

## **Parenting a child with a cleft: The father's perspective**

### Abstract

**Objective:** To explore the impact of having a child born with CL/P from the father's perspective.

**Design:** Individual qualitative telephone interviews.

**Participants:** Fifteen fathers of children born with CL/P were recruited throughout the UK via advertisements.

**Results:** Supported by a number of sub-themes, four overarching themes were identified: Variations in Care and Support; Appraisals of the Cleft; Perceptions of Treatment; and Looking Back and Moving Forward.

**Conclusions:** Fathers reported experiences comparable to those previously reported by mothers, in addition to a number of further support and information needs. Participants played a key role in supporting their family through the treatment process, yet fathers are underrepresented in the research literature. Recommendations are made for the adequate inclusion of fathers in future research and in relation to methods of support for fathers through their child's diagnosis and treatment.

## Introduction

While the birth of a child is an emotional and stressful time for any new parent, requiring a significant transition and the establishment of new familial roles and routines, the birth of a child with a health condition places a significant additional burden on the family. Following a diagnosis of cleft lip and/or palate (CL/P) in their child, parents are likely to feel shocked and daunted by the potential challenges that lie ahead. Non-specialist Health Professionals (HPs), such as sonographers or midwives, are usually the first point of contact for parents. Sadly, non-specialists often lack the specific knowledge and skills needed to support the family appropriately (Knapke et al., 2010). The quality of information available at this time and the manner in which it is delivered has a significant influence on the level of distress experienced (Vanz and Ribeiro, 2011). In the UK, the geographically closest multidisciplinary cleft team is expected to contact the parents within 24 hours of diagnosis and to assist families throughout the child's treatment pathway. In addition, charitable organisations such as the Cleft Lip and Palate Association (CLAPA) offer supplementary information and support to all those affected by CL/P in the UK.

Besides having to engage with a multidisciplinary regime of care, other on-going challenges exist for parents. CL/P is associated with a number of syndromes and additional conditions, which may provoke further health complications and/or developmental delay in the child. Parents have also reported encountering negative reactions to their child's cleft from friends, family and members of the public; in some cases this causes considerable distress (Nelson et al., 2012). Additionally, previous research has highlighted the physical and emotional demands, time and financial costs, and logistical complexities of having a child with a health condition, such as CL/P (Locker et al., 2005; Kramer et al., 2008; Reichman et al., 2008). Based on the assumption that their child may experience social difficulties as a result of being 'different', concerns relating to how the child integrates with their peers are also a common cause of distress for parents (Nelson et al., 2011). Parents may also have to grapple with the possibility of having another child with CL/P, and of future generations of their family being affected. If not dealt with effectively, these challenges can have long-term adverse effects on the parents, and ultimately on the child (Chuacharoen et al., 2009).

Due to the number and variety of challenges facing a parent of a child with a cleft, a recent review of research has emphasised the on-going need for the implementation of appropriate support, in order to achieve psychological wellbeing and positive adjustment for families (Nelson et al., 2012). However, almost all of the literature which currently exists on this topic (including that cited above) has focused exclusively on the experiences and support needs of mothers, resulting in a distinct lack of research involving the fathers of children born with a cleft. Furthermore, where fathers have been included as participants, mothers' views have dominated, due to the unequal representation in published studies (Nelson et al., 2012). No study has specifically investigated the experience of having a child with CL/P from the perspective of the child's father.

Research in the broader field of child development has demonstrated the significance of the father's role in relation to the child's overall wellbeing and developmental trajectory. This role is key, and cannot be replaced by another family member (see Lamb, 2010 for a review). Moreover, fathers have a considerable influence over maternal wellbeing and the dynamics of the family unit as a whole. While paternal involvement has numerous benefits, an absent father, or a reduction in the ability of a father to cope with difficulties, places the entire family at risk for emotional and behavioural problems (Kvalevaag et al., 2013; May, 1996). Some research has also suggested that fathers may react and cope differently compared to mothers in response to their child's health condition, specifically in that the father adopts a supportive and information-seeking role (Deeney et al., 2009; Ahmann, 2006). Despite the important and varied role of the father, a paucity of research on the perspectives of fathers is common in the field of cleft research, and in paediatric psychology more widely (Soderstrom and Skarderud, 2013; Phares et al., 2005; Featherstone, 2004). As a result, health professionals are unable to access the full story, and subsequently any familial support that is implemented is likely to be limited in its scope.

In light of the potential psychosocial impact of having a child with a cleft, the significance of the father's role in relation to familial adjustment, and the recent call for the implementation of appropriate parental support, it is imperative that the information and support needs of fathers of children with CL/P be identified and addressed. Thus, the aim of this paper was to explore the impact of having a child born with CL/P from the father's perspective.

## Method

### *Design and Participants*

In view of the lack of existing literature, and in order to collect detailed, rich data to inform future research, an exploratory, qualitative approach was adopted. Qualitative approaches are considered appropriate when the research area under scrutiny is new, or is being explored from a new perspective (Morse and Richards, 2002). For example, qualitative approaches within the field of appearance have been used to investigate women's experiences of an altered appearance during chemotherapy (Harcourt and Frith, 2008), and the appearance-related concerns of young people with psoriasis (Fox et al., 2007).

