born with Cleft: an Application of Self-Determination Theory', *Psychology and Health* 32.4 (2017): 459-482.

⁴⁴ 'Spoiled identity': Goffman, *Stigma*, 14.

⁴⁵ Christina Havstam, Katja Laakso and Karin C. Ringsberg, 'Making Sense of the Cleft: Young Adults' Accounts of Growing Up with a Cleft and Deviant Speech', *Journal of Health Psychology* 16.1 (2011): 22-30; Omiya *et al.*, 'The Process leading to Affirmation of Life'; Pauline A. Nelson, 'Qualitative Approaches in Craniofacial Research', *Cleft Palate and Craniofacial Journal* 46.3 (2008): 245-251.

⁴⁶ Nelson, 'Qualitative Approaches'.

⁴⁷ Havstam *et al.*, 'Making Sense of the Cleft'; Omiya *et al.*, 'The Process leading to Affirmation of Life'.

addition, other researchers have investigated the application of Quality of Life measures with CLP.⁴⁸ These qualitative studies provide a rich narrative from which we can describe the experiences of individuals born with CLP. Nelson⁷¹ has highlighted an overarching need for qualitative approaches to investigate the experience of individuals and families affected by CLP [delete – repetition of point above?]. Qualitative methods can help in understanding the lived experience of people born with CLP and their families in context and may also help to clarify the previous contradictory and inconsistent findings that are present in the existing literature. Havstam *et al.* conducted a qualitative study with 13 young adults (25-34 years) born with CLP in Sweden.⁴⁹ Their aim was to explore the experience of growing up with CLP and associated deviant speech. This research emphasized the important role that parents can play by speaking openly with their child about how to present to other people.

Experiences of teasing were reported by all participants and, although it was not always a dominant feature of childhood, teasing was perceived to be the most negative consequence of CLP. The extent of identification with the ‘world’ of CLP varied widely – some young adults expressed the benefits of joining a cleft palate association as it was, potentially, an excellent opportunity to learn more about cleft and meet others with similar experiences; however, others did not want to be grouped with other people on the basis of one feature they believed to be fairly insignificant to their identity. Moreover, the authors found that some participants felt special because of their CLP due to the extra attention received from parents and classmates during difficult times of treatment and also because of the ability of many others to see qualities in people beyond their appearance. These findings resonate with previous

⁴⁸ Masnari *et al.*, ‘Stigmatization’; Broder *et al.*, ‘Examination of a Theoretical Model’.

⁴⁹ Havstam *et al.*, ‘Making Sense of the Cleft’.

research demonstrating that high self-esteem is common among persons with CLP.⁵⁰ Such findings serve to reinforce a move to investigating the experience of living with CLP from a positive perspective.

The forgoing has revealed some limitations and assumptions regarding CLP research and in turn validates the argument that a new approach to the study of the experiences of CLP is warranted. We contend that researchers need to pursue more qualitative research with people with CLP. The rich data that qualitative research generates will allow in-depth exploration of life experiences, and allows individuals born with CLP to describe their construction of reality and meanings. Accordingly, we will be able to better understand these experiences and in time develop participant-led theories to challenge stigmatisation by exploring how people with facial difference negotiate their life path in an aesthetically normative world and the role that families play as mediators and role models in this process. What follows is a record of 15 qualitative interviews that were conducted with the purpose of exploring the lived experiences of living with CLP.

Method

The research was funded by a National Institute for Health Research (NIHR) Research for Patient Benefit Grant (PB-PG-0110-21049). This study is nested within a programme of qualitative research undertaken in the development of the Cleft Lip and Palate module for Healthtalk.org. Healthtalk.org is a website that provides 'free, reliable information about health issues, by sharing individuals' experiences of a wide variety of health conditions.'⁵¹

⁵⁰ Martin Persson, Gustaf Aniansson, Magnus Becker and Henry Svensson, 'Self-Concept and Introversion in Adolescents with Cleft Lip and Palate', *Scandinavian Journal of Plastic and Reconstructive Surgery and Hand Surgery* 36 (2002): 24–27.

⁵¹ [Healthtalk.org website](http://Healthtalk.org)

Qualitative researchers with expertise in the patient experience conduct the recruitment and interviewing of participants and analyse data.

