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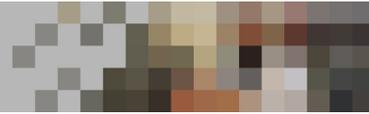
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# Exploring the Experiences of Fathers of Children with a Visible Facial Difference

Fiona M. Perella

A thesis submitted in partial fulfilment of the requirements of the
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# ABSTRACT

This study examined the experiences of fathers of children with a congenital visible facial difference (CVFD), focussing on cleft lip with/without palate (CLP). The face plays a central role in self-concept and social existence for humans and holds vast cultural significance. However, research has been slow to go beyond individual and address the significant wider impacts on the family. Fathers have been particularly neglected. This is surprising given the wealth of evidence regarding the important direct and indirect influences fathers have on child development.

This study aimed to explore how men experience fatherhood in relation to having a child with CLP, their perceived roles within the family and their experiences of support. The study employed a qualitative methodology. Participants were recruited via a national charity and via Twitter. Individual, semi-structured interviews were conducted with eight fathers of children (under the age of ten) with CLP. The data were analysed using Interpretative Phenomenological Analysis, generating three super-ordinate themes: 'Loss of the perfect child'; 'The power of 'normality''; and 'The expectations and roles of fathers'. Participants faced challenges in managing intense and conflicting emotions, with societal and personal conceptualisations of difference having a significant influence. They emphasised their roles as protector and supporter, highlighting the implications of successfully fulfilling these or not. Feeling excluded, insignificant and under-supported were prevalent issues. Support was derived from partners, and self-management strategies (e.g. avoidance, focussing on practicalities) were identified. Unexpected (mainly positive) outcomes of CLP were also acknowledged.

The findings are discussed in relation to the literature on the lived experiences of fathers of children with CLP, other CVFDs and other conditions where relevant. Implications for future research and clinical practice are considered, e.g. taking an actively inclusive approach with fathers, and offering opportunities to speak with a psychologist away from the multidisciplinary team spotlight.

# ACKNOWLEDGEMENTS

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# CHAPTER 1: INTRODUCTION

This chapter provides a review of the literature relevant to this study. In Part I, the importance of conducting research in the field of congenital visible facial difference (CVFD) is discussed. Cleft lip with/without palate (CLP) is the condition focussed on as a sample population. The relevance and need to go beyond the affected individual is highlighted and background information regarding CLP is provided. The research regarding the impact of CLP on families is then considered. Part II then discusses the concept of fatherhood and the importance of fathers in relation to child development. Finally, issues with existing literature are highlighted and current research gaps identified, followed by a brief summary of the rationale for the intended study and the research questions it aims to address.

## 1.1 Literature Review

The literature presented in this introduction was collated by conducting systematic literature searches. For the purposes of a literature review, a search was conducted to identify literature relevant to this study. EBSCOHost was used to search the following electronic databases: PsycInfo, CINAHL Plus and Education Research Complete, from 1980 – 2013. Additionally, ScienceDirect was searched. Google Scholar was used to identity key words and additional relevant material. Online searches of content lists for recent issues of journals identified as relevant by the search were also conducted. As there appears to be a lack of research focusing on the experience of fathers of children with CLP, the searches included visible facial differences more widely. The search terms "visible difference" and "visible facial difference" and their synonyms were used. The search was then narrowed by using terms relating to specific facial differences, such as "cleft lip". All these terms were then coupled with the terms "father" and "paternal" and their synonyms. Due to the paucity of research in this wider field, searches were extended to include the experiences of fathers of children with other chronic health conditions. Papers were chosen for potential inclusion if they offered data on the experiences of fathers of children with chronic

health conditions, CVFD, and CLP. As limited results were produced, the search was expanded to include the terms "mother" and "parent" and their synonyms. As this produced a relatively large corpus of literature, certain strategies were used in selecting papers for inclusion: literature regarding psychosocial aspects was prioritised; literature focussing on medical aspects was discounted; priority was given to meta-analyses and systematic reviews; qualitative studies were given precedence over quantitative studies; and UK-based research was favoured. See Appendix 1 for further details.

**PART I**

**1.2 Visible Difference**

The term "disfigurement" is used to describe "the aesthetic effects of a mark, rash, scar or skin graft or an asymmetry or paralysis to the face or body" (Partridge, 2010, p.335). However, as many authors note, the word 'disfigurement' has negative connotations and its use "is at best unhelpful, and at worst, may exacerbate the difficulties of those affected" (Rumsey & Harcourt, 2007, p.113). It has become increasingly common for the term 'visible difference' to be used instead. Therefore, this less negatively framed language was adopted.

There are no definitive data recording the extent of visible difference in the UK. Estimates indicate that 1 in 111 people in the UK have a significant visible facial difference (Julian & Partridge, 2007). However, separate figures relating specifically to children are not given, which may be a substantially smaller population.

1.2.1 Why Focus on Visible Facial Difference?

The face plays a central role in self-concept and social existence for humans (Cole, 1998) and has vast cultural significance (Partridge, 2010). In both historic and contemporary society, preoccupations with the aesthetics of the human body are evident. People deemed to be 'beautiful' are more often perceived to have positive personal attributes, for example trustworthiness and intelligence (Bull &

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Rumsey, 1988; Zebrowitz, 1997) and are perceived to have better jobs, happier marriages and as more competent parents (Elks, 1990). People with visible facial differences, however, are more likely to be socially stigmatised (Lefebvre & Barclay, 1982).

A wide range of sources throughout history provide evidence of the prevailing value and centrality of physical appearance, including mythology, legends and fairy-tales. Modern media continue to perpetuate these ideas by portraying heroes/heroines as ideologically handsome/beautiful, whilst scars, warts and physical deformities are used to depict ugliness and evil (Partridge, 2010). Advertising unashamedly endorses the 'body beautiful' for society to aspire to achieve. The dominance of this narrative is evidenced by the booming beauty industry in Western society, with millions of pounds spent in pursuit of certain 'ideals' (Rumsey, 2001). Even treatment options for visible facial differences seek to 'normalise' appearance and therefore reinforce the dominant perception that quality of life is enriched by 'better' looks (Rumsey, 1997). Only a few examples against this stereotyping exist and are portrayed sympathetically, such as Harry Potter. Even here, the scar is (a marker of his exceptionality) can be conveniently hidden by his hair.

The face is generally the most visible part of the body; it holds immense psychological and social importance. Given the role it plays in how we understand ourselves and interact with others, and therefore the potential significance of appearing different in this area, this thesis will focus specifically on those who live with a facial difference rather than any other bodily difference.

Visible difference, therefore, may be particularly problematic for children and their families for a number of reasons. On an individual level, the child may suffer bullying and low self-esteem, which may have wider impacts on the family. For parents, there are conflicting feelings, additional burdens due to the above-usual levels of care often required over many years and decisions and dilemmas to be contended with. Parents also experience increased concern regarding the child's welfare and future, which may lead to over-protectiveness and increased levels of child dependence on parents (Speltz et al., 1990). Furthermore, families of

children with a visible difference are often report feeling stigmatized and socially excluded (Nelson et al., 2012a). Therefore, significant impacts might be experienced both in the short and long-term.

### 1.2.2 The Impact on the Family

#### 1.2.2.1 The birth of a child with medical needs

Pregnancy and the birth of a child are usually seen as joyous events. This is also a time of significant transition, requiring adjustment to different roles and demands within the family (Goldberg et al., 1990; Gottman & Gottman, 2007; Kazak & Marvin, 1984). However, the stress that potentially accompanies the birth of any child is particularly evident where serious medical conditions are anticipated (Cohen, 1999; Goldberg et al., 1990; Lightsey & Sweeney, 2008). Although every family is unique, there is a commonality to the experience of responding to the birth of the child with special medical needs that has been frequently described in terms of shock, sadness, fear, grief, guilt, anger and other types of psychological distress (e.g. Carreto, 1991; Speltz et al., 1990).

#### 1.2.2.2 Families and CVFD

With regard to CVFD, as with any chronic health condition, it is not just individuals themselves who have to adjust, but also parents, siblings and wider family systems (Kish & Landsdown, 2000). To date, most psychosocial research in the arena of craniofacial conditions has focused on the impact on the affected individual (Hunt et al., 2005). There is substantial evidence that children with a CVFD respond adaptively, such as demonstrating resilience, with quality parental input (Strauss & Fenson, 2005; Topolski, et al., 2005). However, having a child with a CVFD can have significant and unexpected emotional consequences for parents, giving rise to certain challenges that impact on the whole family (Pope et al., 2005; Rumsey & Harcourt, 2007; Walters, 1997). Parental adjustment is likely to impact the child's psychosocial adjustment, self-esteem and perception of their cleft (Broder et al., 1992; Rutter & Rutter 1992; Werner & Smith, 1982). Therefore, greater understanding of parental experience and adjustment is

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essential in order to identify ways in which parents can be supported by services, indirectly benefitting the child.

However, the impact on the family has received much less attention than the impact on the affected person (Baker et al., 2009). Both the underlying condition and the visible difference itself can cause considerable challenges. For example, Chamlin (2006) found that dermatitis in young children often led to increased dependency, restlessness, fear and behavioural challenges. These may place an additional burden on parents, and potentially negatively impact on the parent-child relationship and the child's adjustment. Partridge (1997) argues that the trauma and bereavement associated with visible difference needs to be considered as a family experience, stating that "holistic care needs to embrace not just the whole person but the whole family" (p.71). However, even where the family is considered, the literature has continued to focus predominantly on the mothers (e.g. Berger & Dalton, 2011; Klein et al., 2006; Prior & O'Dell, 2009), with limited acknowledgment of paternal experience and the impact of adjustment on the child and its system. In a review of the literature on the experiences of parenting a child with CLP, Nelson et al. (2012a) also noted that experiences reported using parents' own words are uncommon. Some authors have also pointed out that research has tended to focus on associated negative experiences, ignoring possible positive ones (Baker et al., 2009; Eiserman, 2001).

The causes of CVFD are diverse, including congenital (present at birth) conditions such as CLP, birthmarks and craniofacial conditions (e.g. Cruzon, Apert); disease (e.g. vitiligo, cancer); trauma (e.g. burns, accidents); and medical interventions (e.g. surgery). Medical advances have led to a fall in mortality but rise in morbidity, increasing the burden on affected individuals, their parents and healthcare systems (Mazer et al., 2008). Consequently there is a significant group of parents who manage the experience of parenting a child with a visible facial difference. This thesis will focus on congenital visible facial difference, specifically cleft lip (with or without palate involvement) as this is the most common difference within this category (Cleft Lip and Palate Association

(CLAPA[1]), 2013a; Cox, 2004). Throughout this study, the acronym 'CLP' refers to cleft lip with/without palate involvement. However, the wider literature on visible facial difference will continue to be drawn upon where appropriate.

**1.3 Cleft Lip and Palate**

In recent years, there has been a growing interest in the psychological and social aspects of CLP (Berger & Dalton, 2009). The condition affects approximately 1 in 700 live births in the UK (CLAPA, 2013a; Mossey & Castillia, 2003). Prevalence varies with ethnicity, geographic location, child gender and social class (Bender, 2000; Mossey & Little, 2002). Cleft lip (CL) is a physical separation of the two sides of the upper lip resulting from their failure to fuse and visually appears as an opening in the top lip.  Cleft palate (CP) is a split or opening in the roof of the mouth due to failure of the palatal shelves to come together, leaving a gap between the nasal passages and the mouth. CP can involve the hard palate and/or the soft palate. CL is usually identified through routine 20 week antenatal screening. CP involvement is usually identified soon after birth, as it cannot be reliably identified by ultrasound scans. The aetiology of CLP remains largely unknown, but is believed to be multifactorial, with interacting genetic and environmental aspects (National Health Service (NHS), 2013a)

The type and severity can vary widely between children. CL and CP can occur in isolation, or together. Approximately 25% of affected babies will be born with a CL, 50% with CL and CP, and 25% with a CP (Sommerlad, 1994). CLP can occur on its own (non-syndromic) or part of a broader set of congenital anomalies (syndromic). It is listed as a feature of more than 200 specific genetic syndromes (Wong & Hagg, 2004). However, for the purpose of this study, only fathers of children with non-syndromic CLP are included. CLP can affect one side (unilateral) or both sides of the mouth (bilateral). CL can appear as a small indentation (incomplete) to a wide gap running into the nostril (complete). CP can appear as an indentation at the back of the soft palate, to an almost complete split in the roof of the mouth (NHS, 2013a). Children may undergo treatment from

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[1] See Appendix 2 for further information about this organisation

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birth into young adulthood to treat aspects relating to both function and aesthetics, including repeated facial surgery, orthodontics and speech and language therapy (see Appendix 3). The lip-repair leaves a scar, but attempts are made to minimise its appearance by positioning it along natural lip lines.

For the purposes of this study, fathers of children with an isolated CP have not been included as there is no visible difference (although it could be argued that 'visibility' includes sounding different to the general population, as this cannot really be hidden).

### 1.3.1 Practical and Emotional Impacts of CLP

Children with CLP face multiple issues from birth, including early feeding difficulties, hearing loss, speech and language problems and numerous hospital admissions for corrective procedures (Bradbury, 1993). As highlighted by Turner et al. (1998), they also face a number of social difficulties, including subtle changes in patterns of interaction, overt bullying, and living in a society that places great value on aesthetics. The problems experienced may vary with age, and extend beyond the child to impact on other family members (Berk & Marazita, 2002; Kapp-Simon, 1995).

Research regarding parents' emotional and psychological experiences in this context has focussed mainly on reactions to diagnosis, maternal stress in the early years and on mother-child attachments (Nelson et al., 2012b). Parents deal with their child's CLP in various ways, from denial of their own and their child's psychological problems, to overt pre-occupation (Broder & Strauss, 1991). They often report a range of difficult emotions around the time of the birth, such as shock, grief, guilt, worry and disbelief (Lockhart, 2003). In addition, feeding difficulties, speech problems and numerous separations due to hospitalization have been hypothesised to impact on early parent-child attachment. The literature regarding the emotional state of mothers of children with CLP is inconsistent. For example, Montirosso et al. (2012) found no difference between mothers in the clinical group and controls in self-reported depressive symptoms.

This is in contrast to Murray et al. (2008) who found that mothers of children with CLP reported higher depression levels than controls.

Although some research suggests that mothers of children with craniofacial conditions report greater stress, lower competence, and increased marital conflict than controls (Speltz et al., 1990), more recent research suggested that CLP has little impact on parents' quality of life (Kramer et al., 2007). Qualitative studies are limited in the CLP field (Nelson, 2009). However, those that exist highlight the nuanced emotional reactions of parents, with affirmative feelings being experienced alongside anxiety and sadness, and they acknowledge potential for positive outcomes, such as recognition of personal strengths (Bradbury & Hewison, 1994; Eiserman, 2001; Johansson & Ringsberg, 2004; Klein et al., 2006).

In a review of the literature regarding parents' experiences of caring for a child with CLP, Nelson et al. (2012a) noted that accounts in parents' own words are rare and qualitative exploration of parents' experiences is sparse. There is also an overwhelming focus on mothers and a tendency for deficit-orientated approaches. This demonstrates the need for further research in this field in general, with particular attention to fathers, who are almost completely absent.

**PART II**

**1.4 Fatherhood and its Cultural Construction**

In order to understand the experiences of fathers of children with CLP, it is helpful to draw on the literature about the roles and experiences of fathers in general. Research into parenting 'norms', particularly fatherhood, has been predominantly conducted within the realms of psychology, family health and sociology. This has led to the development of theories which have had a powerful impact on the way in which we conceptualise fatherhood. This conceptualisation of fatherhood has evolved throughout time. Early psychoanalysts, such as Freud and Abraham, prioritised fathers, giving less consideration to the significant effects mothering may have on child development. The theorists of the mid-twentieth century, such

as Anna Freud, Klein, Bowlby and Winnicott, brought about a shift in perspective. They emphasised the significance of the mother-baby dyad and viewed it as the foundation of 'normal' healthy development (Etchegoyen, 2002).

Changes in the roles and expectations of fathers have been social and cultural rather than theory-driven. Pleck (1984) argued that the conceptualisation of fatherhood has transformed from "moral teacher" prior to the industrial revolution, to "breadwinner" following the industrial revolution, to "sex role model" post-Second World War, to "new, nurturing father". This "new father" is expected to be more actively involved in child-rearing than in the past, fulfilling the dual role of both provider and nurturer, and taking an active role in parenting (Battles, 1988; Lamb, 1997). This has further developed into the modern concept of co-parenting. However, a number of authors (e.g. Fishbein, 1984; LaRossa, 1988) argue these expectations can cause ambivalence, confusion and guilt for many men as they struggle to meet this ideal.

There is little recognition that fathers still face the inflexibility of a patriarchal and competitive world and some researchers (e.g. Fishbein, 1984) have questioned the availability of the expected dual role of provider and nurturer. Meeting the modern expectations of fatherhood is challenging when parallel changes to support this dual role have not widely taken place in relevant institutions, such as employment and healthcare. Furthermore, aside from legal entitlements, the culture of some work environments may compound these challenges due to long hours, target-orientated working etc. Despite changes in legislation (such as entitlement to family leave as well as paternity leave), these have not necessarily filtered down to employers. Also, although paediatric services aim to provide a family-centred approach to care, many continue to only be available during working hours. Turya and Webster (1986) found that fathers were 2.3 times more likely to bring their child to a health clinic appointment in the evening compared with during the day. Such flexibility in services remains uncommon. Many fathers also complain about how they are excluded during pregnancy and birth (e.g. Fenwick et al., 2012).

Over recent decades, research regarding fatherhood has received increased attention. However, as many authors (e.g. Klein et al., 2010; Phares et al., 2005) note, fathers remain hugely under-represented. Additionally, fatherhood research appears to have remained focussed on the extent and nature of fathers' involvement, rather than looking to understand their experience of fatherhood (Lupton & Barclay, 1997). Furthermore, although societal awareness of the varied roles and importance of fathers has continued to increase, particularly as a consequence of media attention (i.e. specific websites and magazines for fathers, and rights campaign organisations), mothers continue to be seen as the primary care-taker with fathers in peripheral roles as helpers (Greer, 2001; Hall, 1994).

## 1.5 Masculinity and Coping

The concepts surrounding masculinity are closely linked to those of fatherhood. Modern views of the 'new man' down-play differences between the sexes. Paradoxically, the new man is required to be sensitive and emotionally expressive, whilst also expected to be strong, take responsibility and act as a 'rock' for other family members to lean on for support (Chesler & Parry, 2001; Cook, 1984; Phares et al., 2005). Whilst fathers are increasingly socialised to want more from their role, and indeed are expected to deliver more, there is a lack of cultural and institutional support. Holland (1995) argues this is important because the style and degree of fathers' involvement is influenced by their perception of their roles, as well as the extent to which they are supported. The extra demands and expectations placed on fathers could lead to feelings of guilt and failure if they perceive themselves as having failed in meeting them (Jordan, 1990).

When interviewing first-time fathers as part of a longitudinal study, Barclay and Lupton (1999) found that participants commented on a lack of support and availability of services specific to their needs. In order to be able to provide appropriate services for men, it is important to consider the relationship between masculinity and help-seeking behaviour. Several studies (e.g. Condon et al., 2003; Lundqvist & Jakobsson, 2003; Morse et al., 2001; Pohlman, 2005) suggest a potential relationship between characteristics of masculinity and health status,

where the need to be strong and in control impedes the needs or desire to ask for help. This has significant implications for the way in which fathers' needs may be properly understood and tailored help offered.

In exploring the experiences of fathers of children with cancer, Chesler and Parry (2001) found that they reported feeling excluded and uncared for, as they were perceived to neither need nor want support. The authors posit that dominant masculinity and fatherhood discourses are entrenched within the systems men exist in (support, employment, and healthcare), significantly shaping their experiences of parenting a child with a chronic health condition. However, they also noted an element of positive transformative experience for some fathers, an area in need of further exploration in other chronic conditions, including visible differences.

## 1.6 The Importance of Fathers

The wider fatherhood literature highlights the complex and multi-faceted influence fathers have on the development of their child (Lamb, 2010).

### 1.6.1 Direct Influences

Research has shown that fathers influence children in nearly every characteristic studied. Active father involvement is associated with positive outcomes in a child's social functioning and development (Amato & Rivera, 1999), cognitive development, academic achievement (Nord et al., 1997), language development (Tamis-LeMonda et al., 2002), emotional wellbeing (Flouri & Buchanan, 2003; Williams & Radin, 1999) and physical health (Cabrera et al., 2000; reviewed in Lamb, 2010).

### 1.6.2 Indirect Influences

Saracho and Spodek (2008) highlighted the importance of acknowledging the indirect effects fathers have on child development. The quality of parent-child relationships, as well as child adjustment, has been shown to be affected by the

quality of the parental relationship (Cummings et al., 2010; Gable et al., 1994). The stress of having a child with a VFD has been linked with increased strain on the relationship between parents. This suggests a potential for lower quality parent-child relationships and increased risk of maladjustment of the child (Speltz et al., 1990).

Several authors argue that father involvement also has a beneficial effect on the mother-child dyad (Hovey, 2005). The level of support fathers provided to the child's mother influences the quality of the mother-child relationship, and indirectly, child adjustment (Lamb, 2000). This three-way relationship is a dynamic system, and the perceived helpfulness of fathers positively correlates with perceived family functioning (Gavin & Wysocki, 2006). However, the personal impact of having a child with a VFD may make providing this support difficult, therefore clinicians working with these families need to ensure that the fathers' needs are met and they are appropriately supported in their own right.

### 1.6.3 <u>Relevance to Visible Facial Difference</u>

Literature pertaining to experiences of fathers of children with chronic health conditions lags behind the general research into fatherhood (McNeill, 2004), which highlights the complex and multidimensional roles fathers play and at the direct and indirect influences they have on their children (Lamb, 2010). Research shows that parental acceptance is significant in a child's self-concept; dissatisfaction with body-image is believed to develop from the age of 2-3 years (Gilbert et al., 2002). Parents unwittingly communicate their feelings about the different appearance; these are likely to be internalised by the child (Kearney-Cooke et al., 2002), influencing the development of their body-image and self-esteem. Beard et al. (1989) argued that parents' ability to provide 'attuned acceptance' was the most influential factor in the child's adaptation. Helpful comments from parents are usually internalized and used as positive self-talk (Thompson et al., 2002), whereas lack of support exacerbates negative emotions (Furness et al., 2006). There is some evidence to suggest that both the expectations of and the support offered by the family are highly influential on the child's coping strategies (Rumsey, 2001). Wysocki and Gavin (2006) also found

that adolescents demonstrated better engagement in treatment and reported better quality of life when fathers were actively involved. Therefore, it is important not only to understand the experiences of fathers of children with a VFD, but also to provide them with appropriate support to cope with their own reactions to their child's situation and the challenges they face, in order that they can be in the best position to support their child.

Various studies have reported elevated levels of stress in parents of children with craniofacial conditions (e.g. Pope & Ward, 1997; Speltz et al., 1990). This, particularly when maintained over time, has been associated with poorer child adjustment and social competence (Krueckeberg & Kapp-Simon, 1993; Pope et al., 2005).  Family psychological health is acknowledged as crucial to children's psychosocial health (Kent et al., 2000), therefore fathers' perspectives need to be understood. Different risk and resilience factors have been associated with adjustment for mothers and fathers (e.g. Britton & Moore, 2002; Sloper, 2000), indicating that it would be insufficient to generalise findings from maternal experiences and adjustment to paternal experiences and adjustment.

**1.7 The Experiences of Fathers in the Context of Childhood Health Issues**

1.7.1 <u>Fathers' Experiences of Parenting a Child with a Chronic Health Condition</u>

In the past two decades, researchers have begun to pay more attention to the role and perspectives of fathers of children with chronic health conditions (e.g. Drotar, 1997; Seiffge-Krenke, 2002). Several authors suggest that fathers often face different stressors than mothers and may use different coping mechanisms (Gavidia-Payne & Stoneman, 1997; Katz, 2002; Speechley & Noh, 1992). Dewey and Crawford (2007) argue that this is influenced by their different experiences of and with their chronically ill child, therefore supporting the call to move beyond the emphasis on mothers and incorporate fathers (Ievers & Drotar, 1996). However, where this shift has begun, the focus has tended to remain on adjustment and the factors that influence it (e.g. Azar & Solomon, 2001; Brazil & Krueger, 2002). Few attempts have been made to explore in-depth the wider

experiences of these fathers in this context or the meanings they attribute to them.

Clark and Miles (1999) explored the experiences of fathers of children diagnosed with severe congenital heart disease. Their findings suggested that many conflicting emotional reactions were expressed: elation at becoming a father, grief at the loss of the 'healthy' child, and desire to develop bonds but awareness of the potentially fatal nature of the condition. Fathers also struggled with managing their feelings whilst simultaneously trying to maintain a position of control and strength for others. Research has also focussed on fathers of children with cancer, where fathers reported intense negative emotions, including shock, fear and denial (Chesler & Parry, 2001) but they also often felt excluded from their child's treatment (Sterken, 1996). However, in line with Clark and Miles (1999), fathers also expressed the need to 'be strong' and stay optimistic, ignoring their own reactions. However, in relation to hydrocephalus, Hornby (1992) also highlighted the potential for personal growth for some fathers as an outcome of parenting a disabled child.