Fathers were recruited via a press release and through advertisements placed in a variety of locations (e.g. the CLAPA website). Since this was an initial, exploratory study, fathers of children of all ages and all types of cleft (with/without an additional syndrome) were invited to take part. Participants' ages ranged between 31 and 58 years, with a mean age of 39 years. Participants were recruited from across the UK, with representation from most regions. All fathers identified as White British, were either married or living with their partner, and were currently employed at the time of interview. The majority of fathers had one child born with a cleft, while one father had two. One father was born with a cleft himself. The children's ages ranged from four and a half months to 24 years (<1 year old = two; 1-2 years = five; 2 years = two; 3 years = one; 4 years = two, 5 years = one; 8 years = one; >20 years = two). Two children were born with a Unilateral Cleft Lip (UCL), ten with a Unilateral Cleft Lip and Palate (UCLP), three with a Bilateral Cleft Lip and Palate (BCLP) and one with a Cleft Palate only (CPO). One child had also received a diagnosis of Pierre Robin Sequence (PRS).

Once informed consent had been obtained, individual, free-response recorded telephone interviews were conducted until saturation was achieved (fifteen fathers). In qualitative research, saturation occurs when no new information is being obtained, thus determining the sample size (see Braun and Clarke, 2006). In a qualitative study such as this, it is the content of the interviews, rather than the number of participants, that is considered important (see Howitt and Cramer, 2011). As such, a sample size of fifteen was considered acceptable. All interviews were conducted by the first author; this researcher has a background in psychology and is trained in

qualitative interviewing techniques. Although the interviewer aimed to cover a number of key topics within the course of each interview and had prepared prompts to elicit further information when necessary, participants were otherwise allowed the freedom to relay their own story. Topics which the interviewer aimed to cover included: family context (e.g. number of previous children, family history of cleft); early experiences (e.g. thoughts about becoming a father, child's diagnosis and birth); the first year (e.g. the impact on the family, the reactions of others, experiences of surgery); early childhood (e.g. child's speech development and additional health concerns, child starting school); adolescence and adulthood (e.g. child's friendships, romantic relationships and academic achievements) and any positive aspects of having a child with a cleft. Interviews lasted between 40 minutes and one hour.

### *Ethical considerations*

Ethical approval was obtained from the University of the West of England Research Ethics Committee. The research followed the British Psychological Society's Code of Ethics and Conduct (BPS, 2009) at all times; participants were made aware of key issues including confidentiality and their right to withdraw. In addition, participants were advised that the researcher was not able to provide them with advice or counselling at any point; participants were directed to relevant organisations should they wish to seek further information and support.

### *Data analysis*

Thematic analysis (TA) was used to analyse the interview data. TA is primarily a method for identifying and organising patterns within a rich data set, though it is also often used to interpret various aspects of the subject matter (see Howitt and Cramer, 2011). For this research, an inductive, data-driven approach to analysis was taken, adopting a pragmatic framework (see Fishman, 1999). The goal was to report a rich, overall description of the whole data set, rather than explore particular aspects in more detail. In accordance with Braun and Clarke's guidelines (2006), the following steps were taken:

- 1) Becoming familiar with the data
- 2) Identifying interesting features of the data

- 3) Searching for themes
- 4) Reviewing themes
- 5) Defining and naming themes
- 6) Producing the report

Analysis was seen as a recursive process, and detailed notes were written throughout. Themes were subsequently chosen for their prevalence and/or their importance (or ‘keyness’) in relation to the research question. Emerging themes were initially identified by the first author. Themes were then checked and discussed until agreement was reached between both authors. A summary of the resultant themes was also sent to participants to confirm the accuracy of the analysis (*see* Braun and Clarke’s 2006 guidance, Step 4; Yardley, 2000).

As the father’s perspective has not yet been explored in any detail, a primary aim of this paper was to bring the father’s voice to the fore. In order to achieve this, participants’ quotations take prominence over the narrative throughout the following section.

## Results

Four main themes were identified, each with a number of sub-themes. These findings are visually represented in a ‘thematic map’ (Figure 1). All participants have been given pseudonyms to preserve anonymity.

### **Theme 1: Variations in care and support**

#### **1. 1. Responses of non-specialist Healthcare Professionals**

Most fathers in this sample had received an antenatal diagnosis. This experience was generally reported to be extremely upsetting, not just because fathers had been told their child had a cleft, but also because of the often insensitive way in which this information was delivered.

Ryan - *My partner was crying her eyes out and we were left alone in this room. Then a staff nurse put a piece of paper in front of us and I will always remember it said 'how to deal with a disabled child'.*

The immediate offer of a termination following antenatal diagnosis was a prominent and distressing memory for some fathers, particularly as they had received no information about what a cleft was or what it may mean for their child's future.