In-depth interviews were conducted in two parts.⁵² First, individuals were invited to tell their story of living as an individual born with CLP. Second, a topic guide was used to further probe and prompt participants, to generate richer data about their experiences. An advisory panel of lay people affected by CLP, health professionals and academics assisted in the development of the research and development of the topic guides. The topic guide included topics pertinent to living with a cleft lip and/or palate and engagement with cleft services in the U.K. and life for young adults and older adults that are no longer engaged with specialist cleft services (See Appendix 1 **DO WE HAVE THIS?**).

Participants 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 **Aidan Searle**. Participants were given a period of 1-2 weeks before they were re-contacted for their agreement to be interviewed either by video or audio only. Those agreeing to participate signed a consent form prior to interview. 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.

Participants and Interviews

Interviews with 15 adults aged 17- 62 years born with CLP were conducted between April 2013 and April 2014 (9 female, 6 male). All were of White-British origin although one male

⁵² Health Experiences Research Group, *Researcher's handbook Healthtalkonline & Youthtalk modules, Version 27*, (Oxford: University of Oxford, 2012).

was born in Canada and one female was born and living in Northern Ireland. Of the 15 interviewees all had been born with cleft lip and palate except one female who was born with an isolated cleft palate. Three adults interviewed were also parents of children born with CLP. Further details can be found in Table 7.1. Interviews were conducted by AS in participants' homes across the U.K. Twelve interviews were conducted face to face and video recorded and 3 interviews were audio recorded via telephone. The interviews ranged from 22 minutes to 66 minutes duration and the mean was 55 minutes.

[INSERT TABLE 7.1 ABOUT HERE]

Results

Five key themes emerged from the thematic analysis:

- Support from others (family, peers and professionals)
- Perception of self (appearance and speech)
- Public awareness and social interaction
- Experience of treatment and outcomes
- Treatment and health professional communication

In addition to these key themes the findings are presented within 3 transitional life stages:

- Transition to primary education
- Transition to adolescence
- Transition to higher education and/or employment.

The transition to primary education

The experience of going to primary school was where individuals born with CLP reported that they first developed or 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:

I can't remember exactly when 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. (Iona)

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

I don't actually recollect much about, you know, 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 was her first sort of experience of what was... to come basically, all the questions and everything like that. (Lizzie)

Individuals recalled turning to their parents for advice and support to help them understand and cope with these peer judgements. All the participants said that their family background was overwhelmingly positive and one in which having CLP did not single them out for differential treatment. As a result, the family context emerged as a supportive environment, one that nurtured the whole child, rather than dwelling on CLP. In this respect, the family context not only contrasts sharply with the challenging encounters of primary school, but also provides the building blocks for the development of psychological growth and wellbeing.

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.

(Hannah)

My father was very ill from the [participant'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, so I was very lucky really. (Karan)

I don't know, I think just 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. (Lizzie)

However, one individual felt that the family support he received came more from his mother than his father;

I don't know about guidance, but quite strong confidence, kind of getting confidence from my mother, who I guess mothers tend to be more emotive and fathers don't. I guess that's probably a terrible generalisation but broadly true. So I guess quite a bit of support then from my mother, I always felt that I was able to chat any kind of anything through really. Although I guess with father it felt like a bit more of a formal relationship, but less so as I got older perhaps. (Jon)

Transition to adolescence

In adolescence individuals born with CLP became more autonomous in their decisions and competence in life. While the primary school environment invoked a sense of difference in children, as adolescents they did not passively succumb to these negative experiences.

Buoyed by a supportive family environment, they developed a repertoire of coping strategies which enabled them to take these negative experiences and turn them into opportunities for positive self-growth.

One strategy was to re-frame the negative social interactions, and re-categorize them into 'standard' bullying and 'CLP specific' bullying.

But yeah mainly, mainly it was just kind of... you know, 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 kind of cleft, as I say, might occasionally have been a catalyst, might have set you apart. (Jon)

Another strategy was being open about the condition and prepared to talk to others which served to increase their connectedness to others in their environment. For example, Iona was also proactive in seeking out and creating a support network.