Across wider paediatric literature, various studies have indicated that fathers' levels of distress are increased compared to norms and similar to that of mothers' levels of distress (e.g. Frank et al., 2001; Hoekstra-Weebers et al., 1998). Furthermore, findings within diabetes research suggest that paternal adjustment had a greater impact on the child's level of adjustment than the mother's adjustment did, potentially acting as a risk factor for the development of emotional and behavioural problems in children (Chaney et al., 1997; Connell & Goodman, 2002). Other studies have made similar claims (Roberts, 2003; Timko, et al., 1992). Paternal exclusion from research may therefore be a significant limitation.

### 1.7.2 Fathers' Experiences of Parenting a Child with a CVFD

As highlighted, fathers are significantly under-represented in paediatric research (Phares et al., 2005). However, in a few cases, attempts have been made to include fathers in research regarding CVFD. In a case-control study looking at

reports of stress in families of infants with single-suture craniosynostosis[2] (SSC; Rosenberg et al., 2011) 246 mothers and 210 fathers of cases, as well as 253 mothers and 220 fathers of controls, completed the Parenting Stress Index (PSI). Parents of infants with SSC demonstrated only slightly higher levels of child-related stress than parents of healthy children. Further analysis revealed this related to unexpected health and appearance issues, suggesting the violation of the common assumption that one's child will be physically normal and have no 'beyond normal' needs as central to the higher scores. Within the SSC group, mothers reported higher parent-related stress and fathers reported higher child-related stress (they perceived less adaptive child behaviour, greater child demandingness, parent isolation or parent depression).

Although high participant numbers (including fathers) were achieved, several limitations are evident. Firstly, the narrow focus on 'stress' does not allow for the influence and ramifications of other aspects of psychosocial experience to be explored. The use of a standardised questionnaire, with restricted response options, compounds this limitation. Furthermore, given that the PSI is a general measure designed for use with 'typical' families, it may not have allowed the distinctive aspects of parenting a child with a craniofacial condition to be captured.

Another study looked at stress and family satisfaction in the context of children with port-wine stains (PWS) (Miller et al., 1999). Various standardised questionnaires were completed by 24 mothers and 22 fathers. The degree of distress experienced was associated with the child's age, family cohesion, parental worry, and satisfaction with communication from professionals. However, as initial *T*-tests found no significant difference in scores between mothers and fathers, they were pooled for further analysis and combined results reported, again limiting opportunities to understand the specific experiences of fathers.

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[2] A craniofacial condition in which a skull suture is permanently fused, resulting in an abnormal skull shape and a possible impact on neurodevelopmental functioning.

One study has recently attempted to specifically explore fathers' experiences in relation to craniofacial anomalies (Klein et al., 2010). A variety of conditions were included: hemifacial microsomia (abnormal development of the lower face); Apert syndrome; achondroplasia (short-limbed dwarfism); and CLP. Participants commented on the fulfilment of being a parent, as well as concerns and difficulties. Most participants were hopeful about their child's future; however, some expressed on-going concern. A particular concern was societal reactions to their child, and in the case of girls that they might not be easily accepted if they do not fit the female stereotype of beauty. A third of fathers cited medical difficulties as the greatest challenge, as well as the general emotional burden. These results fit with the positive and proactive parenting style reported by the mothers (Klein et al., 2006) and also demonstrated fathers' awareness of their child's strengths and personal qualities.

However, several limitations were evident in this study. For example, the research followed a primary study of the experiences of mothers, who were then asked for permission to contact the fathers, thereby placing them in a gate-keeper role, which may have impacted on the type of participant eventually recruited. The resulting sample size of nine fathers was quite small considering the largely quantitative methodology (although some qualitative elements were incorporated). Lastly, the short, structured nature of the interviews will have impacted on the level of detail obtained by the researchers. The fact that the interviews were conducted by telephone may also have had implications in terms of how the participants engaged with the researcher and therefore may have impacted on the type and depth of information they provided. These issues all have implications for the wider consideration of the results and demonstrate the need for further, in-depth exploration of this topic. Furthermore, the few available studies were conducted in America, where privatised medical treatment is the norm and therefore financial concerns may play a role in influencing the experiences of fathers which has less relevance to the UK population.

### 1.7.3 Fathers' Experiences of Parenting a Child with CLP

Nelson et al., (2012b) presented the only research to focus specifically on parents' experiences of their child's CLP treatment, although wider literature suggests this may be anxiety-provoking for them (Baker et al., 2009; Eiserman, 2001; Johansson & Ringsberg, 2004; Klein et al., 2006). A total of 24 mothers and 11 fathers were recruited. Grounded Theory was used in exploring this issue, which highlighted the emotional tensions experienced during long-term CLP treatment. This was characterized by conflicting emotions regarding their child's 'normality' and 'difference', as well as regarding surgery, and worries about stigmatisation of their child and their family. Parents' views in relation to having a child with CLP have previously focussed on mothers' perspectives in the child's early life. Nelson et al.'s (2012b) study furthers existing research by exploring the longer-term experiences more in-depth and by including fathers' views. An additional benefit is that the research was conducted in the UK. However, mothers outnumbered fathers and, furthermore, where both parents participated, couples were predominantly interviewed together. It is likely, therefore, that mothers' perspectives are dominant, leaving a lack of clarity about fathers' perspectives.

In their broader study about experiences of parents of children with CLP, Johansson and Ringsberg (2004) also interviewed the majority of their 12 participant fathers jointly with the mothers. Findings highlighted the difficult reactions experienced when seeing their child for the first time, the mixed reactions from other people and hopes and concerns regarding the process and outcome of surgery. However, the fathers' voices are once again immersed amongst views expressed by mothers.

Berger and Dalton's (2009) questionnaire-based study looked at psychosocial adjustment of adolescents with CLP and their parents; of a total of 277 participants only 14 were fathers, therefore specific results relating to fathers were not reported. Similarly, in Turner et al.'s (1997) research into psychological outcomes of children with CLP and their parents, 130 parents were recruited

however the number of fathers recruited was not given and no distinction was made between mothers and fathers in the results.

One study has attempted to specifically explore the experiences of fathers of 'children who are not the same' (Baumann & Braddick, 1999), using Human Becoming Theory (Parse, 1992) to analyse transcripts of semi-structured interviews. This is a nursing theory that suggests people define the meaning of their health and well-being based on their chosen values (Baumann & Braddick, 1999). Of the 16 participants, six had children with CLP and two involved other craniofacial differences. Other conditions included Down Syndrome, severe learning disabilities, and major cardiac anomalies, with four of the children experiencing more than one major anomaly. Findings were presented in broad terms, with no differentiation between the fathers of children with significantly different conditions, and are therefore of limited use in understanding the nuances specific to fathers of children with CLP.

## 1.8 Issues with Existing Research on Fathers

Costigan and Cox (2001) highlighted the difficulty in recruiting fathers, which may also explain their limited presence in research in general. Silverstein (2002) argued that paediatric research has remained theory driven; dominant discourses about child-bearing and child-rearing within theory have centralised mothers, and fathers have been marginalised as a consequence. Strikingly, even the sole study specifically exploring fathers' experiences of parenting a child with a craniofacial anomaly was part of wider research exploring maternal perspectives (Klein et al., 2006). In addition, data collection involved brief structured telephone interviews and a small sample (9 fathers). Both these factors may have affected the quality of data collected.

However, the assumption that fathers of children with chronic conditions hold a restricted role in simply supporting the mother is beginning to be challenged in recent research (e.g. Pelchat et al., 2003). Research regarding fathers' experiences has increased in the past two decades, possibly as a consequence of the 'involved father' discourse and increased awareness of the role of the

father in child development (Lamb, 2010). However, fathers remain woefully under-represented in research and clinical treatment within paediatric psychology (Phares et al., 2005). Furthermore, various problems are evident in the available literature. Historically, fathers have predominantly been seen in the role of 'breadwinner', and as a consequence there has been a lack of attention to their role in (or experience of) child-rearing (Zimmerman et al., 2000). As West (2000) notes, past research involving 'parents' usually means 'mothers'. Furthermore, even where they are taken into account, it is often from a matricentric perspective (Robinson & Barrett, 1986). Studies involving both parents often fail to distinguish between mothers and fathers when reporting results, so it remains unclear what contribution fathers have made and how representative the findings are of their experiences. Where the distinction is made, samples often have a much higher percentage of mothers, for example in Berger and Dalton's (2009) study only 5% of participants were fathers, and only 16.5% in Baker et al.'s (2009) study. These issues make it difficult to establish what contribution fathers have made and how representative the findings are of their experiences. In particular, we rarely hear the voices of fathers articulating their concerns, struggles and triumphs, therefore know little of the nature of their experiences (Chesler & Parry, 2001).

The majority of studies employed standardised measures to examine predefined concepts. The limitation of this approach is that additional factors, which may be relevant to the experience, are not explored because there is no opportunity for novel information to emerge. In addition, only tentative conclusions can be drawn from studies using mothers' reports on behalf of fathers as they are not based on first-hand accounts. Whilst qualitative researchers have begun to directly explore the experiences of fathers of children with chronic health conditions, McNeill (2004) argues there is a continuing need for in-depth understanding of their experiences and the subjective meanings they attribute to their situation. In light of these limitations, there is a need for in-depth exploratory research into fathers' experiences of parenting a child with a CVFD. Furthermore, it is important to consider fathers' diverse experiences in the context of the social-political, cultural and relational influences in which they occur (Lundqvist & Jakobsson, 2003; Pohlman, 2005). Linked to this, existing research does not tend to highlight men's positive experiences, which could provide valuable information in terms of the

way we conceptualise fatherhood in this context, as well as informing service provision. Furthermore, we know little of the experiences of fathers from different cultures in relation to how they experience having a child with a CVFD. Looking beyond research, services also tend to take a matricentric perspective with fathers being seen as secondary carers (West, 2000). Conducting further research with fathers will not only help to inform practice, research and policy, but will also help to reduce the stereotype that fathers are uninvolved with their children or uninterested in their own contribution to the family system (Mitchell et al., 2007).

## 1.9 Research Questions

The literature base regarding the experiences of fathers of children with chronic health conditions is beginning to expand. However, within the field of CVFD, and concerning CLP specifically, there remains a paucity of research. As discussed, research that does exist has many limitations: investigating deficit-focussed, pre-defined concepts using small sample sizes, and perpetuating the lack of clarity in the failure to differentiate between findings from mothers and fathers in 'parent' studies, to name but a few. As result, fathers' experiences in this area remain poorly understood. The present study will therefore aim to contribute to the literature by gaining a more fine-grained understanding of what it is like to be a father of a child with a CVFD, specifically CLP, by adopting a qualitative methodology and recruiting fathers directly. Although guided by the researcher's prior knowledge, the semi-structured nature of interviews used for Interpretative Phenomenological Analysis (IPA) should allow salient experiences to emerge, developing an in-depth understanding of their experiences (see Chapter 2).

The research questions are:

1. How do men experience being the father of a child with CLP?
2. How do fathers of children with CLP perceive their roles within the family?
3. How do fathers experience being supported in this context?

# CHAPTER 2: METHODOLOGY AND METHOD

This chapter outlines the chosen research methodology. Consideration is given to the rationale for adopting a qualitative approach, the researcher's epistemological position and the relevance of IPA to this study. This is followed by details of the method employed, including recruitment, data collection, and analysis procedures.

## 2.1 Methodology

### 2.1.1 Why Choose a Qualitative Approach?

Qualitative research aims to develop deep understandings of how people perceive their social realities and subsequently, how they act within the social world (Hughes, 2006). Qualitative methodology aims to enable to the collection of fine-grained detail of experience and understanding. This can involve a variety of tools and techniques, for example interpretative analysis of transcribed verbal data or discourse analysis of published text. Relatively little is known about how men understand their experiences as fathers of children with CLP or the meanings derived from them. This suggests, therefore, that it would be appropriate to use qualitative methods when exploring these aspects.

Attempting to structure research in this area aimed at testing specific hypotheses (where a quantitative approach may be better suited) would be premature. The research questions are therefore exploratory in nature and aim to allow for the participants' own understandings, meanings and explanations to be expressed without limiting data to set, pre-determined options. In addition, the aim was to understand the idiosyncrasies of these experiences rather than seek to 'discover' a single objective 'truth'. Ashworth (2003, p.24) argues that qualitative research is able to reveal the detail of the "diverse experiences of individuals and…provide a hearing for the voices of the excluded" in a way that quantitative research cannot.

2.1.2 <u>Epistemology</u>

We all hold frameworks of beliefs and assumptions, implicit and explicit, about the world around us. Inter-related concepts of ontology (what is there to know?), epistemology (how and what can we know?), methodology (what approach do we take to gaining knowledge?) and method (how are data collected?) inform these perspectives (Denzin & Lincoln, 2005). It can be argued that it is not possible to completely set aside this knowledge (Heidegger, 1962), therefore it influences all research. Willig (2001) emphasises the importance of researchers identifying and being transparent about their position in relation to this.

Epistemological positions can be broadly understood to exist on a continuum. At one extreme lies the realist stance that assumes that a single 'truth' about a reality exists and is discoverable, therefore seeks objective knowledge using a paradigm of cause and effect. Historically, psychological research has largely been conducted from a realist epistemology (Henwood & Pigeon, 1992). At the opposite end lies the relativist position, which argues that knowledge is socially constructed within systems of meanings and through discursive practices, and is therefore primarily concerned with the search for meanings (Willig, 2001). Perspectives such as critical realism exist between these positions.

A critical realist epistemology assumes 'real' phenomena exist and are examinable, but that our understanding can only ever be partial at most (Nightingale & Cromby, 1999). Specifically, it acknowledges that meanings are negotiated within a particular context and that the particular context will also influence how the experience is constructed; "…representations are characterised and mediated by culture, language and political interests rooted in factors such as race, gender or social class" (Pilgrim & Rogers, 1997, p.37). Furthermore, these experiences are meaning-rich and the language used to describe them reveals something about that meaning (Larkin et al., 2006). As this research was concerned with exploring individual experiences, and the critical realist position emphasises the search for meaning, there was a good fit between the aims of the research and the researcher's epistemological position. In

addition, this perspective acknowledges the researcher's active role in attempting to make sense of participants' sense-making (Smith & Osborn, 2003).

### 2.1.3 <u>IPA</u>

IPA is committed to exploring personal lived experiences, the meaning of these experiences and how people make sense of them (Smith & Osborn, 2003). It draws on three theoretical underpinnings; phenomenology, concerned with people's perceptions of the world and their experiences; hermeneutics, the study of interpretation and is concerned with the way in which people understand and make sense of these experiences; and idiography, concerned with the particular and individual rather than the general and nomothetic (Smith et al., 2009).

IPA therefore emphasises that people are not passive entities subject to an objective reality, but instead holds that "…they come to interpret and understand their world by formulating their own biographical stories into a form that makes sense to them" (Brocki & Wearden, 2006, p.88). When adopting IPA as an approach we strive to understand the participant's personal world, but must accept that only partial knowledge can ever be gained. As direct access to participants' experiences is impossible, the analysis produced "is always an *interpretation* of the participants' experiences" (Willig, 2008, p.57). Thus, a 'double hermeneutic' is involved, with researchers trying to make sense of the sense-making process that participants engage in (Smith & Osborn, 2003). The result is a co-constructed account. IPA is therefore concerned with trying to understand experiences from the point of view of the participants, consistent with its phenomenological origins, but also draws on both empathetic and questioning hermeneutics in permitting the researcher an element of critical appraisal of these accounts (Smith, 2004).

#### *2.1.3.1 The advantages of IPA for this research*

Several reasons highlight IPA as the most appropriate approach given the particular aims set out. Firstly, IPA seeks "the detailed examination of human lived experience…in a way which as far as possible enables the experience to be

expressed in its own terms" (Smith et al., 2009, p.32). This is in keeping with the aim of exploring the individual experiences of men as fathers of children who have a VFD. Secondly, IPA allows an exploratory approach within an analytic framework, which is appropriate for under-researched topics. The commitment to the idiographic perspective allows the role of social, cultural and biological influences to be acknowledged. The potential to uncover both individual perspectives and shared elements is important and relevant, as this is a population whose perspectives are rarely explored or voiced (Shaw, 2001). Thirdly, IPA goes beyond phenomenology in acknowledging a double hermeneutic, i.e. the researcher's role and their influence on the conclusions drawn from the data. The emphasis on interpretation over mere description also means that a more coherent narrative can be developed from synthesised data (Langdridge, 2007). Finally, a key strength of IPA is the potential to reveal unanticipated phenomena (Shaw, 2001). The flexible and open-ended methods involved in data collection allow participants to raise aspects of experience which may not have been anticipated by the researcher. Therefore it does not restrict the data to pre-defined constructs determined by the researcher, and thus can be argued to more accurately reflect participants' experiences.

### 2.1.4 The position of the researcher in relation to the research

As discussed, IPA recognises that knowledge is produced as a result of the participant-researcher relationship (Larkin et al., 2006). Kvale (2007) notes that a researcher's personal biography, presence, experiences in the field and reflexivity they bring to the role are important and influential factors on this process. It is therefore essential to be explicit about my position in relation to this research in order to facilitate transparency and evaluation (Elliott et al., 1999).

I engaged with this research holding a number of identities that may influence it. Some of these I introduce here and expand upon in Chapter 4. I am 30 years old and identify as a heterosexual female of white European ethnicity and middle-class economic status. I do not have children but I am an aunt (in-law) to a child with a cleft palate. I also suffer from facial eczema, which is generally visible at least to some degree. I am a trainee clinical psychologist and my training has

exposed me to a much more critical approach to understanding experiences and distress than the normative ideas and understandings I held prior to commencing training. In terms of theoretical orientation, I favour systemic approaches, looking to the influence of relationships, networks, wider context and dominant narratives in understanding people's experiences. I acknowledge that these factors individually and collectively are likely to have influenced interactions with participants and the way I conceptualised their experiences.

## 2.2 Method

### 2.2.1 <u>Recruitment Procedure</u>

#### *2.2.1.1 Ethical considerations*

Approval for this research was obtained from UEL's School of Psychology Ethics Sub-committee (see Appendix 4). Ethical approval was also obtained from Changing Faces' Research Council (see Appendix 5)[3]. Further ethical approval was not required from CLAPA as they advised that existing approval was sufficient. All material was anonymised by assigning a research code and pseudonym to each participant (including pseudonyms for family members, friends and professionals mentioned). Consent forms were kept in a locked cabinet (separate from transcriptions and demographic details). Electronic information was kept securely on a password-protected computer.

Allen and Baber (1992) highlight the ethical and methodological challenges caused by the inherent power imbalance in the researcher-participant relationship. However, Miller and Glassner (1997) argue that qualitative studies exploring less known topics may go some way to addressing this imbalance, as participants may recognise themselves as experts in this area. In addition, "…providing a non-judgemental and confidential environment, where participants can talk about their experiences in an open and unhurried manner with someone who is genuinely interested in what they have to say, can be of mutual benefit to

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[3] See 2.2.1.3 for an explanation of why Changing Faces are not present here on in.

researchers and participants" (Lowe & Gill, 2006, p.594). Regardless, given the topic under discussion, participants may become distressed when discussing their experiences. At the end of interviews, participants were offered contact information for various organisations in case they required further support (see Appendix 6).

### 2.2.1.2 Invitation to participate and recruitment procedure

The research was advertised on the CLAPA website and Facebook pages. The organisers of local CLAPA branches across the UK were also contacted and provided with electronic copies of the Participant Information Sheet (see Appendix 7) to forward to mailing lists. Hard copies were also posted for circulation at branch events. In addition, the researcher created Facebook and Twitter research accounts (separate to personal accounts), for the sole purpose of advertising the research. No personal data were made available via these media, other than that already provided on the Participant Information Sheet.

Participants were offered the option of being interviewed at UEL, their home, their workplace or via Skype video-link. They were also offered a choice of times, including evenings or weekends. Woods (1988, p.70) argues that offering participants choice regarding the time and location of research interviews is "not only a matter of convenience and availability, but…may give them a sense of control and confidence", thus contributing to development of good rapport. The day before the interview a reminder was sent by text message.

### 2.2.1.3 Inclusion and exclusion criteria

Within IPA researchers use purposive sampling (selecting participants based on criteria that are important to the research questions, Barker et al., 2002) with the aim of obtaining homogenous samples (Smith & Osborn, 2003). This research attempted to adhere to these strategies by implementing certain inclusion and exclusion criteria in order to achieve greater homogeneity of the sample. Inclusion criteria required men to be over 18 years old with a biological child born with CLP. An upper age limit for the child was set at 16 years old. Older children

or adults with CLP may have experienced differences in treatment techniques and timeframes compared to a younger cohort due to medical advances and service developments in the last ten to fifteen years. Involving fathers of a younger cohort would also mean that reflections on their experiences would not be overly retrospective. The exclusion criteria included the child in question having any severe health problems, an acquired visible difference (e.g. scars as a result of trauma), or visible difference secondary to another health condition (e.g. cancer). Exclusion was also based on either biological parent having CLP, as this may have had implications specific to these fathers.

Although the initial intention was to focus on CVFD more broadly, once the project had received ethical approval and had been scoped in more detail some amendments were made. In order to improve homogeneity, focus was placed on CLP as a sample population (as the most common CVFD condition), and everything structured accordingly[4]. Approval was obtained for these amendments (see Appendix 8).

### 2.2.1.4 Consent

Informed consent was sought from all participants. Participants were asked to re-read the Information Sheet, confirm they met inclusion criteria and sign a consent form (see Appendix 9). For the Skype interview, documents were posted in advance and the signed consent form returned. Verbal consent was also recorded.

### 2.2.2 Participants

### 2.2.2.1 Participant numbers

This research aimed to recruit six to ten participants, deemed to be an appropriate number for the completion of IPA within a professional doctorate

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[4] This explains any difference between stipulated inclusion/exclusion criteria and those outlined in documentation provided in the appendices, which may appear to be aimed at a broader audience. This also explains why Changing Faces does not appear again in this account.

context (Smith et al., 2009).  Twenty-three people expressed interest: seven did not respond to follow-up contact; six were excluded as they did not meet inclusion criteria; eight were recruited. See Chapter 4 for consideration of particular recruitment issues and the implications thereof.

### 2.2.2.2 Demographics

Participant details (see Appendices 10a and 10b) were anonymised. All participants identified as white British. Six of the mothers were identified as white British, one as Southeast Asian and one half British half Pakistani. All parents except one were cohabiting at the time of interview. Seven participants held a variety of public and private sector occupations, and one was a full-time student. Their average age was 37 years 3 months. The average age of the children was 4 years 6 months.

### 2.2.3 Data Collection Procedures

### 2.2.3.1 Semi-structured interview

Interviews are "a powerful method of producing knowledge of the human situation" allowing researchers unique access to the participant's lived world and experiences (Kvale, 2007, p.8). In line with the aims and commitments of IPA, Smith et al. (2009) advocate that participants should be encouraged and given the opportunity to tell their story, which will also maximise the potential of obtaining rich data sets. The flexibility provided by semi-structured interviews allows engagement in dialogue led by the participant's answers, positioning participants as the "experiential expert on the subject" (Smith & Osborn, 2003, p.57). Therefore, one-to-one, semi-structured interview was deemed to be the most appropriate data collection method.

### 2.2.3.2 Interview schedule development

Smith and Osborn (2003) argue that the development of interview schedules is necessary in order to force researchers to explicitly consider what they think and

hope might be discussed, as well as potential difficulties that might be encountered and how these might be handled. They suggest this preparation allows better engagement with the participant's account during the interview.

Initially, consideration was given to the broad range of issues to be covered based on areas of interest in relation to the topic, taking into account related research. These were then logically sequenced and broad, open questions were developed for each area with possible prompts added. Questions regarding more sensitive aspects were placed later in the schedule (Smith, 1995). Advice was also sought from other researchers in the field (e.g. Prior, 2012). The schedule was reviewed as part of UEL's research proposal process and feedback incorporated. It was then presented at the London IPA group. Amendments were made based on subsequent discussions but positive feedback was received overall. The final schedule (see Appendix 11) provided a guiding framework but was not rigidly adhered to. This allowed participants to raise topics and perspectives potentially not anticipated by the researcher but which participants considered to be important (Bannister et al., 1994).

### 2.2.3.3 Interview procedure

Attempts were made to ensure that interviews would be able to proceed without interruption, such as checking that participants did not have other obligations and that there was a quiet space to conduct the interview. Five participants were interviewed at home, two at work and one via Skype. Interviews were held in private rooms in order to maintain privacy and confidentiality. Initially engaging in small-talk helped participants 'settle in' to the conversation. The information sheet, style of interview, and consent forms were discussed and participants were then asked to describe their family structure and demographics.

IPA interviews should "start with the most general possible question and hope that this will be sufficient to enable the respondent to talk about the subject" (Smith & Osborn, 2003, p.60), therefore participants were simply asked to talk about their experiences in this context. Conversations were then guided as much as possible by participants, using prompts where necessary and only later

addressing topics not spontaneously considered by the participant. Interviews ranged from 54-120 minutes (average 88 minutes).

### *2.2.3.4 Maintaining safety*

Consideration was given to the researcher's safety. Various safeguards were put in place, such as a third party being aware of the location and anticipated timings of the interviews, and the researcher informing them once the interview was over.

## 2.3 Data Analysis

Smith and Osborn (2003, p.52) state that "there is no single, definitive way to do IPA". Bearing in mind the debates and critiques this position invites, the following method was developed with guidance from a number of papers and books (e.g. Smith, 1996; Smith & Osborn, 2003; Willig, 2001), as well as attending training by Hefferon and Gil-Rodriguez (2012).