Luke – *Offering us a termination within ten minutes of finding out...that was the most upsetting thing, that there must be something wrong with a cleft lip and palate that would actually warrant a termination.*

Due to the lack of information they had received at diagnosis many fathers turned to the internet, but often found this to be more distressing, as websites are not policed and often contain worst case scenarios and upsetting images.

Joshua – *I was quite disturbed by what I saw...I think it caused a lot of my initial fears.*

For fathers whose children received a postnatal diagnosis, the response of the non-specialist HPs at the time of birth was also varied.

Paul – *The body language of the nursing staff completely changed...I heard one of the midwives say 'hide her face, hide her face'.*

In contrast, two fathers found the support available at the time of diagnosis to be very good.

Oliver – *The consultant was brilliant, she spent a lot of time with us...she helped us take it all in.*

Following the baby's birth, many fathers found the maternity staff to have poor knowledge of CL/P and to lack confidence when caring for their child.

Joshua – *We kept asking for help, but we just didn't feel like we were getting anywhere.*

Christopher – *I gathered later that the staff were very apprehensive...they didn't have the expertise for dealing with it.*

After returning home, some fathers found they received very little home-based support from non-specialist HPs.

Michael – *We were promised the support would be there straight away, but for two weeks nobody came to see him or check how we were coping...we just weren't prepared.*

Others found that their child quickly became a 'medical curiosity'.

Andrew – *The health visitor was useless. To be honest it felt like she'd just come to have a look.*

Support from other sources, such as General Practitioners, was also poor at times.

Joshua – *The GP kept telling us the coughing fits were 'perfectly normal for a baby like her', when in fact she'd had a run of several chest infections.*

## 1. 2. Care provided by cleft specialists

In contrast, the care received from the NHS Cleft Teams was reported to be very positive overall. Referrals were picked up quickly and the information provided was comprehensive and explained well. Fathers consequently felt prepared for their child's birth and informed about what to expect in the longer term.



Alex – *From that stage the cleft team get involved...I can't praise them enough. They provide a service which I think couldn't be bettered.*

Additional support in the maternity ward, as well as the care received at the time of the child's operations, was also highly commended.

Oliver – *When our baby was born the support was there very quickly, and we were able to establish the best feeding methods quite easily.*

Adam – *We went into the operation knowing exactly what the procedure was, how the day was going to work, what was going to happen afterwards.*

Unfortunately, support from the cleft team seemed to trail off after the first year, and for some it became difficult to contact the specialist cleft nurses.

Jack – *They became very elusive and took weeks to get back to us...maybe they think you can fend for yourself and just let you get on with it.*

Many fathers had had contact with CLAPA and reported receiving high quality information and practical support.

Nathan - *CLAPA were incredible, they helped to allay a lot of fears...straight away I had a source of reliable, quantifiable, qualifiable information from a trusted source.*

### 1.3. Social experiences and acceptance

Telling family and friends about the diagnosis had been a worrying prospect for many fathers. On the whole family and friends had been very accepting, but this was not the case for all. Some fathers commented on the distress experienced by wider family members.

Oliver – *Once we'd gone through breaking the news and getting over the upset...we had absolute total support.*

Paul – *I got comments like 'well, it's not from our side of the family'...I was almost having to absorb their grief, instead of them saying 'what can I do to help?'*

Edward – *My mum can't look at her without crying, even now... The experience of having her as a grandchild for them, I think it's been completely different...they haven't been able to enjoy it really, or get involved.*

It was clear that having practical support from family and friends was a strong advantage.

Jack – *A lot of people we've met in the cleft unit don't have a support network, so they're out on a bit of a limb really...we're lucky to have our parents close to hand and willing to help.*

Fathers observed that siblings had no difficulty in accepting the cleft, and generally had a very positive influence on the affected child, both socially and in terms of development.

Alex – *Our other two children were fine with it, no pre-conceptions...they just wanted to hold him!*

Michael – *Our older children understand what's happening and help out...developmentally our youngest picks up a lot from his older brother.*

However, some fathers also revealed concerns that their other children had been indirectly affected by their sibling's condition.

Michael – *It's like we've lost the last 17 months of them growing up.*

Jack – *Our other son was a bit off the rails for a while because we were darting off to the hospital...putting him here, there and everywhere.*

Parents had encountered a wide range of both positive and negative reactions from members of the public.

Christopher – *There was an enormous range of reactions, with people sticking their face in the pram and saying 'ohh, poor little thing!', which is just as difficult as people going 'eurrrgh'.*

For many fathers, dealing with reactions directly was thought to be the most constructive way of handling this challenge.

Luke – *You could tell if people were interested so we'd say 'yeh, he's got a cleft lip and palate, but don't go worrying about it'. You'd break the ice straight away.*

For some, these experiences highlighted the lack of awareness of CL/P within the general population.

Nathan – *It still amazes me in this day and age...when you explain it, typically you'd get 'oh, I've seen an advert for kids in India like that, I didn't realise it was an issue in the UK'.*

#### 1. 4. A lack of support for fathers

Fathers commented that there was very little support available for men in general, and that having a baby born with a 'complication' had made this more evident.