It does take time to develop ways to deal with it. At first it's very hard and you just want to run away from it all but that's not the answer. I personally found people that I could talk to, whether it be people at school or family and you just kind of you kind of you 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 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. It's not everyone's going to have something that makes them different, and you don't want to be like everybody else, and having a cleft gives you a story, it makes you who you are and it shouldn't be seen as a negative. People might treat you like it's a negative, and they might say things, but you know, I'm sure they're not perfect, and their imperfection might not be noticeable as having a cleft is, so yeah. (Iona)

One male born with cleft lip and palate reported that there was a lot of interest in his visible difference and people were interested in knowing more about the condition.

Most people know. It's kind of you can see it pretty well, that's kind of the first thing that most people notice is the cleft lip. And then they go, 'Oh do you have a cleft lip?' 'Yes, and palate.' Yeah and they're always they're always kind of interested actually. Interest is the main reaction actually. (Josh)

Furthermore, the experience of supportive family environments may positively impact on psychological growth so that strength of character could emerge in adolescence. Indeed, those who had experienced adverse conditions in childhood developed the confidence to fully engage with life in adolescence.

My school years were... bit of a roller-coaster. Of course kids can be very cruel, especially when they don't understand what they don't, you know, with something different 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 what I stand for is the same: don't let them get you down. (Lizzie)

Engagement in creative pursuits and sports suggests that individuals with CLP act as agents within their supportive environments. They experimented with new behaviours and habits and do not let their CLP set the limits of their abilities. Creative pursuits included singing, writing music and performing in public. Physical activities included rock climbing, swimming, and fencing. The participants found that engaging in these pursuits enabled new ways of dealing or challenging the negative peer interactions.

Yeah. I think the what's, 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. (Hannah)

Perhaps not surprisingly, both physical and creative activities appeared to provide an outlet for self-expression enabling the individual with CLP to enhance their supportive environment, accommodate their developing psychological growth and pursue a sense of connectedness with others despite their birth condition.

It's been really good. I mean obviously I go clubbing, as a young adult. 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. (Gemma)

Transition to higher education and employment

The final transition among adults born with CLP was from education to employment. Participants were either employed or, if in higher education, had work experience. The working environment was generally found to be supportive and for many it was a transformative experience, liberating them from the negative attitudes they experienced at school and allowing them to develop psychological growth in the adult world.

It was kind of a last minute decision to take a year out, and it was just kind of just a regular job in a restaurant, nothing it was definitely beneficial and yeah 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. (Iona)

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. (Elliott)

Career paths taken by individuals born with CLP included education, healthcare, and other caring professions, career pathways that require good interpersonal skills and where communication has a key role. Taking these career paths emphasizes individuals' sense of autonomy, and an ability to engage with society, rather than withdraw from it and succumb to its normative judgements.

I have never felt, though I said I'm self-conscious about the way I look, I have never, since I've come here, ever felt that anyone's looked at me and said, 'Hey, you know, that guy, he's just a little bit too ugly for the post', no, not at all. Oh it affects my confidence in sort of funny areas. Yeah, no, I... if any, in a way... hmm I think it's probably contributed to me being more outgoing in some ways because I had to be. (Ryerson)

In the occupation I am, 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. And... I've always kind of known since I was 10 really that I wanted to work with children. I've got it mapped out, and I know what I want to do. And just, I mean knowing what I want to do has helped me

as well. I've developed that confidence to just get out there and do what I want, sort of thing. (Gemma)

Discussion and conclusions

This chapter has reviewed the CLP literature with regard to living with CLP and presented data from in-depth interviews with individuals born with CLP. While the existing academic record would propose that living with CLP is a negative experience, contemporary qualitative research reveals that that people with CLP are not passive bystanders to the processes of stigmatisation but actively engage with and test the assumed normative limits of their lives. The thematic analysis of the data contributes to a greater understanding of the transitional periods implicated in the development of psychological growth and well-being in individuals born with CLP from childhood to adulthood. These include: transition to school, transition to adolescences and the transition to further education/work. These lifespan events register as 'normative transitions', widely acknowledged transitions that occur in the lifespan and tend to coincide with 'developmental change'.⁵³ As a result, our findings confirm the general development of psychological growth and well-being from adolescence into young adulthood. These transitions may also be coupled with periods of potential vulnerability and uncertainty, as well as opportunities for psychological growth and well-being. Key to these transitions is how individuals internalize the influence and response of family and peers, as well as those of the wider social institutional context. Individuals born with CLP encouraged questions and embraced 'open' dialogues with others in their communities and this dialogue served in the development of psychological growth and well-being.