### 2.3.1   Open Engagement with the Data and Initial Response

### *2.3.1.1 Transcription*

Interviews were transcribed verbatim, with identifying details changed or omitted. The process of listening and re-listening involved in transcription is an important element of engaging with the text (Tilley, 2003). IPA requires some attention to interactional aspects of interviews, therefore the researcher's questions, responses and comments have been included, as well as false starts, significant pauses, interruptions and laughter (Smith & Osborn, 2003). Margins were left on both sides for notes.

### *2.3.1.2 Reading and re-reading*

Each transcript was read several times to increase familiarity with the content and structure, as well as develop a better sense of each participant's account. This process encouraged reflection on initial thoughts and reactions to the data, whilst

attempting to bracket pre-conceptions (Willig, 2001). This helped guard against conducting a "quick and dirty reduction" (Smith et al., 2009, p.82). The location of rich data and contradictions was noted.

### 2.3.2   Initial Exploratory Coding

Arguably the most time-consuming and intricate element of analysis, this coding involves exploration and coding of the text at three levels: descriptive; linguistic processes; interrogative and conceptual (see Appendix 12). Notes for each level were made in the right-hand margin, using different colours to keep track of the different steps. Other observations were also noted. Several questions were also held in mind: 'what does the participant achieve through offering this particular understanding?', 'what other meaning might such experiences have?' and 'how else could they be understood?'. Key words/phrases which seemed to capture the essence of the account were underlined.

### 2.3.3   Making Connections

Next, connections between exploratory notes were mapped, with the aim of reducing the volume of material without losing the detail in order to generate 'emergent themes' (Smith et al., 2009). These were noted in the left-hand margin. The iterative process involved continuous movement between exploratory notes, interpretation and source text to check that themes were grounded in the data and continued to reflect the participant's own words. Reading, reflecting, re-reading and re-arranging enabled structure to emerge.

### 2.3.4   Clustering Emergent[5] Themes

Emergent themes were then structured into clusters, which were labelled and entered into a spreadsheet with corresponding quotes. Theme mind-maps were then created for each participant. Using a reflexive journal and attending a peer

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[5] The phrase 'emergent' themes is used here for ease of reading and should not be understood to reflect a 'realist' epistemological stance.

supervision group supported this process, facilitating reflection on whether themes were informed by the participant's account or the researcher's beliefs.

### 2.3.5   Cross-case Analysis and Developing Super-ordinate Themes

Once this process had been completed for all transcripts, each participant's themes (colour-coded in order track which theme belonged to which participant) were then moved into small clustered groups on the basis of an element of commonality. This process included discarding themes if insufficiently represented or peripheral to the research (Willig, 2001). A process of abstraction involved identifying themes within themes and elucidating the nature of potential super-ordinate themes. Super-ordinate themes were given a label which reflected this. Reid et al. (2005) advocate a 'less is more' approach, with Hefferon and Gil-Rodriguez (2011) highlighting the danger of under-synthesising data, resulting in a large number of super-ordinate themes. This pitfall was hopefully avoided by raising the level of interpretations, achieving a small number of coherent, well-synthesised super-ordinate themes. For a worked example of analysis see Appendices 13-16.

### 2.3.6   Constructing a Narrative Account

The final task was to develop a coherent narrative account of the findings. Incorporated in this is how the researcher came to the understandings and meanings they have reached in relation to the data and findings. Extracts are used to support the narrative. Three dots […] indicates omitted text (see Appendix 17 for an example of how quotes were refined).

# CHAPTER 3: RESULTS

This chapter presents the findings of the analysis of the eight transcripts. Table 1 outlines the super-ordinate themes and corresponding sub-ordinate themes. It is important to note that themes are not considered as distinct aspects of experience but should be understood as being inter-connected (see Appendix 18).

Each theme will be discussed in turn, supported by direct quotations from transcripts. Divergent experiences within themes are also highlighted. A table of participant representation across themes can be found in Appendix 19.

| SUPER-ORDINATE THEMES | SUB-ORDINATE THEMES |
| --- | --- |
| **Loss of the Perfect Child** | • Shock of Diagnosis<br>• Why Me?: Blame and Guilt<br>• Uncertainty: What Does it All Mean?<br>• The Anxiety Driven Need for Information |
| **The Power of 'Normality'** | • The Changed Child<br>• The Influence of Societal Beliefs<br>• Personal Perceptions: Conceptualising CLP |
| **The Expectations and Roles of Fathers** | • "I fell at the first test": The Centrality of Role as Protector<br>• Who Supports Who?<br>• Unexpected Outcomes<br>• Making Up for CLP: Compensating and Counteracting |

**Table 1:** Super-ordinate Themes

**3.1 Loss of the Perfect Child**

This theme conveys the initially devastating emotional repercussions of the diagnosis, which was present across the accounts. Participants' responses to the subsequent uncertainty are also illustrated.

### 3.1.1 The Shock of Diagnosis

Present in this theme is the impact of diagnosis on the idealised expectations of pregnancy and fatherhood. In terms of psychological impact there was a shared experience of initial shock and disbelief amongst all participants, illustrated by George and Joe:

> *When we first found out, [it] was a massive shock* (George, 54)

> *It was like woah, now having had three children, I mean it was complete and utter shock.* (Joe, 238-239)

This highlights how unexpected the diagnosis was for these fathers. It is also indicative of the idealisations and fantasies that are held by fathers, whereby the potential reality for anything other than ideal is ignored or forgotten. This in itself could also be understood as a way of managing anxiety about the unknown, for first time fathers for example. For Dan, his expectations of the scan compounded this shock:

> *We kind of, just kind of expected to rock up and pick some pictures up, if that makes sense, we weren't prepared for anything to be wrong, so we were in there and sort of it kind of, it blew our minds.* (Dan, 1415-1420)

In many participants' accounts, the moment of diagnosis had an immediate negative psychological impact:

> *Hang on a minute, you know, we we're we're reeling about what you've just told us, we, can we just have some time to think.* (Stuart, 73-74)

This account gives a sense of the overwhelming and devastating nature of receiving the news. The shock appears to be compounded by a huge amount of uncertainty, as highlighted by James:

> *We were too much in a swirl of worrying about what do we do? How do we do it? Does it change things? Doesn't it change things? What are people going to say?* (James, 584-586)

Interestingly, James describes one of the first reactions as worrying about other people's reactions, and seems to indicate an underlying fear of how this will change perceptions of him as a father. Although James described the diagnosis as an initial shock, already having a child appears to have mitigated the impact of the diagnosis, as did his previous experience of CLP:

> I: *What was that like for you finding out?*
> James: *It was alright, I mean it was, it was our second kid so we didn't have as many of the worries about having a kid as you do before…well I knew people with cleft lip and palates before, I've been to school with them and, and I've worked with a guy who's got a cleft lip and palate, so it was like ok, so it doesn't make any difference* (James, 115-125)

This differs from Joe's experience, where having a child with CLP after three 'normal' children appeared to increase his sense of shock. However, this also came across as a somewhat detached response, suggesting that James was burying his emotional reactions and not allowing himself to display any tangible disappointment or worry at the diagnosis to maintain the appearance of strength and composure. The role of fathers in supporting mothers is explored further in 3.3.2.

The timing of diagnosis was also raised by some participants, who shared relief at having found out prior to the birth:

> *We were kind of able to get our head round it so that when she was born actually it didn't matter, we dealt with it, we kind of put it into its boxes and we knew what we had to deal with. (Dan, 825-829)*

Dan reframes ante-natal diagnosis as potentially a more positive experience than post-natal diagnosis, providing him with time to gather information and process his feelings about the diagnosis before the baby was born. This appears to have helped him in managing some of his anxiety, leaving him feeling more prepared (explored further in 3.1.4).

However, also present in many accounts was the loss of the expected (and idealised) pregnancy and fatherhood, as illustrated by John, Nick and David:

> John: *It's amazing in those couple of minutes the amount of things that go through your head, you know the clichéd stuff about playing football and you know and all the rest of it […] it's like having a car crash and everything slows down and your head floods full of things and images of stuff of what's going to happen with you and your son [tearful]*
> I: *That's so touching*
> John: *Ah yeah it was like it was a brilliant moment but then [pause]*
> I: *How long after that did you find out about the cleft?*
> John: *Oh minutes, minutes. And so it was like I, I wasn't able to sort of grieve for oh shit what if all of that doesn't come to pass* (John, 593-607)

> *Even when she was diagnosed I was still excited about having a baby, maybe a shine was taken off possibly* (Nick, 1549-1551)

> *I suppose thinking back on it also we'd put everything on a pedestal and built it up as this really amazing thing – which it is – and then it*

*was just met with disappointment which gradually got less disappointing.* (David, 168-170)

These extracts illustrate the impact of the diagnosis on the perception of having a child and becoming a father. Framing experiences as becoming *"less disappointing"*, rather than getting 'better', suggests that the overall balance of the experience remained negative, with the idealised 'perfect' child and fatherhood lost forever.

### 3.1.2 Why Me? Blame and guilt

Following the initial reaction of shock at the diagnosis, there was a shared sense of wanting to find out why this had happened:

*Why is that happening to us? Why has it happened to me?* (David, 238-239)

*I think that's the big, that was the biggest question we had on our minds first thing, was like so why? Nobody can answer that and that, that's a question that we've kind of had to let go because like I say we thought we'd done everything by the book […] it's just one of those things.* (Dan, 1577-1584)

Dan's active attempt to ensure the 'perfect' pregnancy by doing *"everything by the book"* appears to have fuelled his disbelief at the diagnosis. Both accounts imply the perception of CLP as a punishment; a sense of 'bad things only happen to bad people', fuelling a desire to know what they did 'wrong' to 'deserve' this.

*I still feel it now, so there are some days when I think what did I do wrong?* (Dan, 144-146)

It is also clear from Dan's comment that the sense of guilt and self-blame are not isolated to the pregnancy, but continue to affect fathers over a long period of

time. This sense of responsibility and self-blame was shared by most participants and gave rise to a search for answers:

> *I spoke to dad and he has a great uncle […] who's now 90-something, and he was born with a cleft […] and, it was that, oh God, have I done that, is there something that inherently carried in my genes which has caused that?* (Joe, 276-282)

> *I don't know whether it was a case of wanting to blame somebody or looking for blame and just not accepting that it's just one of those things, that was kind of where it started from.* (David, 497-499)

Joe's family research was a response common to many of the fathers; this can be understood as an initial step in their attempts to alleviate self-blame or perhaps to gain a sense of control. However in Joe's case, evidence of CLP in the wider family serves to reinforce his sense of guilt. David illustrates the struggle in coming to terms with the diagnosis. His use of the word 'blame' rather than, for example 'understanding', indicates his underlying feelings about CLP as something 'gone wrong', for which someone must be responsible.

In contrast, James' account suggested acceptance:

> *Ah, the explanation – I did a bit of reading around and the explanation was quite simple […] it happens, it's one in 700, nobody really knows why. Yeah. Ok, it's just the last bit to form and it doesn't form properly. Shit happens. […] I haven't gone on this big quest to try and find out why, and whether it's because of our family or Layla's [wife] heritage whatever – no, hasn't had any impact at all, so why bother with those questions?* (James, 664-670)

However, this could also suggest an element of masking his initial reaction or presenting himself this way in order to demonstrate acceptance of CLP and down-play any impact on him or his child, in order that neither of them are seen as 'faulty'. It may also be linked to his wife's ethnicity; given that prevalence rates

are higher in Asian populations, it may be that he is holding onto this as a way of mitigating his own self-blame. Mentioning her heritage suggests this may have been an explanation he held. In trying to move away from self-blame, Joe sought other potential causes:

> *I mean I don't know if I'm trying to fool myself or whatever, but it's also indicators that with IVF […] Now I, I wonder if the, the problem with Sam's cleft was because that crucial point of a cell division happened at the point they get plunged into liquid nitrogen and that kind of chucked all this in.* (Joe, 282-297)

Joe appears to acknowledge that he is trying to alleviate his sense of guilt; the potential role of IVF has provided an alternative focus of blame. It may be that needing to use IVF already represents a type of failure. This may explain why he then felt the need to explain that it was needed only because a vasectomy reversal failed (rather than there being something inherently 'wrong' with him). This suggested the need to reassure both himself and the researcher that he was not faulty or damaged, reinforcing his hope that he was not to blame.

For some fathers a lingering question mark remained about their responsibility in causing CLP, as illustrated by Joe:

> *So we are going to go through that process [genetic testing] just to be clear because obviously it's something we might, if it turns out I'm a genetic carrier then Sam will have that and he could pass it on so to be warned to be aware of it.* (Joe, 302-305)

Although Joe maintained his belief that IVF was the likely causal factor, it seems that the role of genetics (and therefore responsibility on his part) remained present in the background, almost as if evidence was needed either way in order to be able to move on.

For others, genetic testing was seen as potentially more damaging:

*I know that if it came back that it was on Sophie's genes, she'd be devastated and she'd think that I'd blame her and vice versa, so if it was me I would feel guilty even more and that Sophie would like hate me if that makes sense so we just decided d'you know what, we're not gonna bother, we don't need to know.* (Dan, 952-959)

This highlights the strength of Dan's potential for self-blame and guilt, and his fears about the impact this could have on his marital relationship. Not knowing appears to be being used as a way of avoiding potential self-blame and as a way to maintain their relationship and move forward as a family.

### 3.1.3 Uncertainty: What Does It All Mean?

*See the thing is there are so many ifs and buts with having – waiting – for a child with a cleft.* (James, 599-600)

The theme of uncertainty emerged in all accounts, spanning from diagnosis across pregnancy, birth, childhood and into the future. Although these uncertainties encompassed a multitude of areas, in the first instance the overriding uncertainty related to the initial ambiguous diagnosis. Seven participants described the difficult period between CLP being identified and finding out a definite diagnosis (i.e. whether it was isolated or syndromic) as illustrated by Dan:

Dan: *The consultant that we'd seen had kind of put into our head that there was potentially other things coming we were like ok well we need to know what those other things are cause we need to plan.*
I: *So you'd sort of been left with this question mark?*
Dan: *Yeah, and it kind of – to then have to wait until say 12 days later to get the NHS appointment was kind of – we just couldn't cope.* (Dan, 192-199)

This presents a clear picture of the anxiety provoked by the potential for additional problems to be discovered; almost as though once the initial confidence that everything would be fine was challenged by the diagnosis then there was no longer any safe ground. Dan describes the shared experience of many of the participants in struggling with waiting for a definite diagnosis. It appears to increase the anxiety and fear-filled fantasies about outcome, giving a sense of a barely tolerable experience.

Divergent to this, James describes a much less anxious response to the uncertainty:

> *Obviously they had to do all the shpiel about we look for increased, you know, other sym…you know cleft related syndromes, those sorts of things, but no there didn't seem to be anything else apart from there's definitely a cleft lip, […] then it was fine we just knew it was happening* (James, 108-113)

It seems as though James is down-playing the potential for CLP to have indicated additional problems, illustrated by *"they had to do all the shpiel".* This slightly dismissive phrasing suggests the initial uncertainty had a limited emotional impact on him. It may be that reflecting from a perspective of many years down the line has diminished his memory of his experience of this. However, as with some other aspects of James' overall account, it may that presenting as somewhat blasé served to reinforce a sense of being seen as strong and unaffected.

Connected to the uncertain diagnosis was the need to make a decision about whether to have further diagnostic tests:

> *We did look at amnio long and hard and I think in the end we decided that, cause it seemed like the risk of it being something much more serious was about the same as spontaneous abortion by actually having the amnio procedure and we just thought 'could we live with ourselves if if it did spontaneously abort and then and*

*they said no it was just cleft lip and palate and we've sort of like caused the, contributed to death of our baby just because we wanted to know?', so we decided not to.* (John, 76-85)

John highlights the dilemmas and pressures this decision creates. Looking "*long and hard"* is indicative of his struggle in the difficult conflict between the desire to know and feel better prepared by having the tests done, and the fear of this potentially resulting in the death of their baby. This links with the fear expressed about how knowing the cause of CLP could result in further blame. The fact that some couples chose to do this despite the potential risks indicates the level of anxiety provoked by the initial diagnosis and fear of the unknown. For several participants, not having these tests had other implications:

*It's just that holding your breath waiting for Sam to come out basically and it's like, when he came out it's like, I don't know, it was a really [pause] calm, kind of, but unemotional* (Joe, 993-996)

Joe appears to have managed the uncertainty about outcome by emotionally bracing himself to the point where he was almost unable to react at all. This self-protective stance is indicative perhaps of the extent of the anxiety he held.

However, receiving the 'good' news of non-syndromic CLP did not mean an end to uncertainties:

*So it was almost like you finished an exam that you were dreading but that afternoon you've got another one, you know, but in a different subject so to speak, you know, it was like that amazing relief and joy that he was fine, um and then oh [pause] oh shit, how do we deal with this then, what do we have to do and I suppose yeah and mixed with that is I suppose the normal anxieties that every parent when they're having their first child has in the sense of shit, what do I do?! what do I do?!* (John, 479-486)

Apparent in John's account is the sense of a never-ending cycle of uncertainty and the rollercoaster of emotions that accompanies this. The metaphor of sitting exams is suggestive of a period of dread and high anxiety, and perhaps his sense of feeling tested by having a child with CLP. However, referring to the anxieties of first-time parents may be an attempt to normalise his feelings. Many of the accounts also highlighted the impact of the uncertainty around diagnosis on the decision about whether or not to find out the baby's gender:

> *I think we did find out with Edward only because it gave us a bit of certainty over something that, over which we had no control – we certainly had control over something and that was a little crutch for us* (James, 581-583)

This suggests a shift caused by the diagnosis from conceptualising surprise as a positive and exciting aspect of pregnancy to a negative and anxiety-provoking experience. James' account illustrates the desire to gain some certainty (if not control) about the future, perhaps allowing him to focus on an aspect of his child that was not about CLP.

### 3.1.4 The Anxiety Driven Need for Information

This sub-theme captures the importance of having information, the manner in which it is obtained and the impact it had on fathers' experiences, which was evident across all accounts. Most participants spoke about the 'need' for information, which appears to be fuelled by a desire to feel better prepared thus reducing their anxiety:

> *Nobody ever explained that or, or prepared us for that and I don't know what, whether the fore-knowledge of that would have actually made any difference but but I think, but it may have* (John, 308-310)

John's account conveys feelings of inadequacy experienced with regard to his ability to parent effectively. This came across in his apparent frustration at not

being given enough information from the outset. This is contrasted by George's experience:

> *I can't emphasise enough really that the amount of information that we had from from before she was born has been phenomenal and the support that we got from the team […], it allays any fears, um, it fills in blanks, it's absolutely brilliant, and they have every aspect covered so never, at no point have I ever felt that I hadn't got enough information but I've also never felt overwhelmed with information* (George, 420-426)

Information which gave a better understanding of his situation was seen as central in 'allaying fears', a common aspect of all accounts. John takes this further, highlighting the importance of services going beyond just information-giving and also supporting fathers in a process of sense-making of the implications of that information:

> *You want somebody to help you make better emotional sense of those statistics, you know you're not buying a car, you're not just looking at a fuel economy of whatever, it's your own little son's life that you're thinking of* (John, 108-111)

This suggests that John felt daunted by the magnitude of the decisions he was required to make and the pressure to 'get it right'.

For George, preparedness also extended to his daughter:

> *If she's armed with as much information as she can get then she can ask, she can answer questions that someone might have* (George, 277-279)

This combative metaphor highlights some of George's underlying fears about the future and places his daughter in a position of being able to defend herself

against other people's potential prejudices and preconceptions. Divergent to this, John describes avoiding information at certain points:

> *I think to some degree I, not buried my head in the sand, but as we weren't going to be finding out any time soon, I kind of, I don't want to keep going over all of the possibilities that it could be something really really horrible because there's nothing I can do about it […] so I kind of wanted I suppose not to know all of the nasty possibilities because that would edge out all of the good possibilities as well and I didn't want to go through the next however many months just waiting with a sense of foreboding, I suppose I wanted to kind of introduce a little bit of optimism as well, cos I think otherwise I would have gone crackers* (John, 129-140)

John is alone in describing avoidance of information as a way of maintaining hopefulness (although others did manage information to avoid self-blame). However, underlying this is his anxiety regarding the outcome and therefore it seems that avoidance also helped him to tolerate the period of uncertainty. Interestingly, John switches between the past and present tense in his comments. His use of present tense in *"there's nothing I can do about it"* suggests an on-going sense of powerlessness in his experiences.

Another aspect shared by all participants was their experiences of, and beliefs about, 'good' information provided by specialist CLP teams versus 'bad' information provided by local hospitals:

> *The cleft team […] you know, brilliant, they're great. The support from the local hospitals hasn't been so great because obviously you know they're not trained to deal with those kind of things* (Nick, 972-976)

The initial lack of information from the local hospital seemed to compound the anxiety created by the diagnosis. Nick's search for information appeared to then

exacerbate his fears and worries. Many participants shared this experience of the internet as 'Pandora's Box':

> *I still think we were left to find a lot of stuff on our own […] but you're then basically left alone with the internet and you can find whatever you want there* (John, 173-180)

John's comment illustrates his sense of isolation following the diagnosis and how overwhelmed and uncontained he was left feeling by the information he found. This highlights the perils of searching the internet in the attempt to feel better prepared.

In contrast to this, the majority of participants spoke about the value of receiving first-hand knowledge:

> *All of those uncertainties, they they reassured us quite well actually […] they've been through it so they can tell us exactly what's going to happen […] they can put emotion to what their saying you know, you feel pretty sure what they're saying is correct and that's gonna happen* (Nick, 360-375)

Parents of children with CLP are positioned as 'experts by experience' and therefore are a trusted source of information. This possibly also normalises participants' experiences by reducing their sense of difference.

## 3.2 The Power of 'Normality'

This theme conveys the significance of beliefs about difference in mediating participants' experiences as fathers of children with CLP, influencing both their self-perception and perceptions of their children. The emotional repercussions of corrective surgery were also present across accounts.

### 3.2.1 <u>The Changed Child</u>

Present in this sub-theme is how fathers experienced their child's changed appearance after the lip-repair operation (at approximately 3-4 months old). All participants described a mixed emotional reaction, for example:

> *He [hospital porter] said to me – and this, this is when I cried – he said you've got a gorgeous daughter [tearful] and he gave me a hug and that was, I just fell apart because she wasn't the daughter that I'd given them, she'd changed, but she was still my daughter if that makes sense? […], I sort of sat on the chair and held her in my arms and cried for about, about 40 minutes I think – I couldn't stop – the last time I cried like that was at my nan's funeral and it was kind of like 'what are you doing? She's fine, she's back'.* (Dan, 859-874)

Dan's account suggests elements of both sadness at the loss of the child he knew, but also relief at the validation of his daughter as beautiful (therefore 'normal'). His description *"I just fell apart"* indicates the strength of his reaction, that perhaps he had been 'holding it together', not fully acknowledging his emotional response to the diagnosis and what that meant for him as a father. There is also an indication of feeling that his response was irrational (*"What are you doing?"*). The comparison of his reaction after the operation to that at his grandmother's funeral also gives a strong indication of the grief he felt at the loss of the child he knew, despite this being tempered by relief.  This is supported by his comment:

> *Comparing the two children, well the two looks, sorry* (Dan, 1165)

Dan became quite tearful at this point; although the interview occurred four months after the operation, it was clearly still very raw. I was also aware from earlier parts of his account that he perceived crying as an unusual and extreme reaction in himself, which again indicates the significance of this experience. The surprise at the degree of difference is also apparent in John's account:

*You sort of think, well I know he's going to look different […] but I didn't appreciate just how much because it's amazing looking back now how, how quickly you didn't see a child with a hole in his face, you saw Daniel, and you no more saw that than you paid particular attention to the colour of his hair, or the length of his fingers, it was just, it was just Daniel* (John, 194-200)

John reflects on how quickly he stopped seeing CLP as a defining feature. This seems to slightly astonish him, perhaps indicating fears and anxiety about this prior to the birth. However, all participants spoke about the lip-repair operation bringing about re-adjustment to the 'new' appearance, as illustrated by Nick:

*I wasn't really expecting it, I mean, we'd said before you know how she's going to look different so expected but not to the extent that it did I suppose,[…] but then you got used to that, just as in the 16 weeks of her life you kind of looked past the cleft, after a couple of weeks, well not a couple of weeks, after a few hours I suppose you could look past the repair and you know you see her again* (Nick, 411-418)

This appears to acknowledge the difference between intellectually knowing the child would look different and the reality when it is your child, suggesting that no amount of preparation will ever feel like 'enough' in pre-empting this reaction. His self-correction regarding time-frames suggests that in fact there was a longer-term impact, but perhaps it felt unacceptable to openly acknowledge it. This may be because he was concerned about being perceived as not responding the 'right' way. Connected with this were comments about 'embracing' CLP, which were present in several accounts:

*We've got pictures of him around the front room to show what he looked like as a little baby and we've said look you know you're a handsome little boy irrespective of of what, if there's anything different it doesn't matter you're you, you're Jake.* (Stuart, 615-618)

This suggests underlying concerns about his child's feelings about CLP as he grows up, but also about what he will make of how Stuart responded as a father. The photos provide 'evidence' of Stuart's fulfilment of the role of parents in providing 'unconditional' love. For Dan, however, the personal meaning of his child's changed appearance was evident:

> *I think the crying was letting go of maybe the blame, cos I think, I think, I don't know why cause like I said I've never done anything to kind of risk my health but I think I did blame myself and they'd made her better and how she, how she would be accepted by society* (Dan, 1171-1174)

> *Now we've moved on from that I kind of think that I can be a normal dad* (Dan, 1228-1229)

These comments depict Dan's emotional reaction to the diagnosis and the implications this had for how he perceived himself as a father. Being able to 'move on' and be *"a normal dad"* are strikingly indicative of his perceptions of how he felt having a child with CLP reflected on him; the abnormal father of an abnormal child. The outcome of the operation appears to have allowed him to stop punishing himself over his 'failure', restoring the 'normality' lost at the point of diagnosis. Achieving 'normality' was also present in other accounts, for example when participants spoke about the multi-faceted reasons for repair:

> *You just have to remind yourself why you're doing it, it's not you know, she has it done now she can heal and her entire childhood can be pretty much perfect* (David, 221-223)

David's comments suggest that underlying beliefs about difference and 'normality' significantly influence the experiences of fathers of children with CLP. It also highlights the continuing sense of guilt and concerns about long term implications, as suggested in the hope for a "*perfect*" ('normal') childhood.