Ryan – *There's more networking for women, not just for cleft, but pregnancy in general...fathers do get forgotten about.*

Some fathers felt they hadn't needed any extra support, while others felt that if their partner was receiving support from elsewhere (the cleft nurse or another parent) then the direct burden on them was helpfully reduced.

Owen – *The support network around him was sufficient really...we were all in it together, I didn't personally feel that I needed additional support over and above what was already going on.*

Edward – *Having the support there reassured my wife, which selfishly was better for me because if she was more settled, I was more settled, it had a knock-on effect.*

However, for several fathers, individual support would have been a valuable resource. Many expressed the belief that they had to remain strong and positive in order to support their wife and child effectively, and therefore had no outlet for their own thoughts and emotions.

Richard – *All the way through I was trying to be...positively optimistic...keeping it together and helping my wife to come to terms with everything...I never had anybody to talk to without my wife being around, and as a dad that would've been a useful way to let off steam...to not have to worry if I did break down.*

## **Theme 2: Appraisals of the cleft**

### **2.1. Aetiology**

Fathers had speculated on the cause of their child's cleft. For some there was a clear genetic link, which led to feelings of guilt.

Adam – *I think it's safe to say my world fell apart when I was told he'd got a cleft...I had to deal with the fact that I'd done it to him, that I'm the reason he's got it.*

For others there was no known family history of CL/P, and genetic testing had not provided many answers.

Oliver – *There's no history in either family...they ran some tests but in our case it's a puzzle and I think it always will be.*

Some had considered possible environmental causes, including age, smoking, taking medication, chemical exposure and a lack of folic acid during pregnancy. A number of fathers had also wondered if the cleft was linked in some way to using assisted methods to conceive.

Andrew – *We had problems with conception so my wife had to take tablets, so as soon as we came away from the scan we were thinking 'it was those tablets'.*

Although many fathers said they had learned to accept that the causes of CL/P were currently unknown, they were interested in finding out more as research in this field progressed.

Christopher – *In the end we had to accept that it's one of those things...but I would love to know the scientific trigger for it...I'm hopeful that someday someone will figure out what it's all about.*

## 2.2. Making comparisons

Almost all of the fathers in this study commented that although a cleft wasn't the easiest thing to have to deal with, it also wasn't a huge problem in the grand scheme of things.

Ryan – *There are some things that happen in life that make you see things for what they really are. I was catching the bus to work and I saw this little girl who had spina bifida. She was very, very poorly and it made me think, you know what, I'm actually quite lucky.*

Some fathers compared their child's cleft to those occurring in other children.

Richard – *Seeing that our son's cleft was nowhere near as severe as some other babies...it's not a great thing to take comfort in, but just to be grounded in terms of the scale of things...there were far more complicated scenarios that other parents had to deal with.*

For some fathers, seeing families who were not affected by CL/P made them wonder why this had happened to them.

Michael – *Sometimes you can't help but feel sad when you see someone walking around with a perfect baby.*

### 2.3. No limits

None of the fathers felt that being born with a cleft would hold (or had held) their child back in life.

Edward – *It's not going to hold him back like we first thought...just like any other kid...it's up to them how far they want to take themselves.*

Having a prior awareness of CL/P and/or knowing someone with CL/P impacted on fathers' appraisals of how having a cleft may affect their own child.

Edward – *Our nurse was actually born with a cleft...that reassured us because we could see straight away she was doing fine.*

Many fathers felt the implications of CL/P would be more severe if the child was female. This was mostly due to appearance reasons.

Michael – *I think perhaps if he had been a girl...there may have been a different perspective on the cosmetic thing.*

Owen – *One doctor told us... 'don't worry, he's a boy, he can grow a moustache'.*

### **Theme 3: Perceptions of treatment**

#### **3.1. Operations**

Although fathers viewed the operations as necessary (due to societal/functional reasons), all commented that any operation was a daunting prospect.

Alex – *You know it's not an option not to get this done...but at the time we were thinking 'are we going to get him back?'*

However, some also viewed the operations as compulsory hurdles which needed to be overcome as soon as possible.

Ryan – *It's something that I've been looking forward to quite a lot...it's the first hurdle to cross...very much a positive step.*

Seeing their child put under general anaesthetic was a particularly powerful event for fathers.

Richard – *The single hardest thing I did was actually handing him over to the surgeon...I don't think anything could have prepared me for that.*

Waiting for their child to come out of surgery was also a difficult experience.

*Jack – You're just on tenterhooks for four or five hours...it feels like an eternity.*

Many fathers commented on the initial impact of seeing their child's appearance change following the lip repair. Many said they missed the cleft, as it was a part of their child.

*Andrew – He looked like a completely different little boy, it was almost as if you'd lost one and gained another that you didn't really know...I still haven't come to terms with it.*

Fathers also reported feeling distressed at the physical trauma resulting from their child's facial surgery.

*Jack – There's all these tubes hanging out of him...he was still sedated and covered in blood, he had quite a swollen face...you couldn't pull him in for a cuddle.*

Fathers also commented on their anticipation/experience of the bone graft operation, which takes place between the ages of seven and nine years.