⁵³ Urie Brofenbrenner, 'Ecology of the Family as Context for Human Development: Research Perspectives', *Developmental Psychology* 22.6 (1986): 723-742.

With regard to stigma theory, many individuals found that starting school can be a transition where individuals encounter their first and sustained instances of ‘stigma learning’, being taunted and treated differently by their peers. Other transitional points for stigma learning are believed to emerge in adolescence, and later when entering the employment market. Goffman refers to these transitional points as ‘occasions of stigma learning’ that can be incidental in nature as well as systematic or planned. The family appears to be the bedrock upon which people with CLP build their lives. Goffman contended that a family can offer ‘a protective capsule for its young’ where negative stereotypes and ideologies associated with stigma are resisted by process of ‘normalization’ and instruction on how people should interact with a stigmatized individual.⁵⁴ In the qualitative research reported here we have noted that the role of the family can support the development of a positive self-identity in the early and teenage years.⁵⁵ While the family context and the schooling context are independent of each other, they do converge, with events happening in the school environment being mitigated by the family and vice versa. The family emerges as a pivotal developmental setting where children feel valued and cherished as ‘children’ and not as ‘children with CLP’. However, the school environment may emerge as posing a particular threat to the development of individuals born with CLP, who may require support from families in knowing how to act with those who provoke stigma.

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

⁵⁴ Goffman, *Stigma*, 46.

⁵⁵ Jennifer G. La Guardia, ‘Developing Who I am: Self-Determination Theory Approach to the Establishment of Healthy Identities’, *Educational Psychologist* 44.2 (2009): 90-104.

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: peers are less likely than parents to coerce, criticize, and lecture and are more willing to give each other personal validity, social status and shared interests.⁵⁶ The centrality of peers in adolescents' social lives means that there is scope to introduce peer-based autonomy- supportive environments. One approach is school pupil-mentoring programmes in which peer-led support could enhance the development of psychological growth and well-being at school to counter sustained instances of 'stigma learning' in the school environment. The findings also suggest that the transition from school to further / higher education and employment were key periods when individuals were liberated from the 'spoiled identities' of earlier years and developed an enhanced relatedness to others.⁵⁷

This research exemplifies the benefits that qualitative research offers to the study of CLP. By using interviewing as our main research method we discovered people who had not let CLP define them but who, instead, had taken ownership and attributed their strength of character to their cleft. Individuals were encouraged to tell their 'story' and did so with great candour often recalling experiences from childhood and adolescence that could be considered to be implicated in the development of 'stigmatised identities'. We learned that they were able to consider their own interests and emotions which in turn fostered volition with

⁵⁶ Reed Larson, Maryse Richards, Giovanni Moneta, Grayson Holmbeck and Elena Duckett, 'Changes in Adolescents' Daily Interactions with their Families from Ages 10-18: Disengagement and Transformation', *Developmental Psychology* 32 (1996): 744-745.

⁵⁷ 'Stigma learning: Goffman, *Stigma*, 46; 'spoiled identity': *ibid.*, 59. Mel Bartley, David Blane and Scott Montgomery, 'Health and the Life Course: why Safety Nets Matter', *British Medical Journal* 314 (19 April 1997): 1194-1196.

engaging in educational, occupational, and personal lifestyle choices. These authoritative and empowered voices are too often missing from the research. Their exclusion from the canon lessens it as a result.⁵⁸ [I have inserted this reference here as there was no corresponding note number for reference 87 in the original ms ok?]

⁵⁸ Dawn Snape and Liz Spencer, 'The Foundations of Qualitative Research', in *Qualitative Research Practice: A Guide for Social Scientists and Researchers*, ed. Jane Ritchie and Jane Lewis (London: Sage Publications Ltd, 2003), PAGES?.