3.2.2 <u>The Influence of Societal Beliefs</u>

Present in this sub-theme is the influence of societal beliefs about difference on participants' experiences. A number of participants described difficulties in experiencing other people's reactions prior to the lip-repair operation. For example, George spoke about the questions people asked:

> *It was quite funny, um, what was fun was the amount of questions people would have in relation to it, like, "can it be fixed?" (George, 93-95)*

Although George uses the words *"funny/fun",* his tone suggested otherwise; that it was difficult to hear these questions, having struggled to come to terms with these very issues himself. Questions also served to repeatedly highlight that his child was seen as 'different' by society, which seemed to add to his own sense of difference.

Conversely, James spoke about people's notable avoidance of talking about CLP:

> *The most difficult, there were some people who said some odd things, you know not quite knowing what to say you know, obviously what does one say to parents of a kid who's got a hole in their face (James, 148-152)*

James acknowledges the awkwardness of some interactions, feeling that people were at times 'treading on eggshells' around him, but also attempts to normalise their reactions. However, it appears this further emphasises a sense of difference, almost becoming a barrier to communication that has to be overcome before 'normal' conversation can resume. It seems that participants often engaged in attempts to make sense of people's responses, either normalising reactions or making allowances for them, but experiencing this as painful nevertheless:

*They're not doing it to be horrible but she didn't look like a normal child if that makes sense so, it was kind of, I found that I wrestled with that quite a lot* (Dan, 365-368)

However, for a few participants these reactions came from family members, which they appeared to find it particularly difficult:

*As soon as it came to showing photographs and things like that they [in-laws] were oh you don't want to show that one, that doesn't show her in the best light, they kind of wanted to show the side of the face that didn't have the cleft on all the time and it got to the point where we got quite angry with it* (David, 315-320)

David's account highlights the unexpected nature of these negative responses, which suggest a perceived lack of understanding and acceptance from what is traditionally seen as an unconditional source of support. This led to anger and sadness, compounding participants' sense of difference.

All participants shared concerns about long-term implications, which manifested in various ways. Central to this were perceptions about the significance of gender in relation to the importance of appearance:

*I see girls sometimes with very pronounced clefts and part of me does think that is worse, to use a a very – I don't have the word to describe how I feel – I don't even think I've ever really thought about it – but I think um well you know obviously that's going to be interesting – ah teenage years for you, um, ah, blokes, boys, I don't know scars sometimes are cool I suppose, scars are more acceptable, scars are part of the tribal thing* (James, 558-565)

*That was always a real concern of mine, that and um also how it would actually look, is she going to be a pretty girl and if she's a pretty girl well is that going to have a massive impact* (David, 756-765)

Many participants shared the view that CLP has a potentially more detrimental impact for girls. Although often perceived and depicted as universally negative, scars are seen as very much 'detracting' from a woman's beauty, whereas they can be perceived more positively for men. Dan's comments highlight the difference between wanting a child to appear *"pretty"* as opposed to simply 'normal'. Apparent across accounts is a sense of participants wrestling with visualisations of an 'imperfect' life for their child, with the perceived handicap being magnified for girls. For some this struggle occurred quite openly, whereas for others it was more of an internal process, but present nevertheless. Related to this, the majority of participants also expressed wider concerns:

> *I don't want him to be classified as special needs cos he's not, he's bright, he's very bright but because he can't form his words in the same way* (Joe, 636-640)

> *Yeah, the future one we thought about a lot, particularly around speech cause you get jobs a lot on your speech I think we were kind of concerned that when she goes to school will she have a lisp or she can't say things properly* (David, 384-389)

These extracts highlight the fear of discrimination and restricted educational and social opportunities throughout life as a result of CLP. This may be fuelled by common societal perceptions, with visible difference often being equated to physical and learning disabilities.

Connected with this was the surprise expressed by some participants about the lack of public awareness about CLP, as illustrated by Dan:

> *For me the only way as a society we're gonna move on from sort of like the gasping I suppose is if we talk about it more, [...] and it was sort of saying I'm not bothered about who knows, I really don't care, cause for me it's kind of the more it's looked at and the more people that are aware of it the better it will be you know we'll be able to move things forward* (Dan, 648-663)

Dan's comments give a clear indication of how under-represented he feels CLP is in the public arena, which connects with perceived societal responses to difference and disability as something to be hidden or not talked about. For Dan, the fear of other people's reactions, and subsequent negative perception of him, appeared to drive the sense of difference he experienced.

### 3.2.3 Personal Perspectives: Conceptualising CLP

This sub-theme captures the way in which conceptualisations of CLP affected (or are indicative of) participants' perception of what it means to have a child with CLP, and in turn what this may mean about them as a father. This appears to change over time for some participants, indicating a shift in their perceptions and experiences.

Interestingly, there was considerable variation in the language used by participants, both within and between their accounts. Several participants commented on language as an important factor in how having a child with CLP is experienced, as illustrated by James:

> *Now should I have been in a situation where I felt that my son's got a deformity or disfigurement or anything negative, you know, words like that, then would there be any infrastructure for me? No. (James, 479-482)*

James highlights a direct connection between fathers' conceptualisations of CLP, their subsequent experiences, and whether support may be needed (or helpful). This is supported by the variety of negatively loaded terms used by other participants who appeared to particularly struggle with the initial diagnosis, such as *"defect"* (Stuart, 94) and *"facial disabilities, deformities if you want"* (Joe, 317). James also highlights the lack of support structures in place for fathers, which may itself influence how fathers express and manage their emotional responses to having a child with CLP. James appears at pains to emphasise that, whilst this may be the case for other fathers, CLP does not hold negative connotations for him. It may be he felt unable to own any negative feelings, instead raising an

important aspect by projecting feelings onto others. The negative connotation of CLP is also present in John's account:

> *You know it's your, it's your little slightly broken child, and that's*
> *sounds horrible but I don't mean it like that, but you know, but you*
> *just want to fix it for him you want him to be like everybody else*
> (John, 767-769)

This vivid description was almost painful to hear, suggesting how painful the diagnosis was for John to receive as the father, and how he experienced an on-going sense of difference between his child and 'whole' children. It also suggests a sense of powerlessness and failure in not being able to *"fix it"*, perhaps highlighting an expectation that he should be able to fix it. The relationship between CLP and fathers' sense of themselves is explored further in 3.3.1.

Repeated use of the term *"a cleft baby"* (David, 204) in David's account is suggestive of how, for him, the diagnosis of CLP became all-encompassing of his child, a defining feature, at least prior to the child being born. However, for Dan, finding out the gender of his child helped to counteract this perspective:

> *I think we were able to then focus on that rather than oh she's gonna*
> *have a facial defect and I think that helped us move on a lot as well,*
> *and kind of use that to focus on different things rather than just*
> *constantly worrying about it (Dan, 1503-1511)*

This highlights how finding out the gender promoted both coming to terms with the diagnosis and beginning to move away from the perspective of his child being defined by CLP. It makes intuitive sense that when CLP is the only thing you know about your child it become the focus of attention. Gaining a wider perspective also appears to have aided this transition:

> *I saw lots of children you know sort of very sick children, life*
> *threatening sort of conditions, I thought you've gotta let this go*

> *because you know she's not, she not going to die, she's fine, she's*
> *just gonna have her lip stitched together and that is it* (Dan, 804-809)

This gives an indication of just how overwhelming the initial impact of the diagnosis was for Dan. Comparison to children with more medically significant diagnoses allowed him to reframe CLP as less devastating. This process of adjustment and acceptance is further supported in how the majority of participants spoke about CLP as having little presence in current everyday life, in contrast to how their experiences during the pre-natal and neo-natal periods were described:

> *As time went on it became relief and then it's just got to the point*
> *where nothing completely fazes us at all now – take, c'est la vie –*
> *just take it take it in our stride so it's good.* (David, 132-134)

David's comments capture the shift in the influence of CLP on his experiences over time, starting with the initial *"relief"* and the diagnosis of non-syndromic CLP and perhaps responding in a more measured way to further issues.

Interestingly, most participants spoke about their increased sense of difference as a result of an aspect of treatment or response by services:

> *I felt a bit horrible cause we'd go for scans and normally you'd have*
> *to pay for it but they'd give us like a load for free and I thought if*
> *Sara didn't have anything you know different about her then that*
> *wouldn't have happened, so that's not very nice. (Nick, 161-165)*

> *The one thing that we were disappointed with, shall we say […] was*
> *that they weren't prepared with any special feeding equipment […],*
> *the hospital didn't have a suitable bottle (Stuart, 159-165)*

These comments illustrate the surprise felt at the lack of practical and emotional resources within local services in response to CLP, and how this served to increase participants' sense of difference and 'abnormality' as fathers.

**3.3 The Expectations and Roles of Fathers**

This theme conveys the roles that fathers perceive as important to fulfil in relation to their children and to their partners in the context of CLP. The emotional consequences, as well as other people's response to fathers' emotional needs, were another notable thread across interviews.

### 3.3.1 "I fell at the first test": The Centrality of Role as Protector

A notable feature of most of the participants' accounts was powerful discourse about the role as protector which formed part of their identity as a father. Central to this was the meaning of CLP in relation to this aspect of their identity.

> *It actually made you more want to be protective and do the right thing and make everything better really and I suppose that's it, you just want to make everything better and make all the pain go away and make all the the heartache and the worry and the anxiety just, just go away […] and I suppose there, you know, there isn't anything that you can do* (John, 683-689)

Interestingly, John adopts the second person pronoun 'you' in this part of the interview. This has the effect of distancing him from the topic, potentially because it is uncomfortable to speak about. Doing *"the right thing"* suggests he holds an internalised script of his role as a man. Indeed, he elaborates on this more explicitly:

> *I imagine any father feels like, you know, everything in your genes and society says that you need to be strong you need to protect you need to, it's your family you know, and suddenly you know there is absolutely sod  all you can do about anything* (John, 583-587)

His use of absolutist language (e.g. *"everything", "absolutely", "sod all")* is indicative of just how powerless he felt. The phrase *"everything in your genes"* may indicate the strength of the sense of having to do something.  It also

positions this sense as innate. Dan further highlighted the interplay of societal expectations of fathers and the sense of failure and powerlessness experienced following diagnosis:

> *I'd kind of failed as a dad, if that makes sense because my - my outlook of what a dad is, if that – and it's quite, I dunno – it's not a bit cave-manish but to protect his wife and to protect his child and I kind of felt I hadn't done that so I felt real guilt* (Dan, 139-144)

> *I don't feel as guilty as I did but I still feel guilty, […] I see my role as protecting my child and I kind of fell at the first test* (Dan, 698-700)

Falling at the 'first' test also suggests his expectation that there are more tests to come, indicating his perception of CLP (or perhaps fatherhood in general) as a series of on-going challenges to be overcome. Several fathers also acknowledged the implication of their protectiveness for the child, as illustrated by George:

> *We may have protected Freya a little bit from possibly, especially earlier on [emotional] I think maybe from interaction with other – not family members or anything* (George, 202-204)

George's reference to preventing interaction with *"other"* people possibly suggests an underlying fear of their reactions and wanting to protect her from potential suffering as a result. His emotional reaction whilst speaking might suggest that it is something that he finds upsetting and continues to struggle with.

Dan anticipated his desire to over-protect his daughter, which although common among parents may be enhanced in response to CLP:

> *I think you know I've just got to let her be a child you know, […] let her be like everybody else yeah, because I think you have that fear as a parent anyway and maybe it's magnified now for me because of the cleft but I, you can't protect your child from everything, and I*

> *think that that, so the feeling guilty and not being able to protect her*
> *from the very start has made me realise I can't protect her from*
> *everything and I think that that's something that I need to make sure*
> *I grasp. (Dan, 1282-1291)*

Dan recognises the potentially negative implications of over-protectiveness as increasing his child's sense of difference and therefore the need to *"let her be like everybody else"*. The comment *"that's something I need to make sure I grasp"* suggests this is for both his sake (in letting go of the guilt he feels) and his daughter's (not exacerbating any sense of difference).

Linked to the idea of role as protector, half of the participants also spoke about their concern regarding the pain their child would experience.

> *And then we know that there will be the operation when he's 9/10 to*
> *take the graft from his hip to insert into his palate which I mean we're*
> *dreading […] it's the worse one by, it's so painful. (Joe, 86-90)*

This dread can be seen to be connected with the desire to protect the child and feelings of powerlessness and failure to be unable to prevent this from happening (or guilt at having caused the problem). Linked with this was concern about the child's increased awareness and expressive ability as they got older and having to manage this in relation to the alveolar bone graft operation. With both physical pain and emotional suffering, fathers expressed a desire to *"make it all go away"*, thereby fulfilling their role as protector.

> *I think it's more painful because like I say, they can talk and they can*
> *verbalise what they're feeling and that's what I'm not looking forward*
> *to.* (George, 460-462)

This could be understood as the child's increased verbal ability to express pain, fear and uncertainty adding to a sense of failure and guilt, whereas the younger child might use a more basic expression of crying. This can be responded to in an equally basic way, through soothing with a cuddle; not being forced to engage

with the meaning of the crying allows fathers to suppress their feelings about it and makes it more tolerable.

### 3.3.2 Who Supports Who?

Another central aspect of several accounts was their perceived role in relation to their partners, which was primarily to provide support and containment, as captured by James:

> *My role as a dad with a cleft is actually probably to be a bit more stoic and probably be a bit more you know, oh well it's nothing to worry about, you know, if Layla is feeling you know a bit worried about anything [...] my role is also to try and keep her a bit more grounded around not getting not getting overly worried about stuff* (James, 528-535)

These comments suggest participants experienced a need to adopt this position more strongly in response to CLP, as demonstrated in *"a bit more"*. The stoic support offered to partners to the detriment of dealing with their own feelings could also be seen as compensating for their sense of failure to protect their child. Also apparent is that fathers' experiences appear to be related to their success in supporting their wife; those who struggled to support them appear to have experienced having a child with CLP as more difficult, almost as if at times they are measuring themselves on how their wife was coping rather than on how they were managing their own feelings and experience at the time:

> *Another thing that had sort of put a strain on, on the relationship at times, because it was felt that I'm not around to help as much as I should be* (Stuart, 290-292)

Several participants described putting their own feelings aside in order to be able to adopt this role and focus on supporting their partner:

*I had to bottle a lot of that up cause as you can imagine my wife was very upset at that time [...] she was an emotional wreck, ah, and that was really difficult to deal with to start off with, so I put everything I was feeling on the back burner, I was just dealing with her and then sort myself out a bit really, yeah.* (David 929-941)

These vivid descriptions highlight the active efforts to contain and suppress their feelings, suggesting that managing both their own feelings and those of their partner was too overwhelming. For some participants putting emotions aside was not an active choice:

*So it was like I, I wasn't able to sort of grieve for oh shit what if all of that doesn't come to pass, or if he doesn't live or if he's really disabled and things, am, because I wasn't the one that was carrying him and so it was almost like you know you did your job months ago you know this is my child now I'm the one that you know, and, so that was really really difficult* (John, 606-611)

*I have a lot of resentment over the first three to six months of Jake's life, just because I, I was struggling to cope* (Stuart, 232-233)

John describes feeling pushed aside by the perception he had no role in the supporting the pregnancy but also not feeling allowed to express his feelings, or not having those feelings acknowledged. Likewise, Stuart's comments reflect the depth of his struggle to coming to terms with the diagnosis and the implications of support not being available. The resentment he refers to appeared to be primarily directed towards his wife, for not recognising his emotional struggle and for expecting a level of support that he was not therefore able to provide. Perhaps on some level it was also directed towards himself for not 'coping' better, compounding his sense of failure. This sense of exclusion and insignificance is also evident in participants' experience of services:

*The only thing is like the happy faces groups, it talks about ah you know if you're a mum come along and it's kind of like ok, but then I*

> *suppose it's what is traditionally, what traditionally happens* (Dan,
> 1714-1717)

James reflected on the possible self-perpetuating cycle of exclusion of fathers
from services:

> *I think it is a good thing, right, that somebody is taking an interest in
> dads' views on these things because [pause] dads – anything to do
> with pregnancy and small children – dads tend to get, not ignored,
> but they're just sort of there […] so I think people tend to ignore
> dads because of that, because dads are just 'get on with stuff' but it
> doesn't mean they're not human beings, doesn't mean they don't
> have emotions* (James, 734-763)

The tendency to *"get on with stuff"* could be seen to perpetuate the assumption
that there has been a limited emotional impact and therefore support is not
needed. *"It doesn't mean they're not human beings"* suggests this exclusion can
be experienced as extremely 'othering' for fathers. James' use of second person
pronouns distances him from this position, as perhaps identification with this is
too painful to openly acknowledge.

Other accounts also highlighted the tendency to focus on practicalities:

> I: *What's it like for you when she has to go for operations?*
> George: *[…] I don't think about it until it's done and I'll just, I'll just
> get on with practical things of oh I've got to be at work at such and
> such, and I've got to go there and pick Oliver up* (George, 376-383)

This appears to serve the dual purpose of reinforcing their sense of fulfilling their
perceived primary role in supporting their partner whilst also allowing them to
disengage with their emotional response. Participants drew support from other
areas or developed ways of managing their emotions. For some, whilst they
perceived a need to adopt a supporting role for their partner, a mutually
supportive relationship was described:

*Charlotte takes on the bulk which allows me not to have to think about it too much* (George, 519-520)

*I think it, we were a bit of an emotional crutch for each other and we got through it really well* (David, 245-246)

George and David express subtle differences in how they experience support from their wives. For George, this appears to enable his avoidance of difficult feelings and worries, whereas for David the relationship appears to perhaps allow more acknowledgement of the emotional impact.

### 3.3.3 Unexpected Outcomes

Present in this theme was the idea that CLP brought about a certain amount of changes in roles and both positive and negative unexpected outcomes, grouped around aspects of parenting.

Unexpected positive outcomes were a shared experience for half of the participants. CLP appears to have an impact on the transition to fatherhood as illustrated by Dan:

*I think it made us become parents sooner, so I think that when you're pregnant you kind of, you're just on like a ride and you just carry on and nothing changes […] I kind of think that it made us go from being people that were just pregnant to actually being parents and I know that – it's, it's hard to explain but it kind of, we had to kind of face up to what life was going to be like* (Dan, 701-715)

Dan appears to be sense-making through social comparison and this positive reframing appears to have allowed him to hold onto some of the joy and excitement of the pregnancy which he expressed had been lost as a result of the diagnosis (see 3.1.1). The development of earlier bonds is also illustrated in John's account:

> *That helped create a bond with him so much, well not so much earlier, but I kind of think that it helped create a bond because there's, again there is that thing that you, you want to take, you want to make it better for him* (John, 763-766)

Wanting to *"make it better"* also relates to perceptions of fathers as protectors (see 3.3.1).

Several participants spoke of personal growth or similar positive outcomes as illustrated by John:

> *I suppose in some ways, and this is so so much a tiny tiny little part of the whole experience, is that it's kind of reinforced that, how can I put it, I ain't prejudiced about stuff, and you know, it's, it's more than that, I suppose it's given me a better appreciation or made me less I suppose judgemental about other people, which has only got to be a good thing (John, 1495-1502)*

John's statement that he is not prejudiced and the word *"reinforced"* suggests a concern about his own reaction to his child's difference. By emphasising that this is a *"tiny tiny little part"* of the experience he also emphasises the difficulties experienced, perhaps not wanting them to be down-played.

In Nick's account, this positive influence impacted the family more widely:

> *They're more accepting of how people look and how they are, so it's been, I think informing them like that has been a positive thing you for their character, you know, for them, so it's been good (Nick, 471-473)*

However, through his emphasis of this being a positive outcome *"for them"*, I am reminded of the negative aspects of the experience for him. Divergent to this, particular challenges around feeding were expressed by most participants, particularly resonating in John's account:

*He wasn't able to suckle and so Hannah would be expressing all of all of the time, which also meant that she wasn't able to feed because you know it was a case of you know every couple of hours she'd be up expressing enough milk for his next feed, and so, because it was breast-milk, the time between feeds was less than if you were using formula, because he couldn't suckle and we would have to be squeezing the bottle it would take at least twice as long to actually feed him and um and he'd just get a lot more, more wind […] ah, you know, the number of times I'd be there feeding him at 3 o'clock in the morning with tears in my eyes cos I just, just unbelievable, never known that you could feel that tired, I'd be driving back from work, I'd stop at red lights and I'd be asleep (John, 271-294)*

This highlights the additional impact of CLP on what is often a difficult period with any new baby, reflecting how overwhelming this experience was. Likewise, James spoke about feeding as one of the most difficult aspects to manage:

*One of the hardest, actually it's very easy to feed a kid with a cleft lip cause you just stick the bottle straight in – they can't refuse it [jokingly], you put it straight in and squeeze it, so that was, that was all fine, apart from all the milk going in circles back up um yeah, so so yeah we'll come onto that in a second. (James, 178-185)*

Interestingly, James conveyed this difficulty in a jovial manner. The initial mention of *"one of the hardest"* suggests that it was such a significant struggle that it was too difficult to reflect openly on it. It may also indicate a reluctance to admit to struggling or to be seen to complain. The image of milk going in circles implies possible feelings of frustration and guilt that this may have created. His attempt at humour and direction to *"come back onto that"* later suggested that he did not feel able to fully share this experience.

David reflected on the adjustment to his role in feeding as having a positive outcome in strengthening the bond with his baby:

*I suppose one thing I do wonder is whether I've got a closer bond with Grace because I fed her quite a lot um, and whether I would have such a close bond if we have another one without a cleft* (David, 849-853)

This suggests the possibility for positive aspects to be seen despite the complexity and difficulties experienced. It also hints at a sense of a shared struggle overcome together.

### 3.3.4 Making Up for CLP: Compensating and Counteracting

This theme, apparent in all accounts, captures participants' responses to CLP in how they parent, in either their attempts to counteract potential impacts regarding how their children are seen by others or by feeling the need to compensate in some way for their child's experience.

Half of the participants described compensating for CLP in their parenting, for example:

*Just a level of patience beyond what I would normally have [...] because you think well you've dealt with quite a lot already and it makes me cross you know* (Joe, 492-497)

*The tendency is to wrap him up in cotton wool and say oh it doesn't matter you know, poor little lad* (John, 854-855)

These comments suggest that they consider living with CLP to be a hardship for their child and therefore they deserve allowances to be made for them. The anger Joe expresses could also be seen to be connected with feelings of guilt and self-blame (see 3.1.2), therefore compensating may also alleviate his own sense of guilt. John's comment suggests he sees CLP as something to be pitied, and therefore adjustments are made accordingly.

For some fathers compensating for CLP also influenced decisions around feeding:

*I didn't feel then that I could suggest to Hannah that we needed to do formula cause I felt as if I was letting everyone down then, it was as if almost to say well no we can't carry on giving what's best for Daniel because I need some sleep and it felt selfish and felt as if um he hasn't got off to the best, you know, the least we can do is to try and make up for that as best as we can.* (John, 317-322)

This highlights the self-inflicted pressure to breastfeed in order to compensate for CLP, and pursuit of this despite the difficulties it caused (explored further in 3.3.4). The idea that suggesting otherwise means *"letting everyone down"* is also closely connected to feelings of guilt expressed in relation to perceived failings in the role of protector (3.3.1). However, the need to live up to certain expectations and ideals (either one's own or those of others) was clearly dominant and overwhelming at the time.

For some fathers this resulted in parenting the child with CLP differently to other children:

I: *So you've noticed some differences in how you parent the children?*
George: *Oh yeah, I'm, I'm probably harder on Oliver than I am on Freya […] I tend to give into things and that's because of, I sometimes think, oh well, she's shy or she'll say something that I would really give Oliver beans over and she'd say the same thing and I've just, I've let it go, ah, which is wrong. Charlotte has even, Charlotte has pulled me up on that as well, so, so I am trying to change.* (George, 611-630)

This highlights how a child with CLP is conceptualised differently to unaffected children (however subconsciously). In George's case, it is interesting that these differences in parenting have wider repercussions; not only are these differences apparent to the rest of the family but they have started to cause friction. In commenting that he is *"trying to change"*, the suggestion is that it is something he is struggling to do.