*Oliver – She's going to be a lot older than her previous surgeries...I think that will hit us hard because her level of understanding will be very different.*

### 3.2. Barriers and facilitators to treatment

A big concern for fathers was identifying and treating additional health complications. This included: hearing and speech development, testing for syndromes, feeding problems and respiratory difficulties. This was particularly stressful if it led to additional hospital admissions or delayed the cleft surgery.



Alex – *The second surgery was cancelled three times, so that was a bit of an emotional rollercoaster.*

Due to the importance of treatment, fathers made observations as to what they looked for in a HP. Having confidence in HPs was extremely important; this was facilitated by the knowledge that HPs were experts in their field, practiced their skills regularly and had a wealth of experience.

Luke – *You know the surgical team do this day in, day out...and they do it extremely well.*

However, some fathers commented that multidisciplinary team meetings were potentially very intimidating.

Richard – *We had a couple of meetings with the whole cleft team...it's comforting to know so many people are caring for your child...but that was quite overwhelming.*

Meeting other parents with children born with CL/P allowed fathers to share experiences and ask questions.

Jack – *We were lucky because we had somebody to talk to that had already been through it.*

### 3.3. A long journey

Fathers perceived their child's cleft treatment to be an ongoing journey, but preferred to take things gradually.

Jack – *We're just seeing how it goes really, not pushing him too much and just sort of taking it one step at a time.*

For all fathers, the first year of their child's life had been very intense. Although things generally became calmer after this, fathers remarked that treatment remained a prominent aspect of life.

Jack – *The first year of his life has just been one big blur...we're enjoying the smooth bit in between but we know there's lots to come.*

Owen – *It occupied our lives for a long time, there was regular treatment and it was a big feature of life.*

Fathers also commented that during times where there was a heavy focus on treatment, other areas of life became disrupted.

Michael – *I work on commission so it's financially stressful taking time off...we've had to go to three different hospitals, all an hour away...it affects my relationship with my wife, because I don't see her for a week...you lose fun time with the other kids because we can't go out as a family.*

#### **Theme 4: Looking back and moving forward**

##### **4.1. Personal growth**

Upon reflection, fathers felt they had become better people and parents as a result of their child being born with a cleft. Some felt their general outlook on life had changed, while others believed their relationships had been strengthened. Many stated they felt more knowledgeable about CL/P and fatherhood, and believed the experience to be a great learning curve.

Edward – *Having babies before, it was a lot like having blinkers on...this opens your eyes to what else is out there. We're learning all the time.*

Fathers believed their children would also grow up/had grown up to be well-rounded characters as a result of their experiences.

Andrew – *Overcoming operations and things, I suppose he's quite a resilient kid now.*

Adam – *If he hadn't been born with a cleft, what would he be like? His cleft is immensely personal but it's something that will make him who he is.*

#### 4.2. Giving something back

As a direct result of the care they had received, almost all fathers stated that they wanted to 'give something back'. For some, this meant providing direct support to other families. For others, this had led to efforts to raise money and awareness within their local area. Some fathers volunteered for charitable organisations, such as CLAPA.

Edward – *We now offer our support and experiences to expecting parents...because we've been through it we're trying to reach out to other people.*

#### 4.3. The future

Fathers' most common concern for the future was their child being teased as a result of the cleft. Nonetheless, fathers believed that teasing is likely to happen to everyone at some point; therefore the best way to approach these concerns was to be as open as possible with their child about the cleft.

Nathan – *The day she comes home telling me she's being teased will break my heart, but there's nothing we can do about that. We've given her every single tool we can think of, mostly in terms of self-confidence and an outgoing personality, and tried to make sure she's aware of what happened to her, so she understands and can explain it to other people.*

Fathers also expressed some caution around creating too much of a focus on the cleft; while they felt it important to prepare their child, they did not want to 'pigeonhole' them. Many said that they would leave treatment decisions to their child once they were old enough.

Adam – *I'm keen that his cleft doesn't define him or interfere with his childhood. If further treatment isn't compulsory and he's happy looking a little bit different, that's absolutely fine.*

Fathers also had some concerns about their child developing romantic relationships.

Joshua – *There's a real thing about fathers and their little girls, 'no boy's knocking on my door' kind of thing, but actually, I'm worried that no one will.*

One father commented that further corrective surgery may help to reduce the incidence of teasing.

Luke – *I'm very happy the bone graft is happening. We know he's just starting to feel sensitive about the cleft, so if we can get it done now then it might help.*

Another common concern was the possibility of fathers having another child with a cleft. However, this was not seen as something which would prevent future pregnancies, but was focused on being more prepared the next time around.

Nathan – *We wanted to have a second child and just wanted to know, were we likely to go through this again? It's about not wanting the shock factor.*

Linked to this was the concern of increased probability of CL/P within future generations.

Paul – *I suppose the big thing is if my daughter wanted to have a family...I think that might be a tough one for her and would probably raise all these emotions again.*

Overall, fathers' experiences seemed to convey their child's cleft as an underlying stressor in an otherwise normal father-child relationship.