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Seven participants expressed an alternative response, seeking to 'counteract' CLP rather than compensate for it. For some, this was illustrated by highlighting their child's personal qualities and abilities:

> *You don't think of her as oh that's Freya with the cleft, it's oh that's Freya the pain in the arse, that's Freya who's really funny, or that's Freya who done that, you never, I never do think of, I never think of her cleft any more* (George, 263-267)

> *He's good at lots of stuff, you know, he's very into running at the moment so he runs sort of semi competitively and yeah, he's just, he's just he's cool* (James, 407-409)

These comments suggest that CLP is seen to detract from the child, making them 'less' than 'normal' children. This connects with fears expressed by other fathers that their child would be seen as 'special needs' (explored further in 3.2.2). In highlighting their child's abilities and achievements they are painting a picture of the unimpaired child. This indicates an underlying desire for the researcher to see the child as 'normal' and perhaps reflecting a deeper concern about perceptions of an 'abnormal' child on them as an 'abnormal' father. Connected to this was that all participants wanted to show photos of the children, or timed interviews so that I could meet the child in person at the end, as if to evidence their 'normality'.

Another aspect of counteracting was fathers actively working against difficulties thrown up by CLP or their own worries, as illustrated by Nick:

> *I've always tried to build this big strong bond with her and just make her feel like um you know that she's you know there's nothing wrong with her face or anything like that […], just trying to instil confidence in her so when she goes to especially secondary school and people notice um she won't feel so belittled by them but, you know, she knows what's happened (Nick, 221-227)*

Nick's comments suggests that feeling prepared is important. In particular he adopts an active role in developing his child's self-confidence and resilience. This relates to ideas of fathers as protectors (3.3.1) and beliefs about the importance of aesthetics (3.2.2). Overall, the accounts demonstrated that fathers often tend to use these two strategies in conjunction with each other, compensating in their own parenting/reactions but counteracting in response to others.

# CHAPTER 4: DISCUSSION AND CRITICAL REVIEW

This chapter summarises the results then discusses the ways in which these findings address the research questions, as well as situating findings in the existing literature. Implications for clinical practice and further research are considered. This study is critically reviewed and, finally, personal reflections are offered.

## 1.4 Summary of Results

The main themes generated were: 'Loss of the perfect child'; 'The power of 'normality''; and 'Expectations and roles of fathers'. These interconnected themes capture the complexity of participants' experiences, highlighting their nuanced emotional responses at various points of the journey of having a child with CLP, subsequent responses to these emotions, and the influence of personal and wider societal understandings about difference on their felt and lived experiences.

The super-ordinate theme 'Loss of the perfect child' conveys the fathers' emotional responses to the diagnosis. This included the initial shock experienced, which was followed for many by a sense of guilt and self-blame, sometimes partly expressed as anger towards others or anger at the injustice of the diagnosis. The anxiety caused by the uncertainty created by the diagnosis (both immediate and future-focussed), as well as the guilt experienced at their self-perceived responsibility, commonly led to a search for information and answers, or alternative explanations about the cause.

The super-ordinate theme 'The power of 'normality'' depicts the direct and indirect influences of both personal and societal narratives and conceptions on participants' perceptions and experiences of both their child as 'different' and their personal identity – what this meant about them as a father. Connected with this were vivid descriptions of their reactions to their 'changed child' as a result of corrective surgery. This sub-theme illustrated the nuanced and conflicted responses they experienced, as well as the moral dilemmas some fathers grappled with about what it means to change their child.

The super-ordinate theme 'Expectations and roles of fathers' portrays the complexity of playing particular roles within the family. The sub-theme "I fell at first test" illustrates participants' own expectations of a father's role in relation to his family, particularly his child, which was primarily one of protector. It also illustrates the adverse impact that having a child with CLP can have on fathers, with regards to their sense of fulfilling this role and the wider impact this has on their identity as a father. Fulfilling the related role of supporting their partner had further personal consequences for participants; they often suppressed their own emotional reactions in order to be able to manage their partner's feelings. However, for some fathers this devalued position was imposed by others (their partners or services). In both circumstances, participants described feeling excluded and unimportant to varying degrees. Also captured were participants' later responses to CLP, in terms of the impact on their parenting of the child, the minimisation of CLP in family life and efforts to emphasise other aspects of their child as a way of 'counteracting' CLP. In addition, participants described various unexpected outcomes, both positive and challenging. These included: unexpected parenting roles in relation to feeding (which in itself gave rise to both difficulties and affirmative experiences); personal growth; constructive influences on other children; and bonding with their child.

## 1.5 Addressing the Research Questions

This research aimed to explore the experiences of fathers of children with CLP, and how these experiences were managed. The research questions are addressed and discussed in the context of existing literature and psychological theory.

### 1.5.1  How Do Men Experience Being The Father of a Child With CLP?

The results depict a complex and nuanced picture of the ways in which these men experienced their positions. All participants began their accounts at the diagnosis. The shock and disbelief described points to their unpreparedness for the purpose of the scans and the reality that problems may be discovered. Whether implicit or explicit, the expectations of an idealised pregnancy, 'perfect' child and fatherhood were evident across accounts. The loss of these outcomes as a result of the diagnosis had an immediate and lasting negative impact, including feelings of shock, anxiety,

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uncertainty, failure and grief. This is well-documented across CLP and wider visible facial difference literature (Bradbury & Hewison, 1994; Cadogan et al., 2009; Chuacharoen et al., 2009; Martin, 2005; Nelson et al., 2012a; Rey-Bellet & Hohlfeld, 2004). As highlighted by Cabrera et al. (2000), several theorists have noted the two-way relationship between gender identity and the meaning and practices of fatherhood (e.g. Daly, 1993). Blankenhorn (1995) argues that effective fatherhood is seen as an essential aspect of masculinity. Within western societies, the concept of 'the father' is highly gendered; it denotes 'maleness', the possession of male sex organs in good working order and the proven ability to produce sperm and impregnate a woman (Lupton & Barclay, 1997). Therefore, diagnosis of CLP not only provokes the loss of the expected 'perfect' child but could also be argued to have a negative impact on men's self-concept and identity; producing an 'abnormal' child gives rise to both a sense of failure and to a perception of being an 'abnormal' father, therefore inherently challenging their sense of masculinity.

Findings from the present study indicate that for some fathers, the rest of the pregnancy was experienced in a predominantly negative light. One participant verbalised this as *"disappointment which gradually got less disappointing"* (David, 171). The shock and anxiety appears to have been exacerbated by the initial uncertainty regarding diagnosis, namely whether the cleft was isolated or symptomatic of a syndrome. This gave rise to dilemmas regarding whether or not to have further diagnostic testing, which could potentially be harmful to the child. Nelson et al. (2012a) reported similar increased levels of parental anxiety as a result of the limitations of prenatal scanning. Current participants reflected on the reality that some of these anxieties were possibly linked to being a first-time father. Indeed, one father who already had children acknowledged the benefit of the child with CLP not being his first as he felt more experienced as a father and did not have to contend with the additional anxieties this created. However, this could also be seen as fathers attempting to normalise some of their experiences, minimising the impact of CLP.

Several fathers described 'needing' to find out the baby's gender. This had differing significance for different fathers. For some it was an attempt to combat the anxiety experienced and find some 'safe ground'; for others, it provided an alternative point of focus and one that could be seen positively. Also apparent in this aspect of accounts

were societal discourses regarding gender and appearance; specifically that aesthetics are more important for girls than boys and therefore CLP would have a more negative impact for girls. Several fathers acknowledged holding these views; others reported receiving these comments from other people.

Another central aspect was feelings of failure, guilt and self-blame experienced following diagnosis. Some participants expressed 'just-world' beliefs (Lerner, 1980), which reflected a sense of punishment, that 'bad things only happen to bad people' and giving rise to questions such as 'why me?', 'what did I do wrong?'. This led participants to speak to relatives to ascertain if there was any family history of CLP. Some took this further, considering genetic testing in the future. One father spoke about the decision not to pursue testing as avoidance of finding out about potential culpability, due to the fear that this would lead to further self-blame and damage to the marital relationship. This connected to participants' feeling of failure in their role as protector (explored further in 4.2.2), and also to the anxiety driven search for information (explored further in 4.2.3).

Although some fathers commented on the startling nature of their child's appearance at birth, the findings also demonstrate a process of adjustment following this. Several fathers reflected on no longer seeing the cleft or seeing past it, others stated it was just part of who their child was. This is consistent with Nelson et al.'s (2012b) findings that parents stop seeing the child with CLP as different to other children. However, they also noted exceptions to this arising when their perception of the child was filtered through different lenses, for example other people's reactions. Coming to accept their child's appearance caused certain conflicting emotions at the time of the lip-repair operation. Whilst pursuing surgical interventions meant they fulfilled their 'moral' obligation to 'normalise' their child. This clearly also had significant emotional consequences for fathers. In line with Nelson et al.'s (2012b) findings, all fathers talked about the 'changed child' with all but one expressing mixed feelings about the outcome of the operation. This included joy and relief that the child was ok and that 'normality' had been restored, but also grief for the loss of the child they had come to know and love, a strong and unexpected reaction. Some fathers commented on it feeling like a different child had been returned. However, apparent in several accounts was the sense that having a more 'normal' child meant that they felt like a more 'normal' father,

with the idealised visions of fatherhood lost at diagnosis coming back into focus to an extent.

Contradicting expressions of valuing the unchanged child were indications of underlying negative perceptions of the child's difference, evidenced in the language some participants used to describe CLP. Examples included 'defect', 'facial disability' and 'deformity', with one participant commenting on wanting to 'fix' his 'slightly broken child'. This paints an interesting picture of how fathers conceptualised the child with an unrepaired CLP. These feelings are inevitably influenced by wider societal beliefs and discourses about difference, which were reinforced when fathers had to contend with other people's reactions. These ranged from asking if the cleft could be fixed, not knowing what to say and general awkwardness. Nelson et al. (2012b) found that fathers expressed forgiving views with regards to the reactions of strangers, often framing them in a benevolent way. Current participants expressed similar views, with one father even stating that he would have reacted in the same way if in their position. Some participants also reflected that often emphasis was placed on their child's other features (e.g. big eyes), which was experienced positively, consistent with findings by Johansson and Ringsberg (2004).

However, participants' responses differed in relation to difficult reactions from family members. Three participants explicitly spoke about the unexpected nature of negative responses from extended family – a perceived lack of understanding and acceptance from what is normally seen as an unconditional source of support. Connected with awareness of wider societal perceptions of difference, all participants expressed concern regarding the long-term impact of CLP, including fear of discrimination, specifically barriers to educational and social opportunities, particularly for girls. This supports findings by Cartwright and Magee (2006), Klein et al. (2006) and Klein et al. (2010). The presumption that girls would be more severely affected was also reported by Johansson and Ringsberg (2004).

Interestingly, one participant explicitly commented on the potential for research to develop a 'skewed view' of experiences as there is a tendency for participants to focus on difficult aspects and 'forget' positive elements. The tendency for research to focus on negative experiences has also been highlighted by Eiserman (2001) and Baker et

al. (2009). Despite the difficulties expressed, unique and unexpected outcomes were apparent in the current findings, although to a lesser degree. These included elements of personal growth for fathers (for example, feeling emotionally "stronger" as a result of this experience), positive influence on their other children in making them less judgemental of others, developing a stronger marital relationship and feeling closer as a family. Similar findings have been noted in the wider literature (Bradbury & Hewison, 1994; Eiserman, 2001; Klein et al., 2010). One father also reflected on the stronger bond developed with his child through his unexpected role in feeding her, discussed further in 4.1.2. In addition, there was a sense of overcoming a shared adversity with the child, strengthening bonds. This is in line with findings by Eiserman (2001), who explored positive outcomes for individuals with a facial difference (e.g. inner strength and service to others).  In addition, other recent studies posit that caring for a child with medical needs can promote parental resilience (Baker et al., 2009; Case-Smith, 2004; Feragen et al., 2009; Lightsey & Sweeny, 2008; Vermaes et al., 2007).

### 1.5.2   How Do Fathers Of Children With CLP Perceive Their Roles Within The Family?

Fathers play many roles within the family, each of which is associated with certain ideas, competencies and action patterns (Cabrera et al., 2000). The birth of a child with unexpected differences or medical needs is likely to either significantly challenge some of these expectations or conversely might embed them more deeply. A particularly strong shared experience concerned participants' perceptions and enactments of their roles in relation to their child and partner. Participants predominantly described being a 'protector' as central to their identity as a father, which is consistent with the hegemonic conception of masculinity in Western society (Locock & Alexander, 2006). Perceptions of the significance of this role come not only from men themselves but also people around them (e.g. Moran-Ellis, 1989). Therefore, although this is perhaps typical to all fathers, it could be seen as enhanced for fathers whose children are visibly different.

The findings demonstrate that a CLP diagnosis causes fathers to experience a sense of failure and powerlessness, which for some was particularly devastating. The need to protect is also projected into the future, with all participants relaying fears about how their child will be treated by others in the future, whether at school, in the workplace or

socially. Paquette (2004) highlights that in general fathers play a key role in empowering children and promoting their contact with the outside world; this includes initiative-taking in unfamiliar situations, exploration, chance-taking, ability to overcome obstacles, bravery in the presence of strangers and ability to stand up for themselves. In line with this, several fathers in the present research described taking steps to try to pre-empt the consequences of potential problems relating to CLP, such as building the child's self-esteem and confidence. However, this may be for their own benefit as well as the child's; to feel that they are doing everything within their power to protect the child, thereby managing their own feelings of guilt and self-blame. This extends to the desire, but ultimate inability, to protect their child from painful operations, which supports findings by Nelson et al. (2012c).

Also evident was the relationship between fathers' conceptualisation of CLP and their parenting of the child. Those who held particularly negative conceptualisations, indicated by the language they used, also described compensating for CLP (e.g. being more lenient or tolerant, or making allowances). This is consistent with Tobiasen and Hiebert's (1984) findings that parents of children with CLP were significantly more tolerant of behavioural difficulties displayed by the child than parents in a control group. This is likely to extend to children with other health-related problems. Interestingly, the majority of participants demonstrated another, usually simultaneous, response that has been termed here as 'counteracting'. This included volunteering information about their child relating to their abilities, pretty physical features or strength of personality. Although this is relatively common in the wider disabilities literature (e.g. Meyer, 1995; West, 2000), this had not been reported previously in relation to CLP. This also extends Klein et al.'s (2010) craniofacial anomaly study where participants were directly asked to identify their child's strengths. In addition, almost all fathers demonstrated a desire to show the researcher their child's appearance, in photos (pre- and post-operatively) and on three occasions in person. This could be understood as attempts to demonstrate the child's 'normality', reinforcing statements that CLP was not all-encompassing, and perhaps also evidencing themselves as 'normal' fathers. Hegemonic masculinity places less powerful men in a subordinate position, which may include those who have children with significant health conditions (Courtenay, 2000), giving rise to the sense of failure participants experienced, as discussed above. This demonstration may therefore serve to counter the potential inferiority they experience.

The second central role identified was as a source of support for their partner, in line with wider research (e.g. Browner & Preloren, 1999; Locock & Alexander 2006; Reed, 2009; Williams et al., 2011). This involved reassuring, containing and 'grounding' them, providing a counter-balance to their anxieties and concerns. However, this had significant implications for the fathers with regards to addressing their own emotional needs. In order to be able to fulfil this role, many participants described 'bottling up' or putting aside their own emotions. Similar findings were noted by Ekelin et al. (2008) and Locock and Alexander (2006). Implicit in this is that dealing with both their own and their partner's emotions at the same time would be too difficult. However, as a result, their suppressed feelings were left ignored. One father noted that when he finally brought the subject up after six months, his feelings came as a surprise to his wife, who thought he was coping well. However, for some, putting feelings aside was not voluntary but imposed on them by others. This reflects the idea that being available to actively support partners is not just self-enforced but also often expected from the women themselves and wider society.

Several fathers described their difficulty in being made to feel that they (and their emotional responses) were insignificant compared to the mother and that there was no space for them to express their own struggle in coming to terms with the situation. They also expressed feeling excluded by their wife and/or services from the point of diagnosis; excluded from the pregnancy, from their child's care and from accessing support. This resulted in feelings of resentment and anger, and for two participants, damage to the marital relationship (further explored in 4.2.3). Within systemic theory, emotional difficulties suffered by one member of the system are understood to be a product of the relationships within the system (Dallos & Stedmon, 2006). Perceiving fathers solely as supporters rather than direct participants in this context clearly reinforces their sense of exclusion (Draper, 2002; Locock & Alexander 2006). As posited by Statham et al. (2001), men need to be supported for their own well-being and to be able to be supportive to their partners. Therefore, fathers require thoughtful recognition of their needs as individuals and as part of a couple (Locock & Alexander, 2006).

Interestingly, some fathers described finding themselves in unexpected roles in relation to feeding the baby. Having planned that the mother would breastfeed, fathers

expected to have little involvement in this aspect. However, the diagnosis meant breastfeeding was not feasible. For most couples, giving breast milk (over formula, which would have been logistically easier) remained important, perhaps as a way of compensating for the child not having the 'best start' in life. Unanticipated were the additional difficulties this resulted in for some fathers, particularly lack of sleep due to increased involvement in feeding at night because mothers were occupied with expressing milk. One father commented on feeling that the feeding cycle was never-ending, indicating how overwhelming this seemed.

For fathers of children with a cleft palate there were further personal implications. These included feelings of frustration at the milk coming back through the child's nose rather than being ingested, and guilt at their inability to get feeding techniques right and therefore feeling that the child suffered as a consequence. Feeding has been highlighted as a major issue in several studies (Johansson & Ringberg, 2004; Oliver & Jones, 1997; Young et al., 2001). These problems served to reinforce fathers' sense of difference on a daily basis. Although unexpected involvement with feeding was not commented on as a particularly positive or negative aspect (more simply as a surprise), one father did reflect on the beneficial outcome this had in terms of developing his bond with the baby. This seems important given the literature regarding fathers' direct and indirect influences on child development, as outlined in Chapter 1.

### 1.5.3  How Do Fathers' Experience Being Supported In This Context?

Apparent in the findings was that fathers felt excluded from traditional sources of support. Several participants, unsurprisingly, described their partner as their main source of support (when sought). This supports findings across wider literature (e.g. Goble, 2004; Katz, 2002; Pelchat et al., 2003; Sullivan, 2002; West, 2000). However, the shape this support took varied in different relationships. For some fathers, their partner taking on the bulk of responsibility in relation to CLP treatment allowed them a level of disengagement and therefore managing difficult emotions through avoidance. Others described having a mutually supportive relationship with their spouse, and felt less ignored at an emotional level. Participants' accounts suggested that those who had a more supportive marital relationship found their experiences of cleft to be more manageable than those who felt unsupported. This is consistent with Miller et al.

(1999) who found that family satisfaction had a 'buffering' effect in relation to parental stress in parents of children with port-wine stains, also noted in findings from studies in other areas of health, such as spina bifida (Kronenberger & Thompson, 1992).

This may reflect that within this sample, for the participant whose marriage ended shortly after his child's birth and the father who reported that his marital relationship was particularly strained following the diagnosis and birth of his child, both seemed to reflect having the most difficulty in adjusting or managing their experiences. St.John et al. (2003) similarly found that having a child with a craniofacial anomaly negatively affected the stability of the parental relationship when difficulties were already present. From a family systems perspective, difficulties experienced by one family member will have effects for all members, who are seen as inherently interconnected (Dallos & Stedmon, 2006). Therefore, if fathers feel excluded and unsupported, this is likely to have ramifications for their partner and child.

The majority of participants reported poor experiences of local services at diagnosis and birth, which centred on an apparent lack of knowledge regarding a relatively common condition and ability to provide adequate information and support. This left fathers with a sense of bewilderment at the lack of preparedness of these services, often resulting in them feeling frustrated and anxious rather than reassured. In addition to this, fathers reported experiencing being treated 'differently', for example sonographers insisting they keep scan pictures for free, as if out of pity, which fathers did not appreciate. This, coupled with multiple other perceived and real failings at a local level, for example not having appropriate bottles available after the birth, left fathers with an increased sense of difference. Some participants' also experienced frustration at not being able to find out the definitive cause of CLP, which may have contributed to their sense of powerlessness. Nelson et al. (2012b) reported similar findings.

This is in contrast to the generally positive experience of specialist services. Unsurprisingly, fathers reported feeling reassured and comforted by the wealth of information, expertise and on-going support provided. However, one area in which the findings indicated some mixed views related to how the fathers experienced the MDT meetings. One participant compared this intimidating experience to auditioning for 'X

Factor'. This perception might result in the need to present as coping well, when it is apparent in the findings that not all of them were. Another participant explicitly commented on the benefit of the one-to-one meeting with the researcher as facilitating more open dialogue regarding difficulties, openly reflecting that he was much more reserved in front of the MDT. This may also be related to wanting to preserve his position in supporting his wife. Similar points are highlighted by McNeill (2004). Therefore difficulties may be well-masked and go undetected by professionals and close family members. Locock and Alexander (2006) similarly noted that, in the context of pregnancy complications, women often failed to recognise the impact on their partner because men managed to hide their distress so well. Fathers withholding emotions in order to protect loved ones is a common finding in the existing literature (e.g. Jones & Neil-Urban, 2003). Men are therefore less likely to receive mutual support and their distress is less likely to be taken into account in decision-making processes (Locock & Alexander, 2006).

All participants commented on the benefit of contact with other parents of children with CLP, gaining their fist-hand experiences and perspectives in relation to treatment and, more importantly, outcomes. Fathers found it particularly helpful to see first-hand the appearance of children that had already been through various stages of treatment. This provided an informal source of support and also served to normalise their feelings and experiences. In addition to this, CLAPA were seen as a particularly trusted and up-to-date source of information, perhaps due to the first-hand experiences of many of the staff.

In the majority of cases, the anxiety created by the shock of the diagnosis and the perceived lack of information and support from local services, appears to lead to a search for information. In a meta-synthesis of qualitative research regarding men's experiences of antenatal screening, Dheensa et al. (2013) noted that information seeking acted as a coping-mechanism for men when complications arose. The desire for detailed information was also reported by Byrnes et al. (2003). Krahn et al. (1993) found that feeling ill-informed at the time of diagnosis negatively impacted on parents' perceptions of CLP. Unsurprisingly, all participants reported turning to the internet to find more information (also found by George et al., 2007). However, the findings

suggest that this unguided search often only served to increase the uncertainty and anxiety experienced.

For fathers in particular, this search for information appears to serve as a way of managing emotional responses and sense-making of the situation. This is in line with findings by Dheensa et al. (2013), who suggested that feeling better informed gave men a sense of control and empowerment when interacting with healthcare professionals. However, this also led to further anxiety as some of the information found was incorrect or not applicable to them, or gave rise to further questions and uncertainties.

Perhaps more common strategies were avoidance and focusing on practicalities, also found by McNeill (2004). Some participants commented on the lack of support structures specifically for fathers and chose to engage more directly with emotional difficulties by offering support to other fathers themselves. This was seen as mutually beneficial, allowing them to process their own responses as well as supporting others. This is supported by Ringsberg et al. (2002) who reported that sharing experiences with other people who have the same chronic condition is usually experienced as helpful. It follows that this would extend to parents of children with long-term conditions. The pattern of wanting to be a source of support for their partner while relying predominantly on self-support has also been noted by McNeill (2004).

### 4.2.4 Summary

This research adds to the existing literature in several important ways, in both providing novel contributions and in expanding upon current understandings. By focussing solely on fathers and using qualitative methodology to explore their experiences in relation to CLP, this study begins to address the paucity of literature in this area, highlighted in limitations of previous research (e.g. Baker et al., 2009; Berger & Dalton, 2009; Phares et al., 2005). The hope is that this will contribute to reversing the 'invisibility' of fathers in paediatric research (Saracho & Spodek, 2008). In addition, it is unusual even in the wider literature to hear men speak about their internal world and emotional lives. Within CLP literature this study is unique in prioritising fathers' voices and emphasising accounts of fathers'

experiences in their own words. The findings further our knowledge and understanding by illuminating the complexities and subtleties of fathers' experiences of having a child with CLP, as well as highlighting their on-going conflicting emotional responses and tensions. These are apparent not only at significant points, such as diagnosis, birth and surgery, but throughout the child's longer-term treatment and overall development.

This closely mirrors findings within existing CLP literature. Nelson et al. (2012b) used constructivist grounded theory to explore the experiences of 35 parents of children with CLP across the treatment programme. Within their model a key subcategory, 'managing emotions' (which the paper focusses specially on), highlighted conflicting emotions, uncertainty and stigmatizing reactions as characterising aspects of managing emotions over an extended period of time. However, because there was no differentiation between accounts given by mothers and fathers, any potentially gendered aspects of these experiences have been overlooked. The present research addresses this issue in relation to fathers, with findings highlighting specific aspects such as the impact (simultaneously positive and negative) of adopting certain the roles in supporting mothers.

Themes identified here also connect with themes outlined in Johansson and Ringsberg's (2004) phenomenographic study. Their first theme, 'Unexpected event: having a child with CLP', illustrates how participants' understood their experiences of having a child with CLP. One subtheme describes participants' experiences of first meeting their child. This differs slightly from the present study, where more emphasis was placed on the experience of diagnosis rather than first seeing their child. The second subtheme focusses on support from professionals, and the third subtheme emphasises treatment from the Child Health Centre. Again, this differs somewhat from present findings in that it predominantly focussed on outside sources of support and does not consider the roles and positions taken up by the parents themselves. The second main theme, 'Reactions', consists of two subthemes. The first illustrates how participants experienced the varying initial reactions of family and other people. This closely connects with stigmatizing experiences described by fathers in the current study.

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The second describes people's reactions after the lip-repair surgery. The difference here is that less attention is paid to personal reactions to the changed child, which featured so heavily in the present study. Overall, it is unclear whether fathers' accounts reflected all or only some of these themes, as for some subthemes the authors only give supporting quotations from mothers. This may be because fathers did not although this could be due to selection of these quotes over any from fathers' accounts rather than an absence of supporting data from fathers.

Furthermore, the findings also reflect those in the wider paediatric long-term conditions literature focussing on fathers (Ablon, 1990; Daniel et al., 2005; Kearney & Griffin, 2001; Larson, 1998; Nelson, 2002). For example, similarities were found with Baumann and Braddick's (1999) research into the meaning of the experience of fathering as described by fathers of children with congenital anomalies. Their findings outlined three themes. Firstly, they noted a desire to grasp the situation, mingled with disturbing feelings, while facing one's own limits which gave rise to comforting views; this mirrors the desire to seek information in order to feel more in control and therefore reduce anxiety as expressed by fathers in the present study. Secondly, they noted comfortable-uncomfortable ways of being with others emerge as fathering shifts one from the familiar to the unfamiliar; similar experiences were noted in this study, where fathers struggled with managing other people's reactions and noticing people's changing reactions to them as fathers.

A final aspect described was the rise of both joy and sorrow when confronting the always changing now and the unpredictable future; this mirrors the anxiety about the future, both short and long-term, held by fathers in this study. This overlap between findings of this research and that in other areas of paediatric research can be understood to indicate that perhaps some of the experiences spoken about reflect core aspects of fatherhood and parenting, rather than being condition or situation specific. Therefore the present findings can be seen to further inform our understanding of fathers' experiences in paediatric contexts more widely, and perhaps of fathering in general. An example of this is the position men adopt in relation to supporting their partners (discussed further in

4.3.1), which at times is to the determinant of their own emotional well-being. As noted by Chesler and Parry (2001), fathers' experiences are clearly influenced by gender identities and roles, as well as the current gendered organisation of services and support structures. These therefore, need to be considered in future research and service provision.

## 4.3  Implications and Recommendations

### 4.3.1 Implications for Further Research

Treatment for CLP, and therefore fathers' related experiences, might extend over a period of 20 years (Nelson et al., 2012b). This study focused on the experiences of fathers with children of infant, pre-school and primary. This degree of heterogeneity was necessary in order to ensure sufficient recruitment. However, including fathers of children of a relatively wide age range has implications in terms of their lived experiences at the point of taking part in this research. For example, it could be argued that fathers of older children may have experienced a cumulative effect of other people's negative reactions. Equally, it could be argued that fathers of younger children would not have had as much opportunity to experience positive aspects such as personal growth, coping and adjustment to the situation. In attempting to maintain a certain degree of homogeneity by focussing on younger children, the opportunity to gain the views of fathers of older children was limited. Future research could take a prospective, longitudinal focus, conducting multiple interviews with fathers over time. This would allow a developmental perspective, taking into account their experiences at various transition points in the family life cycle (Carter & McGoldrick, 1998). Furthermore, it might be of value to follow in the footsteps of related literature (e.g. Prior & O'Dell, 2009), taking a more relational approach and interviewing fathers and children together. Alternatively a whole-family approach would enlighten the interaction between family scripts (e.g. regarding gender, roles, difference) and lived experiences of fathers, as well as how the children experience being parented by their father in relation to this context.

Although not necessarily novel, an interesting picture emerged of the role that fathers play in relation to supporting mothers. However, the current findings meaningfully

extend the existing literature around this by highlighting the significant and potentially damaging impact that adopting these roles has on the men and their own emotional well-being. Further in-depth attention to this specific aspect may yield important findings to better inform clinical practice and service provision. Perhaps most importantly, future research should aim to explore the experiences of fathers from minority ethnic backgrounds and diverse communities, as CLP occurs more frequently among Indian and Oriental populations (Weigl et al., 2005). Some literature exists highlighting that experiences in relation to visible difference are likely to be connected to cultural and ethnic membership (Papadopoulos et al., 1999), as well generational influences (Hughes et al., 2009). However, little research has been conducted in the CLP field (particularly in the UK) and none specifically exploring the experiences and perspectives of fathers. This may have significant implications in terms of access to services and treatment decisions. However, it is possible that cultural implications and stigma may make recruitment difficult.

### 4.3.2 Implications for Clinical Practice

This study is relevant to clinical psychology because these men's voices are absent (or at the least under-represented) in literature and practice to date. The findings confirm that both pre- and post-natal periods can be difficult for a variety of reasons. Fathers described challenges that consisted of common responses and worries, and may therefore have previously been less visible to service providers. Nelson et al. (2012b) suggest that, in accordance with the UK's policy on 'family-centred' care (Department of Health & Department of Education and Skills, 2004), services should offer routine family assessments which incorporate parental emotional and social well-being, extending along the care pathway (Rumsey & Harcourt, 2007). I suggest that careful consideration be given to fathers in this context, as paternal well-being has significant implications for the child, the mother and the family as a unit. Routinely offering a separate space to 'check in' with fathers may mean they are more likely to access support when needed, which would have an overall positive effect for the wider family.

As discussed, fathers play an important role in their child's development and are a central source of support for mothers. Some fathers commented on the experience of healthcare professionals talking past them to the mother. Clearly there is a need to

ensure that both parents are addressed and that fathers are included in their own right, not just seen as there to support the mothers. Taking a more actively inclusive approach with fathers may be important, as well as routinely offering them the opportunity to speak with a psychologist away from the MDT spotlight. The full MDT setting may feel intimidating (as well as being geared towards discussing the child), therefore making it difficult to raise any personal issues. As highlighted in the findings, many men in this context become adept at masking their true feelings, which may also mean that MDT members may not pick up on difficulties during their contact with fathers.

Where difficulties are identified, taking a family approach to intervention may also be particularly helpful.  Circular patterns can be seen to exist; parental response to adversity influences the child's response, which in turn affects parents' response (Patterson & Garwick, 1994). For example, over-protectiveness can stem from parents' fear of other people's reactions. This may conflict with the child's developmental needs, e.g. autonomy, or compound emotional and social difficulties they are experiencing, resulting in greater distress for both (Alderfer & Kazak, 2006) and potentially further over-protection. Intervening at a family level allows an integrative view of adjustment, difficulties and ramifications for the whole family (Kazak, 1989). Adopting a systemic approach also allows problems to be placed in the wider social context, potentially de-pathologising and normalising difficult experiences (Dallos & Stedmon, 2006). Furthermore, a social constructionist perspective, which emphasises the importance of language and culture in 'constructing' experiences (Harper & Spellman, 2006), would also acknowledge the influence of dominant cultural discourses regarding masculinity and VFD, which are clearly central to these fathers' experiences.

Bocian and Kabak (1978) suggest that the way the initial informing conversation about diagnosis is handled by professionals plays a critical role in parental adjustment and coping, which in turn has significant implications for the child's development (Rutter & Rutter, 1992; Werner & Smith, 1982). From a systemic perspective, recognition is given to the co-construction of experiences as a result of interaction between clinicians, patients and families (Altschuler, 1997). Training and development at local level is needed to improve experiences at diagnosis and birth, as the findings

highlighted that participants felt under-informed and poorly supported at these points, contributing to a more negative overall experience. Gaining knowledge and expertise is difficult when seeing relatively few cases each year (Hodgkinson et al., 2005); although the role of the specialist nurse liaison appears to be helpful, ensuring local hospital staff have up-to-date knowledge of CLP and appropriate equipment is essential in limiting negative experiences for parents. Hodgkinson et al. (2005) note similar tensions given the structure of CLP services, and the need for further training at local level.

Finally, all organisations (NHS and voluntary sector) need to be mindful of the language they adopt, e.g. specifically addressing mothers *and fathers* in information or invitations to support groups would help fathers to feel more actively included, potentially enabling increased access to support.

## 4.4   Critical Review

### 4.4.1 Quality in Qualitative Research

An important consideration in any research is 'quality'. However, the criteria and frameworks used to judge the quality of quantitative research cannot be applied to qualitative research in the same way (Smith, 2003). Several authors have suggested frameworks which may be more appropriately applied to qualitative work. I have drawn on Yardley's (2000) four key principles to inform and evaluate this research. These principles, and my attempts to address them, are discussed below:

#### *4.4.1.1 Sensitivity to context in which the study is situated*

I have attempted to demonstrate sensitivity to the multiple contexts that guided and influenced this research by outlining the existing literature (both relating to the topic of investigation, and to IPA's theoretical underpinnings). In addition, providing participant demographic details, pertinent personal information, and details about the charity through which some participants were recruited, further contextualises the data. I was also aware of the dominant discourse that men are difficult to recruit into research and held in mind the power imbalance that could occur when positioned as an 'expert'.

Recruiting through a charity and public forums rather than the NHS, and interviewing in participants' home or workplace, meant there was less focus on me as a perceived 'expert' health professional. At the beginning of interviews I also emphasised participants' 'expert by experience' position.

### 4.4.1.2 Commitment and rigour

According to Yardely (2000), commitment and rigour involve in-depth engagement with the topic and comprehensive application of data collection and analysis processes. As a result of my initial reading the absence of fathers became increasingly apparent, which led me to engage further with this particularly neglected aspect. The significance of the fathers' experiences became increasingly apparent during interviews, and was further reinforced by a review of the literature regarding fatherhood. This evoked a greater sense of responsibility to the participants and their accounts, as well as to my overall commitment to the research. However, I also acknowledged that qualitative analysis is not defined by a particular finishing point, and that continuation of analysis could always lead to further insights. With this in mind, I hope that this account delivers meaningful insight into the experiences of these fathers, prioritising their voices.

Aware of my inexperience using IPA, I drew on the knowledge and experience of other IPA researchers in the field of CVFD (Prior, 2012). I also attended IPA training and IPA peer-researcher groups, where I presented my interview schedule for discussion prior to commencing data collection. Part of my review process involved discussion of my data and themes with a peer-researcher, as well as receiving supervisor feedback. This allowed me to check coherence and transparency of themes.

### 4.4.1.3 Transparency and coherence

Yardley (2000) describes transparency as the clarity with which the various stages of the research are outlined; coherence is achieved through careful analysis followed by careful presentation and discussion of findings. Both convergence and divergence within accounts should be attended to. I endeavoured to achieve a high degree of transparency and coherence by carefully describing participant recruitment, interview schedule construction, interview procedures, and steps of analysis, and by providing

an overview of both the hierarchical relationship between super-ordinate and sub-ordinate themes and their interconnectedness. I also described my epistemological position, theoretical orientation and personal influences which are likely to have impacted on my understanding of the topic. Furthermore, attending reflexive groups aided transparency of my own assumptions, expectations and feelings, which may have influenced the engagement with and analysis of the data (see 4.6.2). Steps taken in striving for coherence are also discussed in 4.4.1.2.

### 4.4.1.4 Impact and importance

The validity of qualitative research rests on its success in informing readers of a phenomenon that is interesting and important in nature (Yardley, 2000). I endeavoured to bring participants' shared and divergent experiences alive by carefully selecting quotes and attempting not to over-refine them, which helped to maintain their integrity. Attention was also paid to the language used and observational aspects during interviews. Although this study mainly confirmed findings from wider paediatric literature, it is unique in directly and solely addressing the experiences of fathers within the field of CLP. I hope this research will achieve an impact in several ways: a) publishing the research in a journal will further disseminate the findings directly to researchers and professionals in the field, b) sharing findings with the CLP community to increase awareness, and c) hopefully utilising the research results in contributing to training for professionals in this field. All participants expressed that they were pleased an interest was being taken in their views or that they found having the opportunity to talk about their experiences valuable. For some it was the first time they had really done so. In this sense, the research has already been of importance and had a significant impact.

### 4.4.1.5 Generalizability

In addition to Yardley's (2000) criteria, consideration was also given to the contentious issue of generalizability of findings from qualitative research. It is important to re-iterate the emphasis on idiography within IPA, with the aim to inform not to generalise. Sampling issues are further explored in 4.5.2.

### 4.5  Methodological Limitations

#### 4.5.1 <u>Recruitment</u>

An interesting aspect that came to light was that the majority of participants became aware of the research through their wives/partners (or in one case, his mother, and the separated father through his ex-wife). Many initial expressions of interest came from women, either asking for further details or suggesting their husbands may be interested and providing direct contact details. This has potentially significant implications for future research involving fathers and should be considered when designing recruitment strategies. Interestingly, two fathers made arrangements to participate but dropped out at the last minute (see Appendix 20 for reflections).

#### 4.5.2 <u>Sample</u>

IPA aims to gain insights to particular phenomena, which is only achievable by selecting participants for whom the research topic is directly meaningful (Smith et al., 2009). As discussed, purposive homogenous sampling is theoretically consistent with IPA. This sample was homogenous in that all participants were biological fathers of children with a cleft lip of primary or pre-school age, and all fathers identified as white British. However, the lack of diversity within the sample with regards to ethnicity, race and religion could also be seen as a limitation, especially given the higher prevalence of CLP in Asian populations. Concerns may also be raised regarding using CLAPA as the main recruitment route (rather than recruiting via the NHS). It could be argued that this may result in a biased sample, in that they may differ in important ways from those who have not sought or received such support. However, Prior and O'Dell (2009) argue that families accessing such organisations have a diverse range of experiences and issues.

#### 4.5.3 <u>Interviews</u>

Although interviewing is considered to be the central technique of qualitative data generation, it is worth noting critiques levied by some authors. Potter and Hepburn (2005) argue that the use of interviews poses a number of problems. These include:

deletion of the interviewer (omission of their questions); specificity of analytic observations; unavailability of the interview set-up; and failure to consider interviews as interactions. I attempted to address these concerns by: incorporating questions/comments in some extracts; presenting transcriptions with line numbering and separate lines for interviewer and participant; giving detailed contextualising information about the interview set-ups; and not only acknowledging but centralising the perspective of interviews as interaction, which is theoretically coherent with IPA.

### 4.5.4 Researcher-Participant Interaction

I was mindful of my position as a trainee clinical psychologist and how this might affect participants' perceptions of me. To help set up the participant-researcher relationship I began interviews by explaining that I was interested in their account of their experiences. Following reflection on the process of the first interview, I decided to start the digital recorder right at the beginning of subsequent conversations. This allowed small-talk to lead more naturally into the interview, making a less obvious 'start' which I felt put participants more at ease as they were less conscious of being recorded. I was careful not to rush interviews, fitting in with participants' needs and creating space and time for discussion of sensitive issues (Stevens et al., 2010). I also considered the possible impact on participants (and therefore data) of being a female researcher interviewing men about an emotionally difficult topic. However, research suggests that men report perceiving females as more supportive (Barnett et al., 2012), empathetic and accepting (Myers, 1989), therefore it is likely this had a positive influence on participants' ability to share their accounts.

## 4.6 Personal Reflections

### 4.6.1 My Position in Relation to the Topic

Embarking on this process, I was initially drawn to exploring the social aspects of the lives of children with VFD, which was influenced by my own experiences in relation to this. However, during initial literature reviews I became increasingly aware of the absence of fathers' voices and developed the present study from that observation. Throughout the process I remained mindful of my position as a woman of child-bearing

age with my own intermittently visible facial difference. I reflected on the effect this may have had on participants and therefore the data generated. However, as participants were reflecting on their own experiences (and specifically in relation to CLP), any impact is likely to be minimal. My experiences inevitably influenced my choice of topic to research, as well as the assumptions and expectations I held in relation to it. I hope that engaging in a process of reflexivity enabled increased awareness of how my experiences may have influenced my research and provided transparency for the reader.

### 4.6.2 Reflexivity

Interpretations and insights are bound in part by the researcher's capacity to reflect (Brocki & Wearden, 2006). Active engagement in reflexivity during the process of research is therefore important in ensuring quality analysis (Shaw, 2001). I endeavoured to do this in several ways, e.g. attending an IPA reflexive group and engaging in conversations about assumptions and expectations of the interviews and overall research. This was pursued in the hope that becoming more aware of the conceptions I held would help in 'bracketing' them to some degree. These conversations were recorded and transcribed for future reference and reflection (see Appendix 21). Making post-interview reflexive notes recorded thoughts and feelings evoked by each session, which could then be considered before engaging in subsequent interviews.

Despite these attempts to maintain awareness of my own assumptions and expectations, it is impossible to completely detach oneself from these influences. One potential influence in the analysis of the data may be a gender-stereotyped interpretative bias, i.e. that social learning leads to stereotyped beliefs or understandings about gender that in turn bias the interpretation of the qualitative data provided by these men. However, as discussed, one of the strengths of Interpretative Phenomenological Analysis is the open acknowledgement that only partial knowledge of participants' experiences can be obtained and that the analysis produced is the researcher's interpretation of the experiences described.

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**APPENDICES**

**Appendix 1: Literature Search Strategy**

For the purposes of a literature review, a search was conducted to identify literature relevant to this study. EBSCOHost was used to search the following electronic databases: PsycInfo, CINAHL Plus and Education Research Complete. Additionally, ScienceDirect was searched. Google Scholar was also used to identity key words and additional relevant books.

The search term "visible difference" and "visible facial difference" and their synonyms were used. The search was then narrowed by using terms relating to specific facial differences, such as "cleft lip". All these terms were then coupled with the terms "father" and "paternal" and their synonyms. As limited results were produced, the search was expanded to include the terms "mother" and "parent" and their synonyms. Due to the relatively large wider corpus of literature this produced, certain strategies were used in selecting papers for inclusion. Due the focus of this research, literature regarding psychosocial aspects was prioritised and literature focussing on medical aspects was discounted. Where possible, priority was given to meta-analyses and systematic reviews, qualitative studies were given precedence over quantitative studies, and UK-based research was favoured. Articles not written in English were excluded.

**KEY**

**\* :** Truncation of words is represented by an asterisk (\*). This creates searches for varying endings of words and where multiple spellings exist. All forms of the word are then searched by the database, e.g. father\* would also search for fathers, fathering, fatherhood.

**" " :** Enclosing a phrase in double quotations marks ensure the exact phrase is searched for.

**Or:** Using 'or' between search terms broadens the search by including all terms in one search.

**And:** Using 'and' between search terms narrows the search by only including results incorporating all search terms used.

| Numbers | Terms | PsycINFO | CINAHL Plus | Education Research Complete | Science Direct |
|---------|-------|----------|-------------|---------------------------|----------------|
| S1 | **"Visible difference\*"** | 58 | 27 | 13 | 4,720 |
| S2 | **"Visible facial difference"** | 3 | 1 | 0 | 3 |
| S3 | **"Facial disfigure\*"** | 107 | 81 | 11 | 1,004 |

| S4 | **S2 or S3** | 107 | 82 | 11 | 1,006 |
|---|---|---|---|---|---|
| S5 | **Father*** | 36,122 | 9,056 | 16,373 | 158,524 |
| S6 | **Parent*** | 196,952 | 84,133 | 118,153 | 1,391,466 |
| S7 | **Paternal** | 6,889 | 2,379 | 1,347 | 40,770 |
| S8 | **"Facial anomaly"** | 1 | 2 | 1 | 1,968 |
| S9 | **"Facial abnormality"** | 3 | 5 | 0 | 1,348 |
| S10 | **Craniofacial** | 655 | 1,891 | 192 | 40,240 |
| S11 | **"Cleft lip"** | 290 | 1,875 | 126 | 13,570 |
| S12 | **Apert's** | 6 | 10 | 8 | 768 |
| S13 | **Crouzon** | 14 | 32 | 7 | 2,075 |
| S14 | **Hare-lip*** | 5 | 7 | 3 | 2,460 |
| S15 | **Harelip** | 14 | 1 | 54 | 23 |
| S16 | **"Hare lip*"** | 5 | 7 | 3 | 2,460 |
| S17 | **Craniosynostosis** | 31 | 172 | 21 | 3,647 |
| S18 | **Mother*** | 95,358 | 45,226 | 47,357 | 432,638 |
| S19 | **"Father child relation*"** | 4064 | 1143 | 915 | 509 |
| S20 | ***Facial Terms*** S1 or S2 or S3 or S8 or S9 or S10 or S11 or S12 or S13 or S14 or S15 or S16 or S17 | 1105 | 3,761 | 356 | 55,364 |
| S21 | ***Father (inc. parent) Terms*** S5 or S6 or S7 or S19 | 213,610 | 89,048 | 128,948 | 1,478,434 |
| S22 | ***Mother & Facial Terms*** S18 and S20 | 91 | 155 | 29 | 9,046 |
| S23 | ***Mother & Father & Facial Terms*** S21 and S22 | 42 | 51 | 15 | 6,048 |
| S24 | ***Father (only) Terms*** S5 or S7 or S19 | 39,481 | 10,112 | 16,963 | 182,581 |
| S25 | ***Father & Facial Terms*** S20 and S24 | 23 | 40 | 5 | 4,290 |
| S26 | ***Cleft & Father Terms*** S5 or S7 or S19 | 14 | 33 | 4 | 1,910 |

**Appendix 2: Information about CLAPA (CLAPA, 2013b)[6]**

"CLAPA is the only UK-wide voluntary organisation specifically helping those with, and affected by, cleft lip and palate. It is unique.

CLAPA was set up in 1979 as a partnership between parents and health professionals. It provides support for new parents, and for people with the condition and their families, from infancy through to adulthood.

CLAPA National Office is based in London with a network of branches (branches are all run by volunteers) and many other regional contacts in the United Kingdom, all committed to providing the support needed by families affected by cleft lip and/or palate.

Branches are run by people who have themselves benefited from the organisation, often working in partnership with local health professionals. CLAPA's key functions are to:

- Organise local parent-to-parent support through its nation-wide network
- Run a specialist service for parents and health professionals seeking help feeding babies with clefts
- Develop support for children and adolescents affected by clefts at school and in social settings through such activities as confidence-building camps
- Encourage and support research into causes and treatment of cleft lip and palate
- Represent the interests of patients and parents, influencing policy on future treatment of cleft lip and palate
- Conduct educational seminars for health professionals and the general public
- Raise funds in the community for equipment, literature and services
- Publish and distribute a range of information leaflets, increasing public awareness of the condition
- Support projects in countries where cleft treatment is limited or unavailable"

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[6] This information was obtained directly from CLAPA's website; no page numbers are available.

**Appendix 3: Typical CLP Treatment Timetable (National Health Service, 2013b)[7]**

"Most children with clefts receive the same type of care plan tailored to meet their individual needs. A typical care plan timetable:

- Birth to 6 weeks: counselling for parents, hearing test and feeding assessment
- 3 months: surgery to repair a cleft lip
- 6-12 months: surgery to repair a cleft palate
- 18 months: speech assessment
- 3 years: speech assessment
- 5 years: speech assessment
- 8-11 years: bone graft to the cleft in the gum area (alveolus)
- 11-15 years: orthodontic treatment and monitoring jaw growth
- 18 years+: if needed, jaw surgery, lip and nose revision surgery, and final replacements for any missing teeth"

Revision surgery may also occur at other points in childhood if necessary.

---

[7] This information was obtained directly from the NHS Choices website; no page numbers are available.

## Appendix 4: UEL Ethical Approval

| **ETHICAL PRACTICE CHECKLIST (Professional Doctorates)** |
|---|

**SUPERVISOR**: Ken Gannon  **ASSESSOR:** Joy Coogan

**STUDENT:**  Fiona Perella  **DATE (sent to assessor):** 10/02/2012

**Proposed research topic**: Exploring the experiences of fathers of children with a visible facial difference

**Course**: Professional Doctorate in Clinical Psychology

1. Will free and informed consent of participants be obtained?   YES

2. If there is any deception is it justified?   N/A

3. Will information obtained remain confidential?   YES

4. Will participants be made aware of their right to withdraw at any time?  YES

5. Will participants be adequately debriefed?   YES

6. If this study involves observation does it respect participants' privacy?  NA

7. If the proposal involves participants whose free and informed consent may be in question (e.g. for reasons of age, mental or emotional incapacity), are they treated ethically?   NA

8. Is procedure that might cause distress to participants ethical?   YES

9. If there are inducements to take part in the project is this ethical?   NA

10. If there are any other ethical issues involved, are they a problem?   NA

**APPROVED**

| YES | | |
|---|---|---|
| | | |

**MINOR CONDITIONS:**

**REASONS FOR NON APPROVAL:**

Assessor initials:  JC  Date:  13/1/12

## RESEARCHER RISK ASSESSMENT CHECKLIST (BSc/MSc/MA)

**SUPERVISOR**: Ken Gannon          **ASSESSOR:** Joy Coogan

**STUDENT:**     Fiona Perella          **DATE (sent to assessor):** 10/02/2012

**Proposed research topic**: Exploring the experiences of fathers of children with a visible facial difference

**Course**: Professional Doctorate in Clinical Psychology

Would the proposed project expose the <u>researcher</u> to any of the following kinds of hazard?

1       Emotional                    NO

2.      Physical                     NO

3.      Other                        NO

         (e.g. health & safety issues)

If you've answered YES to any of the above please estimate the chance of the researcher being harmed as:                    HIGH / MED / LOW

**APPROVED**

|     YES     |  |  |
|-------------|--|--|
|             |  |  |

**MINOR CONDITIONS:**

**REASONS FOR NON APPROVAL:**

Assessor initials:  JC          Date:  13/1/12

Please return the completed checklists by e-mail to the Helpdesk within 1 week.