Nathan - *Other than the obvious things we're just going to have the same hopes and fears that any parent's got.*

## Discussion

This research provides compelling evidence for the necessity of addressing fathers' information and support needs, in both clinical practice and applied research. A number of discussion points have been generated by the analysis of participants' responses. These are outlined below and subsequent recommendations are summarised in Table 1. The authors recognise that the development of appropriate resources would facilitate the implementation of these recommendations, and this should be a priority for researchers in the field.

### *Diagnosis and postnatal care*

The majority of fathers in this study perceived the responses of non-specialist HPs to be poor. This included sonographers, nurses, midwives, health visitors and general practitioners. Recent research has produced similar findings, with parents expressing dissatisfaction with the care they have received from non-specialists (Robbins et al., 2010; Vanz and Ribeiro, 2011; McCorkell et al., 2012; Williams et al., 2012). In contrast, care received from the specialist cleft teams, as well as additional support provided by CLAPA, was highly praised. Previous research has suggested that the information and support families receive is crucial in determining how well families adjust to the cleft and its implications (Vanz and Ribeiro, 2011). The present research reinforces this finding, and demonstrates that while a lack of support can invoke significant distress, positive experiences of support can facilitate coping and adjustment.

Although a potentially large undertaking, it is recommended that basic, standardised training be implemented for any non-specialist HP who may come into contact with a child born with CL/P, to raise awareness of the condition and to provide HPs with the skills and confidence to deliver the diagnosis sensitively, and to care for the family appropriately. The implementation of such training has been suggested previously (McCorkell et al., 2012; Nelson et al., 2012). Although screening for a cleft at the anomaly scan has only recently become

compulsory in the UK, it is crucial that HPs communicate a diagnosis and its implications effectively, regardless of the type of condition. In addition, relevant and appropriately written materials should be available at the time of diagnosis. As a minimum, families should be directed to CLAPA, or an equivalent authoritative support organisation, as a reliable source of information immediately following a diagnosis. This is essential to support parents in the time between diagnosis and referral to the cleft team, and to avoid the risk of misinformation and further distress.

### *Fathers' information needs*

Fathers stated that having reliable information and being prepared for treatment was essential. Unfortunately, it was clear that some of these information needs had not been satisfactorily addressed; a finding which parallels recent research (Nelson et al., 2012; Williams et al., 2012). Of particular importance was the need for information surrounding the aetiology of CL/P, and resulting worries in relation to causal factors. Currently, there is a lack of knowledge in relation to the aetiology of CL/P for all affected individuals, but for some fathers this uncertainty had caused considerable distress. This was most apparent in those who had received the least information, or reported having received conflicting information. This was considered particularly crucial if fathers wanted to have another child, or if they were concerned about the possibility of CL/P occurring in future generations. Research investigating the genetic and environmental causes of CL/P is therefore of vital importance, as is access to genetic counselling, in order to provide more detailed and reliable information to parents. This is particularly important given that parents' beliefs about causation and responsibility have been found to impact on their own psychosocial adjustment (Nelson et al., 2009). This study also supports the finding that parents who were born with a cleft themselves may require additional support to cope with potentially heightened feelings of guilt (O'Hanlon et al., 2012).

Fathers raised a number of smaller, but important points in relation to the way cleft teams engage with families. First, they expressed the view that families can feel overwhelmed during large team meetings. Care is therefore needed to avoid this and to ensure that both parties achieve their aims. One father expressed the view that

receiving a booklet explaining each team member's role in advance of the meeting was useful. This may also help to assure fathers that each team member is a specialist within their field. In addition, fathers could be encouraged to bring a list of pre-prepared questions with them to the meeting. Second, fathers may benefit from information and support regarding the range of reactions they may experience from members of the public. Understanding why this can happen, and learning some useful coping strategies, may reduce the harmful impact of negative social interactions (Stock et al., 2013). Third, fathers could be better prepared for how their child may look following surgery. Although fathers had been warned about this by the cleft team, many said that having the option to view photographs of other children following surgical repair would have been helpful, to give them realistic expectations. This issue has not been raised in the literature before and although relevant for both parents, may be especially pertinent for fathers, the majority of whom (in this study) expressed a strong wish to be fully prepared at every stage. A final area of anxiety for fathers was how best to raise the topic of the cleft with their child, particularly once their child became more aware of their 'difference'. This was linked to deeply-rooted concerns surrounding teasing and bullying, particularly if fathers had experienced teasing themselves at some stage. Sadly, teasing and bullying are likely to be a cause for concern among those who are visibly different from societal norms (Rumsey and Harcourt, 2005). Fathers had their own views on how best to handle this issue, but commented that they had never been offered professional advice. This is of importance since parental perceptions of the cleft and the way these are communicated may influence their child's adjustment (Bellew, 2012). Linked to this is the possible parental belief that surgery is a 'quick fix' to any appearance-related bullying. Although only one father commented on this, it is an issue which has been identified in another recent qualitative study, in which parents 'invested great hope in the power of physical treatments, as a key way of resolving associated problems' (Nelson et al., 2012). This is of concern as the lack of a relationship between appearance and psychological adjustment has been repeatedly demonstrated (Moss, 2005; Ong et al., 2007; Billaud Feragen, 2010; Brown et al., 2010).