**UEL**
University of
East London

www.uel.ac.uk

**School of Psychology**

**Professional Doctorate Programmes**

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ
tel: +44 (0)20 8223 4966   fax: +44 (0)20 8223 4937
e-mail: mno.davies@uel.ac.uk   web: www.uel.ac.uk/psychology

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If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853

POSITIVE ABOUT DISABLED PEOPLE

123

## Appendix 5: Email Confirming Ethical Approval from Changing Faces

RE: Thesis re: fathers

To: Fiona Perella

Cc: sallym@changingfaces.org.uk

Henrietta Spalding

**Henrietta Spalding**
(HenriettaS@changingfaces.org.uk)
27 July 2012 15:54:37
Fiona Perella (fionaperella@hotmail.co.uk)
(sallym@changingfaces.org.uk)

Hi Fiona

I'm pleased to report that we've now heard from our Adviser, Susan Harrison who was very impressed indeed with your proposal so we would be happy to support your project.

She does make some small points which I have listed below:
· Your NHS indemnity (see ethics application) won't cover this research. But UEL indemnity will.
· The list of support organisations is rather long. We're not even sure that The Disfigurement Guidance Centre is operational any more
· When you have a very small sample complete anonymity can't be guaranteed. If participants have unusual features – let's say the Somali elderly father of a child with an unusual disfigurement – it's quite hard to disguise that in the write up. So I think it's better to explain pseudo-anonymity to participants, if not actually using this term.

She also offers a contact at http://www.fatherhoodinstitute.org/ who she'd be happy to make contact on her behalf if you want another link to a relevant organisation.

Do hope this is helpful and if you can let me know how you would like to take this forward, I'd be happy to discuss next steps.

Best wishes

Henrietta
---
This email and any files transmitted with it are confidential and intended solely for the use of the individual or entity to whom they are addressed, and should be treated by the recipient accordingly. If you are not the intended recipient please notify the sender immediately. You should not copy it or use it for any purpose nor disclose its contents to any other person.
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**Appendix 6: Support Sheet**

# Support Organisations and Useful Contacts

### CLAPA

CLAPA is a UK-wide voluntary organisation specifically helping those with, and affected by, cleft lip and palate.

**Website**: www.clapa.com
**Address**: CLAPA, First Floor, Green Man Tower, 332B Goswell Road, London, EC1V 7LQ
**Call**: 020 7883 4883
**Email**: info@clapa.com

### Changing Faces

Changing Faces is the leading UK charity that supports and represents people (and their families) who have disfigurements to the face, hand or body from any cause.

**Website**: www.changingfaces.org.uk
**Address**: Changing Faces, 33-37 University Street, London, WC1E 6JN
**Call**: 0845 4500 275 or 0207 391 9270
**Email**: info@changingfaces.org.uk

### Let's Face It

A support network for people with facial disfigurement, their families, friends and professionals.

**Website**: www.lets-face-it.org
**Address**: 72 Victoria Avenue, Westgate on Sea, Kent, CT8 8BH
**Call**: 01843 833724
**Email**: chrisletsfaceit@aol.com

### Headlines – Craniofacial Support Group

**Website**: http://www.headlines.org.uk/ **Email**: info@headlines.org.uk
**Address**: Headlines, 8 Footes Lane, Frampton Cotterell, Bristol, BS36 2JQ
**Call**: 01454 850557

### British Association for Counselling and Psychotherapy

This is a service which will enable potential clients to find a suitable counsellor with whom they feel comfortable, in their particular area.

**Website**: www.bacp.co.uk
**Email:** bacp@bacp.co.uk
**Call**: Information helpdesk: 01455 883316 / General Enquiries: 01455 883300

**Participant Information Sheet**

*"Exploring the experiences of fathers of children with a visible facial difference"*

You are being invited to participate in a research project exploring the experiences of fathers of children with a visible facial difference. The aim of this information is to help you consider whether you would like to participate. Please take time to read the following information and you are welcome to talk to others about the study if you wish.

**What is the research about?**

The experience of fathers has largely been neglected when thinking about children with visible differences and their families. We hope that by exploring your experiences and views, we can gain a better understanding of how men in this position understand their role in their family, the positive aspects of parenting and the challenges they face and how they cope with any challenges. We hope that this will aid us in understanding how we can best meet the needs of dads.

**Who can take part?**

You are eligible to take part if:
- ✓ You are over 18 years old.
- ✓ You are the biological father of a child with a visible facial difference
- ✓ Your child's visible difference is congenital (e.g. cleft lip)

You are not eligible to take part if:
- ✗ Your child has an acquired visible difference (e.g. scars as a result of burns)
- ✗ Your child has severe health problems
- ✗ Your child's visible difference is a hereditary condition
- ✗ Your child's visible difference is secondary to another health condition (e.g. cancer)
- ✗ Your child has a cognitive impairment (i.e. diagnosed learning disability)

**What will I have to do if I take part?**

A female researcher will arrange to meet with you at a convenient time and place (either at the Changing Faces premises, the University of East London, or at your home, or via Skype). Prior to taking part, you will be given a copy of this information sheet to keep and a consent form to sign. Where interviews are taking place via Skype, a consent form and SAE will be posted to participants and verbal consent will also be recorded. During the meeting, you will be asked to talk about your experiences of being a father, including challenges you have faced and positive experiences you have had, in relation to your child having a visible facial difference. The interview will take approximately an hour. With your permission the conversation will be digitally recorded; this is done because it is important that the researcher gets what you say exactly right. You will be reimbursed if you incur travel expenses to get to the interview.

**Will the information I provide be confidential?**

All the information you give us will be confidential and used only for the purposes of this study. Only the researchers will have access to your information. Electronic data (including digital audio files) will be password protected, and paper files will be kept in a locked filing cabinet. The audio files will be erased after transcription. All identifying information will be removed from the interview transcripts and the write up so that you cannot be identified. Confidentiality can be broken if the researcher believes the participant or another person is at risk of harm, where possible discussing this with the participant first.

**What are the potential benefits or disadvantages to participating?**

We are very excited about this work, as so little has been explored in relation to fathers' experiences in families with a child who has a visible difference. The potential benefits for participants include having the chance to talk openly and honestly about your experiences. The other advantage is that you will be providing information that could be helpful to other people in a similar position. You do not have to talk about anything you do not want to. You will be asked throughout the interview about how you are finding it and you can stop at any time if you want to take a break or if you no longer want to continue. Information and contact details for organizations that can provide further support will also be provided.

**Do I have to take part?**

Taking part is voluntary. If you agree to take part and later decide to withdraw, you do not have to give a reason and no pressure will be put on you to change your mind. You can withdraw from the project at any time, up to the point when the information you give has been incorporated into the overall analysis. Withdrawal from the study will not in any way negatively impact on the support you receive from CLAPA or any other organisation.

**What will happen to the results of the research?**

This research will help health professionals involved in the care of children with a visible facial difference and their families, by increasing their understanding of fathers' experiences. The study is being conducted as part of my Professional Doctorate in Clinical Psychology degree at the University of East London. The results will be written up and presented as a Doctoral Thesis and it is hoped that the study will result in a published article. Participants will be given a summary of the results if desired.

**Is there any other important information I need to know?**

This research has been approved by the UEL's Research Ethics Committee.

**How can I find out more about taking part?**

If you would like more information about this study or have any questions, or if you think you would like to participate in the study please contact Fiona Perella (Trainee

Clinical Psychologist) by email: fionaperella@hotmail.co.uk or telephone: 07818 405 660.

If you have concerns about this study at any point, you should discuss these with Dr Ken Gannon (Research Director, k.n.gannon@uel.ac.uk, Tel: 020 8223 4576)
**or**
Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Email: m.finn@uel.ac.uk, Tel: 020 8223 4493).

**Thank you very much for considering taking part in this study.**

Fiona Perella                                          Dr Ken Gannon
Trainee Clinical Psychologist                 Research Director

## Appendix 8: Email Confirming Approval for Changes to Original Study

-----Original Message-----
From: Mark Finn
Sent: 19 November 2012 09:46
To: Kenneth Gannon
Subject: RE: Thesis Ethics amendments

Hi Ken - this is all fine by me and no need to re-submit. Obviously approval from site managers to post on Internet sites is required as normal.

Mark

Dr Mark Finn
School of Psychology
University of East London
Water Lane
London E15 4LZ

020 8223 4493
Rm AE2.19
m.finn@uel.ac.uk

-----Original Message-----
From: Kenneth Gannon
Sent: Mon 19-Nov-12 8:41 AM
To: Mark Finn
Subject: RE: Thesis Ethics amendments

Hi Mark

Sorry to hassle you about this, but I wondered whether you have had the opportunity to look over this request and what you think?

Best wishes,

Ken

From: Kenneth Gannon
Sent: 12 November 2012 12:36
To: Mark Finn
Subject: Thesis Ethics amendments

Dear Mark

I am attaching a revised ethics application and cover letter from one of the clinical psychology trainees.  She wants to interview the fathers of children with a visible difference about their experiences of parenting but has been having difficulties recruiting sufficient numbers.  The changes that she has made to her form are aimed at broadening the potential pool.  This includes removing the age limit on the child (no children will be interviewed, of course) and using a wider range of internet sites.  I am hoping that you will be able to take Chair's action to approve this, though I will, of course, submit it to   the committee if you think it appropriate.

Best wishes,

Ken

Fiona Perella
xxxxxxxxxxxxx
xxxxxxxxxxxxx
xxxxxxxx
xxx xxx

Dr. Mark Finn
Chair of the School of Psychology Research Ethics Sub-committee,
School of Psychology,
University of East London,
Water Lane,
London,
E15 4LZ

9th November 2012

Dear Dr. Finn,

**Study title:    Exploring the experiences of fathers of children with a
                  visible facial difference**

Due to considerable difficulties with recruitment, some changes to my research
proposal are required to promote participation. The following amendments have been
made:

- Removal of upper age limit of affected child.

- Expanding advertising in the following ways:
    - Via online community forums, e.g. HealthUnlocked.
    - Use of 'snowball sampling' via personal contacts, e.g. via email.
    - Via Facebook groups
    - Via non-NHS institutions.

    Advertising will of course be dependent on permission being obtained from the
    relevant webmaster / institution / organisation first.

- Where posts are made on online forums and Facebook pages, a link to a
  webpage (set up by the researcher) will be included. This webpage contains an
  introduction to the study and the participant information. This webpage can be
  found at www.visiblefacialdifferencethesis.webs.com

- The Participant Information Sheet has been amended in line with the above
  changes.

- The email received from Changing Faces confirming they granted approval has
  been included – this had not yet been granted at the time this Ethics Application
  was first submitted.

- o Their point regarding indemnity has been addressed by amending 'NHS' to 'UEL' as indemnity providers.
- o The Disfigurement Guidance Centre contact details have been removed from the Aftercare Information Sheet (see Appendix D) as they do not appear to be active any more. Details for Headlines (a craniofacial support charity) have been added instead. The Skin Care Campaign details have also been removed for brevity.

All changes to the ethics application form and appendices have been highlighted were possible for ease of identification. I would be grateful if the committee would consider the attached revised documents and confirm Research Ethics Approval for the amendments. Please do not hesitate to contact me if there any additional queries or if further clarifications are necessary.

Thank you in advance.

Yours sincerely,

**Fiona Perella**
**Trainee Clinical Psychologist**

Cc Dr Ken Gannon, Research Director

## UNIVERSITY OF EAST LONDON

### Consent to participate in a research study

### *EXPLORING THE EXPERIENCES OF FATHERS OF CHILDREN WITH A VISIBLE FACIAL DIFFERENCE*

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researchers involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent, I understand that I have the right to withdraw from the study at any time, up to the point at which my responses have been incorporated into the overall analysis, without disadvantage to myself and without being obliged to give any reason.

Participant's Name (BLOCK CAPITALS)

…………………………………………………………………………………..

Participant's Signature

…………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

………………………………………………………………………………….

Researcher's Signature

………………………………………………………………………………….

Date: …………………..……

**Appendix 10a: Table of Participant Demographics**

| Pseudonym | Age | Marital status | Length of interview (M:S) | Location of interview | Child's name | Child's gender | Child's age | Child's diagnosis | Position in family |
|---|---|---|---|---|---|---|---|---|---|
| 1: George | 37 | Married | 67:06 | Home | Freya | Female | 7yrs 8m | Unilateral cleft lip and bilateral cleft palate | Second child |
| 2: Stuart | 34 | Married | 78:04 | Skype | Jake | Male | 7yrs 6m | Unilateral cleft lip and palate | First child |
| 3: Joe | 48 | Married | 94:51 | Home | Sam | Male | 3yrs 2m | Bilateral cleft lip and palate | Twin - youngest of 5 (eldest 2 from previous relationship) |
| 4: John | 46 | Separated | 115:08 | Home | Daniel | Male | 3yrs 8m | Incomplete unilateral cleft lip and palate | First child |
| 5: Nick | 29 | Engaged | 119:40 | Home | Sara | Female | 3yrs 4m | Unilateral cleft lip and gum | First child (2 step-children from partner's previous relationship) |
| 6: James | 36 | Married | 53:43 | Work | Edward | Male | 9yrs 0m | Unilateral cleft lip and palate | First child |
| 7: David | 36 | Married | 65:52 | Work | Grace | Female | 1yr 11m | Unilateral cleft lip and palate | First child |
| 8: Dan | 32 | Married | 107:05 | Home | Ava | Female | 7m | Incomplete unilateral cleft lip with notch in gum and palate | First child |

**Appendix 10b: Further Contextualising Information**

George is a 37 year old white British man who works in the emergency services. He lives with his wife, Charlotte, and two children, Oliver (12 years old) & Freya (7 years old). Freya was born with a unilateral cleft lip and bilateral cleft palate, which was diagnosed at a routine antenatal scan at 20 weeks. George chose to be interviewed at his home.

Stuart is a 34 year old white British man who works in IT. He lives with his wife, Anna, and his two sons, Jake (7 years old) and Owen (6 years old). Jake was born with a unilateral cleft lip and palate, which was diagnosed at a routine antenatal scan at 16 weeks. Stuart chose to be interviewed via Skype video link.

Joe is a 48 year old white British man who works in the emergency services. He lives with his wife, Marie, daughter, Madison (9 years old) and twin sons, Joshua and Sam (3 years old). Sam was born with a bilateral cleft lip and palate, which was diagnosed at a routine antenatal scan at 20 weeks. Joe also has two sons, Matt and Tom (in their twenties), from a previous marriage. Joe had a vasectomy after the birth of his eldest two sons. After an unsuccessful vasectomy reversal, the three children from his second marriage were conceived via in vitro fertilisation (IVF). Joe chose to be interviewed at his home. He was keen for me to meet Sam, therefore arranged the interview timing to coincide with Sam returning from nursery as we finished.

John is a 46 year old white British man who works in NHS management. He is separated and lives alone. He shares custody of his son, Daniel (3 years old). Daniel was born with an incomplete unilateral cleft lip and palate, which was diagnosed at a routine antenatal scan at 20 weeks. John chose to be interviewed at his home.

Nick is a 29 year old white British man. He is in full-time post-graduate education. He is engaged to his partner, Yasmine, and they have a 3 year old daughter, Sara. Sara was born with a unilateral cleft lip and gum, which was diagnosed at a routine antenatal scan at 16 weeks. They live together with Yasmine's two sons,

Liam (13 years old) and Charlie (12 years old) from a previous relationship. Nick chose to be interviewed at his home.

James is a 36 year old white British man who is a Public Relations director He lives with his wife, Layla, and their children, Oscar (11 years old), Edward (9 years old), Catherine (5 years olds) and Amelia (5 months old). Edward was born with a unilateral cleft lip and palate, which was diagnosed at a routine antenatal scan at 20 weeks. James chose to be interviewed at work.

David is a 36 year old white British man, who works as a quantity surveyor. He lives with his wife, Jessie, and daughter, Grace (almost 2 years old). Grace was born with a unilateral cleft lip and palate, which was diagnosed eight weeks before birth when an additional scan was carried out due to concerns regarding excess fluid around the baby. David chose to be interviewed at work.

Dan is a 32 year old white British man, who works as a retail store manager. He lives with his wife, Sophie, and daughter, Ava (7 months old). Ava was born with an incomplete unilateral cleft lip with notch in the gum, which was diagnosed at a routine antenatal scan at 18 weeks. Dan chose to be interviewed at his home.

**Appendix 11: Interview Schedule**


**EXPERIENCES**

Can you tell me about your experiences of being a father of a child with a visible facial difference?

> *Possible prompts:*
>
> *Tell me what it was like when you first found out about your child's visible difference?*
> *How has this changed over time?*
> *Can you tell me about the difficulties have you faced?*
> *Can you tell me about the positive aspects?*
> *Any difference in how you feel you parent your other children?*

**IMPACT**

How have these experiences impacted on you?

> *Possible prompts:*
>
> *How have these experiences affected your relationship with your child?*
> *How have these experience affected your relationship with your spouse/partner?*
> *How have these experiences impacted on your work life?*
> *How have these experiences affected how you see yourself?*
> *What impact has this had on the rest of the family?*

**COPING**

Can you tell me about how you have managed these experiences?

> *Possible prompts:*
>
> *What support have you received?*
> *Who from?*
> *What has been helpful?*
> *What has stopped you seeking/accepting support?*
> *What could be offered by services that you might find supportive or helpful?*

**AT THE END**

Is there anything I haven't asked about that you would like to tell me?

Do you have any questions?

How have you found the interview?

**Appendix 12: Levels of Exploration during Analysis**

a) *Descriptive:* the focus is on the content of the participants' talk. Descriptive notes were made regarding key words/phrases and ways in which experiences are described.

b) *Linguistic processes*: the focus is on exploring the specific use of language, including stutters, pauses, hesitation, laughter, pronouns and metaphors. This includes paying attention to non-verbal aspects.

c) *Interrogative and conceptual:* this aims to change the level of analysis from descriptive to interpretative and move towards identifying concepts that might be common to all accounts. Psychological concepts that refer to wider social, culture and political ideas can be introduced, aiming to move towards a higher level of abstraction.

*(Left margin annotations)*

It's all relative – still major surgery

Taking pre-op photos: preparing for change

Antenatal diagnosis = time to come to terms with it

Embracing cleft: not ashamed of her appearance

Documenting the journey

To remember the child he had & loved

*(Right margin annotations)*

Validating his feelings – still major surgery even though other children worse off.

CLAPA page → looking for information → people's real experiences / expertise

antenatal diagnosis = have to come to terms with it / prepare / adjustment

compartmentalising, dealing with it by putting it away (emotions)

ongoing, always more to deal with.

Embracing cleft → part of her, not hiding it

'Not ashamed' → ?some people are, or small part of him is? → influence of society's reaction to difference?

*(Transcript)*

| | | |
|---|---|---|
| 811 | P8: | um, and it kind of made me feel trivial with how I felt but then I kinda |
| 812 | | thought well actually no because to let my child go through major |
| 813 | | surgery was kind of, it – it was <u>hard</u> |
| 814 | I: | hm |
| 815 | P8: | um, so the day that we took he for her surgery, um, I took the iPad and |
| 816 | | took pictures of her before because everyone put on Facebook group |
| 817 | | about how they missed the cleft smile and Jo, my mum's friend who is my |
| 818 | | mum's godson's mum had said that she really missed Jamie's cleft |
| 819 | | smile cause they – Jamie was born and they had no diagnosis so they |
| 820 | | didn't know until Jamie came out. |
| 821 | I: | right |
| 822 | P8: | I spoke to Jo and I said how was that and she said it was very very hard |
| 823 | | and the – I think the fact that we had the diagnosis and were able to |
| 824 | | kind of prepare for us as individuals, for me and Sophie and the kind of |
| 825 | | people that we are was brilliant cause we were kind of able to get our |
| 826 | | head round it so that when she was born actually it didn't matter |
| 827 | I: | yeah |
| 828 | P8: | um, we dealt with it, we kind of put it into <u>its boxes</u> and we knew what |
| 829 | | we had to deal with, um, and then the day of the surgery we took her in |
| 830 | | and I took the iPad cause I wanted some pictures of her before, |
| 831 | | because I'm not ashamed of her at all, of how she used to look and |
| 832 | | we've got pictures of her around some with the cleft, some without, |
| 833 | | cause I want her to grow up knowing that this is what she used to look |
| 834 | | like and this is what she looks like now, cause I want her to know the |
| 835 | | <u>journey</u>   → their journey & her journey |
| 836 | I: | yeah |
| 837 | P8: | um, and when we took her down, so we were able to actually carry her |
| 838 | | down and we took her down one flight of stairs and into the theatre area |
| 839 | | and we put her on to a bed and it was a massive adult bed |
| 840 | I: | hm hm |
| 841 | P8: | and then they put a mask on her for the – to knock her out, |
| 842 | I: | yeah |

25

| | | |
|---|---|---|
| 843 | P8: | and Sophie just fell apart and I was alright with that because I'm again |
| 844 | | back to this old thing of hospitals, she's in the best place, Ms X's done it |
| 845 | | thousands of times before, she knows what she's doing, it's very simple |
| 846 | I: | hm hm |
| 847 | P8: | I kind of – that's how I kind of, I just process things like that and I was |
| 848 | | alright, I was upset because you know my wife is upset and I was |
| 849 | | leaving my daughter to have surgery but I was ok. |
| 850 | I: | hm hm |
| 851 | P8: | so we went, we went to the shop, got something to eat, went back to the |
| 852 | | bed and sat by her bed and Sophie bought a word search and I bought |
| 853 | | National Geographic which I still haven't read [laughter] |
| 854 | P8: | um, but we had to buy something – I've no idea why [laughing] just pick |
| 855 | | it – right yeah I'll have that. Um and we were sat by the bed and so it |
| 856 | | was at 2 o'clock she went down and then she came back at 4.30 and |
| 857 | | she came back on again on a massive adult bed um, in a gown that was |
| 858 | | basically for a toddler not for an infant, um she was with a nurse and |
| 859 | | she was with a porter and this porter was a big black man, huge black |
| 860 | | man and he said to me – and this, this is when I cried – he said you've |
| 861 | | got a gorgeous daughter [became very tearful – pause] and he gave |
| 862 | | me a hug and that was – I just fell apart because she wasn't the |
| 863 | | daughter that I'd given them, she'd changed but she was still my |
| 864 | | daughter if that makes sense? |
| 865 | I: | yeah |
| 866 | P8: | and that when I sort of realised what people meant as in they missed |
| 867 | | the cleft smile, um, and getting that bear hug off that man was kind of – |
| 868 | | I don't think he knew what impact he had on that day but it made it so |
| 869 | | much easier |
| 870 | I; | ok |
| 871 | P8: | so then we sat down and that's when I sort of sat on the chair and held |
| 872 | | her in my arms and cried for about, about 40 minutes I think – I couldn't |
| 873 | | stop – the last time I cried like that was at my nan's funeral and it was |
| 874 | | kind of like 'what are you doing – she's fine, she's back'. She was very |
| 875 | | pale and that was a bit scary, um, but she was hungry and she – I |

**Appendix 14: Initial Themes (Participant 8: Dan)**

1       Shock at diagnosis P3 L72-85
2       Finding out the gender - better if it's a boy P3 L91-97
3       Anxious wait for explanation P3/4 L101-103
4       Petrified about what else it could mean   P4 L104-113
5       Crying at news – an extreme reaction P4 L117-123
6       Too overwhelmed to tell sister P4 L123-125
7       Failed as a dad P5 L139-140
8       Failed in role as protector P5 L142-144
9       On-going guilt - what did I do wrong? P5 L144-146
10      Helpful to hear first-hand experiences P5 L148-159
11      Worry about future appearance P5 L159-161
12      Fear of bullying P5 L162-166
13      Waiting for follow up appointment unbearable P6 L179-183
14      Can't wait: Accessing private services P6 L183-186
15      Wanting a definite diagnosis P6 L188-199
16      Work being supportive and flexible P6/7 L202-208
17      Calmed by 'good' news of just clef P7 L209-215
18      Communication during scan is important P7/8 L215-238
19      Appreciation of NHS services P8 L239-240
20      Waiting very difficult P8 L243-255
21      Pre and Post op photos - Helpful & Scary P8 L261-268
22      CLAPA nurse reassuring P8 L269-270; P9 L291-296
23      Why us? P9 L271-278
24      Needing there to be a reason P9 L278-280
25      Expectations of fatherhood P9 L282-289
26      Wanting more up to date resources P9 L293
27      Prepare for the worst - it can only get better P9 L296-302
28      No more additional scans - a massive relief P9/10 L302-310
29      On-going fear of bad news P10 L310-316
30      Professional advice: enjoy the pregnancy P10 L318-326
31      Accessing CLAPA for support and information P10 L326-329
32      4D scan – helpful P11 L342-352
33      Fear of other people's reactions and his response P11 L353-368
34      Loss of 'normal' child P11 L359-361
35      Internal struggle with feelings P11 L363-368
36      Pride at bond with baby P13 L410-419
37      Ideas of masculinity P14 L442-447
38      Crying with relief - good news of lip only P14 L455-468
39      Searching the internet - bad idea P14 L462-464
40      Focussing on other aspects of appearance P14/15 L471-479
41      Instant love - a new experience    P15 L479-495
42      Appearance not as bad as expected P15 L496-502; P17 L553-561
43      First time dad - what do I do?! P16 L509-510
44      Fast response and support from CLAPA nurse after birth P16 L533-540
45      Pressure from midwife to breastfeed P16/17 L540-547
46      Going home alone - difficult leaving them P17 L564-565
47      Previous fears about his reactions forgotten P18 L576-584
48      Anger and negativity during pregnancy no longer matter P18 L586-590