While practices are likely to vary between cleft teams, there may be a case for developing authoritative guidance relating to some of these topics, for distribution by cleft teams. Although more research on the psychological factors contributing to resilience is needed, parents could, for example, be encouraged to focus

on their child's positive attributes, and to help to build confidence which extends beyond physical and functional attributes alone (Eiserman, 2001; Rumsey and Harcourt, 2005). Raising awareness of CL/P within the general UK population and promoting the value of greater diversity in appearance is also recommended as a priority for the charitable sector.

### *Fathers' support needs*

Meeting other families affected by CL/P was reported to be of significant benefit to those fathers who had been given this opportunity. This was particularly relevant before and during times of intensive treatment, especially if other families were ahead in the treatment trajectory. Speaking to other families may help to allay fathers' fears and promote the adoption of helpful coping strategies. As well as honest and realistic accounts of their treatment journey, families are able to provide positive social support to one another. This is known to promote adjustment in a range of stressful situations (see Cohen and McKay, 1984) and, more specifically, among those affected by CL/P (Baker et al., 2009). In light of the levels of personal growth reported by participants in this study and in other studies (Baker et al., 2009), parents who are 'further down the track' may be able to provide a positive perspective for families with less experience. Similarly, the experience of having previously met someone with a cleft was helpful for some participants in making more positive appraisals of the impact the cleft might have on their own child and in reducing concerns about the future. Fathers also felt that although opportunities to talk about their experiences had been rare, on the occasions this had happened it had been a valuable opportunity for reflection and a therapeutic process. Speaking about their own experiences was described as a helpful way for fathers to make sense of their situation, and as a welcome opportunity to 'give something back' to others. Putting families in touch with others in a similar situation may therefore be an ideal way for cleft teams and support organisations to facilitate adjustment and to create a self-sustaining network of families who are willing to support one another.

After reports of overall satisfaction with the care they had received from the cleft teams in the early stages of their child's life, a number of fathers were concerned to have subsequently lost touch with their cleft team.



Despite their child's treatment becoming less intensive after the first year, fathers felt that a number of issues were ongoing, and that new challenges arose as time progressed. Given the importance that all fathers placed on their family receiving the support they needed quickly and effectively, this finding is of concern. Building on the work of Lansdown and colleagues (1997), the cleft and its treatment may be conceptualised as an underlying stressor throughout life, one which makes continuous calls on energy reserves and coping resources. Furthermore, this research and other recent work have found fluctuations between states of relative adjustment and distress to be common (Clarke et al., in press). Given that CL/P is a lifelong condition involving multidisciplinary care, a lifespan approach to care is recommended, which recognises the need for consistent yet flexible support.

Additionally, the type and intensity of the need for support is likely to vary between individuals. While some fathers stated they hadn't needed support beyond what was already provided, others would have valued the acknowledgement of their individual information and support needs. Namely, this involved opportunities to gather reliable information, and the opportunity to 'take a break' from their primary supportive role and offload some of their own concerns. In view of the range of support needs expressed by parents, a range of interventions should be accessible on a case-by-case basis. Support and interventions should ideally be delivered using a stepped approach, in which all members of the team are involved in delivering basic psychosocial care, including routine questions and straightforward advice for common problems. More intensive, individually tailored face-to-face interventions would then be delivered by appropriately trained psychosocial specialists (see Rumsey and Stock, 2013). Authoritative support organisations, such as CLAPA, could represent an additional resource which supports and compliments the service provided by cleft teams.

### *Accentuating the positives*

In addition to highlighting the support needs of fathers and apparent gaps in service provision, this research has demonstrated some of the positive outcomes that may result from having a child born with CL/P. In CL/P and in related areas of research, positive growth is often cited as a result of overcoming adversity (Linley and

Joseph, 2004; Reichman et al., 2008; Egan et al., 2011). Researchers and clinicians are therefore encouraged to move away from the tendency to pathologise and to recognise individuals' strengths (Rumsey and Harcourt, 2012). Such an approach would teach us about the factors which might facilitate adjustment, and about how to turn the challenges of living with a medical condition into a strengthening experience. As previously mentioned, the adoption by HPs and families of an approach of 'a child with a cleft', rather than that of 'a cleft child' would promote an ethos of care in which the cleft is considered an additional challenge, but not a defining feature (Lansdown et al., 1997).

### *Suggestions for future research*

As well as the clinical implications of this research, a number of suggestions for future work have been identified. Importantly, efforts should be made to include fathers in future studies. In the past, research has either excluded fathers, or claimed them to be difficult to recruit into psychological studies. While this may be the case, and although the findings of this study uncovered many similarities with the needs of mothers, a number of important differences and a broad picture of the unmet needs of fathers have also been highlighted. Researchers should strive to facilitate the involvement of fathers where possible, to make certain that this group is represented in future, and ensure that a fuller picture of the family's circumstances is provided as a whole.