**Appendix 15: Cluster Themes (Participant 8: Dan)**


**A: Shock of Diagnosis & Initial Reactions**

| (1) | Shock at diagnosis | P3 L72-85 |
|---|---|---|
| (3) | Anxious wait for explanation | P3/4 L101-103 |
| (4) | Petrified about what else it could mean | P4 L104-113 |
| (5) | Crying at news – an extreme reaction | P4 L117-123 |
| (6) | Too overwhelmed to tell sister | P4 L123-125 |
| (13) | Waiting for follow up appointment unbearable | P6 L179-183 |
| (14) | Can't wait: Accessing private services | P6 L183-186 |
| (15) | Wanting a definite diagnosis: knowing what you're dealing with helps | P6 L188-199 |
| (20) | Waiting very difficult | P8 L243-255 |
| (23) | Why us? | P9 L271-278 |
| (24) | Needing there to be a reason | P9 L278-280 |
| (34) | Loss of 'normal' child | P11 L359-361 |
| (67) | Benefit of ante-natal diagnosis: time to come to terms with it | P25 L823-829 |
| (107) | Scan as chance to get pictures: unprepared for bad news | P43 L1416-1420 |
| (110) | Shock at potential for cleft to be indicative of more serious problems | P43 L1444-1449 |
| (115) | Joy of pregnancy initially ruined by diagnosis | P45 1511-1517 |

**B: Post Diagnosis: Subsequent Reactions**

| (9) | On-going guilt - what did I do wrong? | P5 L144-146 |
|---|---|---|
| (17) | Calmed by 'good' news of just cleft | P7 L209-215 |
| (28) | No more additional scans - a massive relief | P9/10 L302-310 |
| (29) | On-going fear of bad news | P10 L310-316 |
| (35) | Internal struggle with feelings | P11 L363-368 |
| (38) | Crying with relief - good news of lip only | P14 L455-468 |
| (47) | Previous fears about his reactions forgotten | P18 L576-584 |
| (48) | Anger and negativity during pregnancy no longer matter | P18 L586-590 |
| (50) | Moments of still feeling sorry for self - why us? | P18/19 L606-611 |
| (60) | Working through emotions | P22 L725-728 |
| (121) | Still hoping for answer about the cause | P47 L1576-1584 |

**C: Role as Father: Hopes & Perceived Failings**

| (7) | Failed as a dad | P5 L139-140 |
|---|---|---|
| (8) | Failed in role as protector | P5 L142-144 |
| (25) | Expectations of fatherhood | P9 L282-289 |
| (36) | Pride at bond with baby | P13 L410-419 |
| (58) | "fell at the first test" - guilt at failure to protect | P21 L694-700 |
| (59) | Cleft made him become a father sooner | P21/22 L701-723 |

| (62) | Influence of his own experiences | P23 L753-775 |
| (102) | Wanting to make it all go away | P39 L1300-1304 |

## D: Difficult Experiences with Local Services

| (18) | Communication during scan is important | P7/8 L215-238 |
| (26) | Wanting more up to date resources | P9 L293 |
| (45) | Pressure from midwife to breastfeed | P16/17 L540-547 |
| (108) | Wanting someone present at scans who can explain implications | P43 L1422-1426 |
| (111) | Lack of clarity made process more difficult | P44 L1451-1456 |
| (112) | Appreciative of NHS but areas for improvement | P44 L1458-1476 |

## E: Specialist Services

| (19) | Appreciation of NHS services | P8 L239-240 |
| (22) | CLAPA nurse reassuring | P8 L269-270; P9 L291-296 |
| (31) | Accessing CLAPA for support and information | P10 L326-329 |
| (32) | 4D scan – helpful | P11 L342-352 |
| (44) | Fast response and support from CLAPA nurse | P16 L533-540 |
| (53) | MDT intimidating | P19/20 L639-644 |
| (55) | MDT: Appreciated clarity | P20/21 L663-677 |
| (76) | On-going support from team is reassuring | P28 L939-941 |
| (113) | Supportive cleft team made process easier | P44 L1470 |
| (123) | Language can be off-putting: targeted at mums | P51 L1714-1717; P52 L1739-1745; P53 L1763-1772 |

## F: First-Hand Experiences Helpful

| (10) | Helpful to hear first-hand experiences | P5 L148-159 |
| (98) | Drawing on other people's experiences: informing expectations | P37/38 L1246-1249 |
| (100) | Taking comfort in meeting a mother with a cleft: reassurance that a 'normal' life is possible | P38 L1264-1273 |

## G: Other People's Reactions

| (33) | Fear of other people's reactions and his response | P11 L353-368 |
| (104) | Reactions from extended family | P40/41 L1336-1362 |
| (106) | Grandmother over-compensating | P42 L1387-1392 |
| (109) | Treated differently because problem detected | P43 L1426-1442 |

## H: Internet: Pandora's Box

| (39) | Searching the internet - bad idea | P14 L462-464 |

### I: Worries

| (11) | Worry about future appearance | P5 L159-161 |
|------|-------------------------------|-------------|
| (12) | Fear of bullying | P5 L162-166 |
| (75) | Dealing with stitches: fear of hurting her & getting it 'wrong' | P28 L920-936 |

### J: First Operation: Mixed Emotions

| (21) | Pre and Post op photos: Helpful & Scary | P8 L261-268 |
|------|------------------------------------------|-------------|
| (66) | Taking pre-op photos: preparing for change | P25 L815-819 |
| (69) | Documenting the journey | P25 L833-835 |
| (70) | Operations: self-reassurance as way of coping | P25 L844-845 |
| (71) | Operation: feeling upset and worried | P26 L848-855 |
| (72) | Mixed emotions after operation: beautiful but not the daughter I gave them | P26 L855-869; P36 L1182-1185 |
| (73) | Grieving for lost child: Intellectual vs emotional response | P26 L871-874 |
| (74) | Surprise at difference in feeding: realisation of meaning of repair | P27 L881-890 |
| (90) | Tears: letting go of guilt, she's normal | P34 L1133-1139 |
| (91) | Conflicting feelings about the operation: what does changing her mean? | P34/35 L1143-1159 |
| (92) | Like having two different children | P35 L1165-1169 |
| (93) | Tears: letting go of self-blame | P35 L1171-1180 |
| (94) | Unprepared for extent of difference | P36 L1203-1209 |

### K: It's not all about Cleft

| (40) | Focussing on other aspects of appearance | P14/15 L471-479 |
|------|-------------------------------------------|-----------------|
| (96) | Highlighting positive features | P37 L1232-1235 |
| (101) | Trying to put cleft aside | P39 L1282-1291 |
| (116) | It can't be all about the cleft | P46 L1518-1522 |

### L: Same as All Parents

| (41) | Instant love - a new experience | P15 L479-495 |
|------|---------------------------------|--------------|
| (43) | First time dad - what do I do?! | P16 L509-510 |
| (46) | Going home alone - difficult leaving them | P17 L564-565 |
| (51) | New understanding of being a parent | P19 L614-625 |
| (84) | Doing what any parent would do | P31 L1033-1043 |
| (99) | Normalising feelings of protectiveness | P38 L1255-1261 |

### M: Work

| (16) | Work being supportive and flexible | P6/7 L202-208 |
|------|-------------------------------------|---------------|
| (49) | Work being supportive and flexible was helpful | P18 L600-606 |

## N: It's Not So Bad

| (42) | Appearance not as bad as expected | P15 L496-502; P17 L553-561 |
|---|---|---|
| (52) | Seeing sicker children - puts things in perspective | P19 L625-638 |
| (64) | Coming to terms with cleft - not such a big deal | P24 L802-809 |
| (65) | It's all relative - still major surgery | P25 L811-813 |
| (68) | Embracing cleft: not ashamed of her appearance | P25 L829-831 |
| (103) | Future treatment: reality vs fantasy | P40 L11315-1330 |

## O: Ways of Coping

| (27) | Prepare for the worst - it can only get better | P9 L296-302 |
|---|---|---|
| (56) | Holding onto hope of 'normal' looking child | P21 L677-680 |
| (82) | Getting through it together: mutual support | P30 L994-1003 |
| (88) | Having her Christened: extra peace of mind | P33 L1085-1104 |
| (89) | Both attending appointments: Fear of missing important information | P34 L1116-1124 |
| (97) | Self-reassurance about having a normal life | P37 L1237-1241 |
| (114) | Finding out gender: something else to focus on | P45 L1489-1505 |

## P: Moving Forward

| (30) | Professional advice: enjoy the pregnancy | P10 L318-326 |
|---|---|---|
| (57) | Disclosure: more you do it the easier it gets | P21 L682-688 |
| (63) | Letting anger go: a conscious decision | P24 L794-800 |
| (78) | Decision not to get genetic testing: fear of blame | P29 L949-958 |
| (79) | Feeling ok with not needing to know | P29 L959-961 |
| (80) | Discussions about having more children: not influenced by cleft | P29 L961-989 |
| (95) | Moving on: a normal dad | P37 L1226-1229 |

## Q: Positive Impacts

| (81) | Positive outcome: closer as a family | P30 L989-990 |
|---|---|---|
| (86) | Positive outcome: closer to extended family | P32 L1071-1075 |
| (87) | "stronger for it" | P32 L1077 |
| (117) | Frequent scans helped | P46 L1524-1538 |

## R: Including Dads Important

| (77) | Felt included by professionals | P29 L943-948; P33 L1104-1109; P50 L1679-1684 |
|---|---|---|
| (83) | Being involved is important | P30/31 L1004-1012 |
| (122) | Professionals need to see parents as equal | P51 L1704-1705 |

## S: Giving Back & Raising Awareness

| (54) | Wanting to educate society about cleft | P20 L644-663 |
|---|---|---|
| (85) | Society needs to understand: Empathising with fathers who don't cope well | P32 L1045-1069 |
| (118) | Supporting other fathers: mutually beneficial | P46/47 L1540-1564;<br>P54 L1805-1806 |
| (119) | Wanting to give something back | P48/49 L1616-1626 |
| (120) | Wanting to raise the profile of cleft & reduce stigma | P47 L1565-1576;<br>P48 L1612-1616;<br>P54 L1808-1818 |

## T: Gender & Appearance Narratives

| (2) | Finding out the gender: better if it's a boy | P3 L91-97 |
|---|---|---|
| (37) | Ideas of masculinity | P14 L442-447 |
| (61) | Societal scripts internalised: not wanting to draw attention to difference | P22 L728-743 |
| (105) | Importance of doing as much as possible to minimise scarring | P41 L1363-1368 |

**Appendix 16: Master Table of Themes**

| SUPER-ORDINATE THEMES | SUB-ORDINATE THEMES |
|---|---|
| **Loss of the Perfect Child** | • Shock of Diagnosis<br>• Why Me?: Blame and Guilt<br>• Uncertainty: What Does it All Mean?<br>• The Anxiety Driven Need for Information |
| **The Power of 'Normality'** | • The Changed Child<br>• The Influence of Societal Beliefs<br>• Personal Perceptions: Conceptualising CLP |
| **The Expectations and Roles of Fathers** | • "I fell at the first test": The Centrality of Role as Protector<br>• Who Supports Who?<br>• Unexpected Outcomes<br>• Making Up for CLP: Compensating and Counteracting |

**Appendix 17: Example of How an Extract has been Refined (Dan, 701-715)**

Original extract:

P8:     I think it made us become parents sooner

I:      ok

P8:     if that makes sense

I:      yes

P8:     so I think that when you're pregnant you kind of, your just on like a ride
        and you just carry on and nothing changes,

I:      hm

P8:     um, you go for your scans, you go for your blood pressure tests and you
        know – I went to every appointment with Sophie and I would have done
        that whether we'd had a diagnosis or not – because I wanted to be
        involved and I was, I was really excited, and I kind of think that it made us
        go from being people that were just pregnant to actually being parents and
        I know that – it's, it's hard to explain but it kind of, we had to kind of face
        up to what life was going to be like.

Refined extract:

*I think it made us become parents sooner, so I think that when
you're pregnant you kind of, your just on like a ride and you just
carry on and nothing changes […] I kind of think that it made us go
from being people that were just pregnant to actually being parents
and I know that – it's, it's hard to explain but it kind of, we had to kind
of face up to what life was going to be like.*

**Appendix 18: Interconnection of Themes**
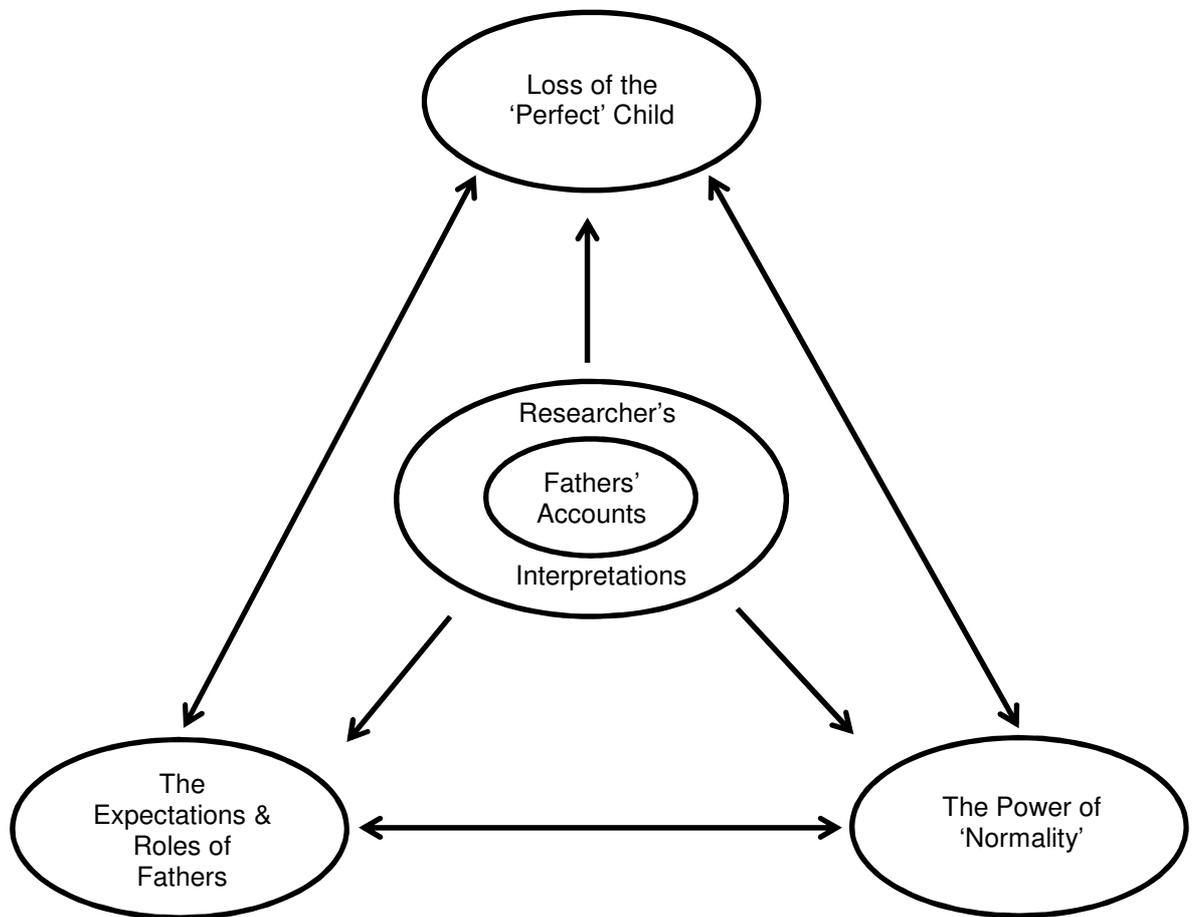
**Appendix 19: Participant Representation Across Themes Table**

| Super-ordinate theme | Sub-ordinate theme | 1: George | 2: Stuart | 3: Joe | 4: John | 5: Nick | 6: James | 7: David | 8: Dan | Present in >half the samples? |
|---|---|---|---|---|---|---|---|---|---|---|
| **Loss of the perfect child** | Shock of diagnosis | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| | Why me? Blame and guilt | No | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| | Uncertainty: what does it all mean? | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| | The anxiety driven need for information | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| **The power of 'normality'** | The changed child | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| | The influence of societal beliefs | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| | Personal perceptions: conceptualising CLP | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| **The expectations and roles of fathers** | "I fell at the first test": the centrality of role as protector | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| | Who supports who? | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| | Unexpected outcomes | No | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| | Making up for CLP: compensating and counteracting | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |

**Appendix 20: Reflection on a Recruitment Issue**

Two fathers made arrangements to participate but dropped out at the last minute, ceasing contact with the researcher. Initial email contact with one gentleman suggested that perhaps having a child with CLP had been difficult, particularly around interactions with services and feeling excluded. Interesting, he had requested to submit a written account rather than be interviewed verbally, explaining this was because he was "far more articulate and precise in writing, and less likely to be misunderstood or misquoted". This was agreed and the interview schedule sent, however no response was received and further attempts at contact failed. I wondered what this meant; perhaps an indication that despite his wish to share his account, the painful nature of his experiences made it difficult to talk/write about. Perhaps being faced with the questions in black and white brought up too much for him to deal with or feel able to communicate. However, I was also aware that during the recruitment process his child had undergone palate-repair surgery, and it may be that it felt too emotionally raw for him to participate at that particular time.

**Appendix 21: Extract of Transcript of Reflexive Group with Peer Researchers (Prior to Starting Interviewing)**

T: What it is that emotionally draws you or another aspect that draws you to this topic?

Me: In terms of me in this, obviously because of my eczema and because it is on my face, there are times when it's barely visible or not there and then there are other times when it's quite bad, I suppose I dip in and out of identifying myself as visibly different or not, so maybe that's why I was drawn to the topic area, and then the dad aspect came from noticing a gap in the literature.

E: I know we've had conversations about, in second year, you really enjoyed your health placements and this is very much a health-related thing so I was curious about that and what it is about health.

Me: yeah, it is, and I have thought about that…again I don't think it was a deliberate or conscious choice, but as a field of interest I suppose I was drawn more to it. For me there is definitely something about working in a physical health context that I've really enjoyed and that I hope to continue with in once I qualify.

T: What is it about physical health that you enjoy?

Me: There is definitely something about how normalised distress is, it's not labelled, or not as pathologised or labelled as mental health difficulties in other contexts – my experience so far is that it's seen as a normal reaction to difficult life circumstances or, you know, it's totally understandable that these parents are going to be really distressed and upset and maybe need support when their child may or may not die of cancer, it's not labelled as health anxiety or dismissed in that way and its nice not to have to fight those battles that we do (from a critical perspective) in 'mental health'. And it's something that touches everyone's lives in some way, it's not 'othered' in the same way that difficulties are within a 'mental health' context, even though it is still mental health but situated in a physical health context.

A: I was just interested in going back to what you were saying about your own experiences of visible difference and what you think you are bringing of that, of yourself into your interviews…what assumptions do you think you have?

Me: It's interesting, because I haven't really thought about it in terms of this project, in terms of my dad's perspective or my thoughts or experiences, or that he would have any kind of perspective on it in particular…so I suppose it's an assumption that difference is something that dads have a certain perspective that might be different to mums. I'm very aware of the fluctuating position I hold, in terms of my skin being good or bad on different days, and so I'm interviewing my first participant on Tuesday and I do wonder if my skin is bad on that day how will that affect things, what he feels able to say, because he will be able to see it. But then I don't know whether because it's a very different type of difference to the one the project is about whether there would be a connection or not for them, whether or not I see one, and how that might affect what they feel able to say or disclose or not…

L: Going back to what you said earlier about there not being very much research with men, so you have any thoughts about why that might be, did that evoke any emotional reaction in you?

Me: I have found myself getting really enthusiastic about wanting to give these guys a voice, if they want to have one, I think because it feels like rather than not coming forward to participate in research they haven't been asked, like there's an assumption that they don't need to be or that they shouldn't be or that it's not important…

T: Do you think that reflects something wider about the beliefs you hold about men generally?

Me: Possibly…

T: …In terms of them not being considered or included in certain domains in the world?

Me: I think there is definitely… specifically in terms of them being dads, like there's all the stuff in the news at the moment about paternity leave and the laws changing around that. It feels very late in the day that we are coming to this way of thinking in the mainstream about dads being important in a child's life when in fact there's bloody loads of literature out there about how important they are and the influences they have, the impact of being around or not around, yeah I just find it quite surprising that more effort hasn't been made to include them or think about them.

A: If you think back to when you decided this is the project was the project you were going to do, what were the kind of things you imagined they'd be saying?

Me: I imagine, and I haven't done any interviews yet, I'd imagine there'd be something about the worry about operations and health aspects, maybe worry about the future and how their child would be received in the world, other people's reaction. I hope there will be things that will come out about coping or what's helped or how they've come to terms with those things maybe. Something I've picked up from other literature is the 'what if I did something wrong', the self-blame, 'did I do something', is it my faulty genes and not having the expected normal child.

E: You know you said a lot of research has been done with mothers or focussing on mothers, I just wondered if you had any ideas of what might be different, if you are anticipating anything different because this is a different group you are looking at?

Me: I wonder if there might be something about the expectations of them, so kind of the, you know, you hear people talk about men as someone's 'rock' or you know having to be 'strong' for the family or for their partner so I wonder if there are differences about expectations about how a father might react differently to difficulties or what their role within that might be, how able they feel to be able to not play that role or to be open about what they are experiencing maybe in a way that mums or women are more free to do.

A: How do you think you will feel if there weren't saying the kinds of things you are expecting them to.

Me: Suppose it would depend on what they are saying! I guess I would have to think about what it is that has led me to have those expectations in the first place. I suppose there's a lot of societal and cultural narratives that I come with that lead me to have those expectations, but I guess it would depend on what they are saying instead.

T: What cultural scripts do you hold?

Me: I think there's definitely that thing about men being strong and having quite gendered roles in relationships, I guess holding that more supportive role in relation to family and relationships.

T: Where do those scripts come from for you?

Me: I guess mainly from my cultural background, which is very strongly family-orientated and those gendered ideas about roles are quite embedded, yeah there is this real…you know mum's being really important in a child's life whereas dads have a more stood back role and that is… not necessarily…it is changing for example from my parent's generation to what I'm now seeing with my friends who have children and the fathers are much more involved and hands-on on a day to day basis than I understand their fathers, my dad's generation, were.

E: And are there any biases that you think are going to pull your research in particular directions?

Me: I suppose that relates to what 'A' was saying about what if they don't say what you think they might…I suppose if I'm expecting them to say something I might be looking specifically for it. I have thought about that in designing my interview schedule, and I've tried to keep my questions as open as possible so that I'm not leading them but some of the potential prompts I have are more guiding I guess, towards specific things.

A: I'm interested in if you had a flare-up of your skin for example, how do you think that might affect the conversations?

Me: I suppose my fear is that it would stop them disclosing, it might hold them back from sharing things they might otherwise have done, that they would feel unable to be as honest maybe about certain things, or not tell me certain things, whether consciously or subconsciously. And because it is variable it might be bad in one interview and then completely clear for the next one and I guess I worry that it may affect what is and isn't shared.

T: What would it be about a flare up that might make them hold back?

Me: I suppose, hypothesising that they might be for example talking about how difficult or their worries about their child's future or other people's reactions to them looking different – I guess I wonder if they might feel less comfortable talking about those things. Something someone else asked me was why I was focussing on visible difference rather than invisible difference, what was it about visible difference, and I think there is definitely something about the fact that we are social beings and the face is seen as being very important in terms of our interactions with others, judgements that are made of you or how you are received by others and how we interact in the world. So I guess, bringing it back to this research, I guess if I've got a dad of a child who is very noticeably different what does that mean to the father? And how able would they be to say something potentially quite negative if they are sat talking to someone who is looking quite different that day? Of course the opposite could happen and they may feel more comfortable sharing because they might think I have a better, personal, understanding of what they are talking about. The other thing that has just come into my mind is them potentially asking me about my experiences and then it's a question of how much do you disclose or share, because it's not about me, where do you draw the line, how do you redirect it back to them?

E: I've had a chat to my supervisor about that because I've also got strong connections to my research in that sense, and about whether to disclose or not, and he told me if they ask to say that you are happy to talk about it after the

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interview but would it be ok if you focus on their experiences first because it's important to capture that and then you are happy to chat to them about your experiences after, so that you are not shutting them down and fobbing them off but also it doesn't take over, it's not your experiences you are wanting to capture.

Me: Thanks. The other thing that's going around my head now is thinking of my position as someone who isn't a parent, and whether they will ask if I have kids or how not having children might have an impact. I did find myself saying to one dad on the phone that I'd just finished working in paediatrics, almost justifying that I have got some knowledge about children or that I have had contact with children. And he hadn't asked or anything but I think I felt like I needed to demonstrate some sort of expertise or something…I think that came from the fact that this particular participant is very keen for me to meet his child, so we've ended up arranging to meet when the family are out but should be coming back from nursery just as we are finishing up. He said "you'll get to experience them for yourself", so he's very keen for me to meet them, he has twin boys one of whom has a cleft lip. It has already been repaired but he'll have a scar.

A: That's really interesting, are there worries about things like is he going to be watching for how you react, do you have to look as though you are really professional and can manage it really perfectly regardless of how you feel.

Me: and it is that thing of am I a professional researcher and clinician, or am I myself who would be down on the floor playing with him for example? Those are two identities that I am still finding a balance between in my working life, but in this context it's different again and very unfamiliar territory. But yeah, really interesting that he was so keen for me to meet the child. I guess it might be that he wants to show me something about how good a dad he is, or maybe that it's not easy and he doesn't know how to say that to me. Thank you, it's really helpful thinking through these questions and where my ideas come from.