As some fathers highlighted, siblings of children born with CL/P may have information and support needs of their own. Within the wider literature, siblings of children with chronic illness have been found to be at risk for negative psychosocial effects (Sharpe and Rossiter, 2002). This has also been found within the broader literature on visible difference, for example, in relation to children with burn injuries (Phillips and Rumsey, 2008). However, in the present research, fathers also felt that siblings had the potential to be a positive influence on the affected child, both in terms of social support and in terms of cognitive and speech development. This may also be the case for less immediate family members. For example, as demonstrated in this study grandparents may also experience some distress as a result of their grandchild's cleft and the treatment involved, particularly given the level of involvement which some grandparents now have in the

upbringing of their grandchildren. Equally, the fathers in this study who had support from family and friends throughout their journey believed the experience had strengthened their family bond and friendship network. Further exploration with extended family members may highlight a number of untapped support needs, as well as opportunities to encourage helpful social support systems.

One father who participated in this research was born with a cleft himself. His responses suggest that the experiences and support needs of affected adults, including those with children born with CL/P, should be a priority for future research. Although a few studies have identified a number of potential difficulties that adults may experience (Danino et al., 2005; Oosterkamp et al., 2007; Baker et al., 2009; Yttri et al., 2011), there is no doubt that research in this area is currently lacking. Although the majority of fathers felt that the cleft would not hold their child back in life, an accurate picture of likely long-term outcomes cannot yet be offered. Research in this area will also enable HPs to adopt a preventative approach as necessary.

Only one father who participated in this research had a child with an additional diagnosis (Pierre Robin Sequence; PRS). PRS is a condition in which the infant's jaw is found to be smaller than normal and the enlarged tongue is positioned too far back in the mouth. This may lead to additional health complications, including breathing and feeding difficulties. Although it is not possible to generalise from these findings, it was clear that additional hospital admissions and health complications presented a significant burden for a number of fathers. Previous research has supported the suggestion that additional complications present an ongoing challenge for children born with CL/P, particularly those diagnosed with co-morbidities, such as PRS (e.g. Hodgkinson et al., 2005). However, individuals with additional diagnoses are often excluded from research. As a result little is known about the specific support needs of this group (Billaud Feragen et al., in press). Further exploration of families affected by PRS and other complications is therefore strongly recommended.

### *Limitations of this research*

A number of limitations of this research must be acknowledged. First, the fathers who participated in the interviews were self-selecting, which may represent a bias. Within research it has been recognised that those

wanting to talk about their experiences are more likely to represent extreme ends of the scale, i.e. those who have had particularly good experiences, or those who have had especially negative experiences (e.g. Peel et al., 2006). However, several fathers commented that they had not had many opportunities to discuss or reflect upon their experiences before; this is likely to have contributed to the motivation of fathers to participate.

In relation to this, eight of the fifteen fathers who participated in this research were recruited through CLAPA. While many parents choose to become members of CLAPA, their membership represents only a proportion of the population affected by CL/P in the UK. As a result, the participants who were recruited into this study through CLAPA may not have been entirely representative of the target population. Nonetheless, many of the themes derived from the present study resonate with the (albeit limited) previous findings in qualitative CL/P research (Nelson et al., 2012; Williams et al., 2012) and related fields (Coffey, 2006).

All fathers identified as White British, were in a long-term relationship, and were in employment at the time of interview. As a result, those with diverse ethnic backgrounds, those reporting a different marital status or less traditional family structure, and those living in lower socioeconomic conditions, were not represented in this research. Given that each of these factors have been implicated in psychosocial adjustment to CL/P (Black et al., 2009; Collett and Speltz, 2006; Persson, 2012; Waylen and Stuart-Brown, 2009), it is important that future research aims to capture a fuller range of experiences. Interestingly, one study identified a similar self-selection bias among fathers; namely that those fathers with less education, less traditional family structures and less optimal environments were less likely to participate in family research (Costigan and Cox, 2001). The same pattern was found for fathers belonging to ethnic minority and working-class groups. Alongside issues of generalisability, this finding also has implications for the way in which fathers (and other groups of participants) are recruited into studies.

No fathers with children in their teenage years took part in this research. As fathers expressed concerns around teasing and bullying and the development of romantic relationships, it would have been interesting to gauge the views of fathers who currently had a child in this age group.

Finally, while this research has provided a unique insight into fathers' experiences which was not previously presented, interviews elicited retrospective views. Ultimately, longitudinal research is needed in order to more accurately capture the journey families embark upon when a child is born with CL/P, particularly given that adjustment is now known to fluctuate over time (Clarke et al., in press).

## Conclusion

This research has highlighted the key role that fathers can play in supporting their family through the treatment process. Subsequently, a greater awareness and a more detailed understanding of the psychosocial impact on fathers of children with CL/P, and their experience of healthcare, is required. Although many of the experiences voiced by fathers in this study parallel those discussed in previous research with mothers, it is important that fathers' views and needs are taken into account when offering support to the family. A number of recommendations have been made in relation to clinical practice and conducting research in the field of cleft lip/palate.

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