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Health Professional communication and the diagnosis and care of infants born with cleft lip and palate in the U.K.

Keywords: Cleft lip, Cleft palate, Health care professionals, sonographer, communication, diagnosis, Clinical Nurse Specialist, midwife, breastfeeding, bottle-feeding

Abstract

Objectives

A qualitative was conducted to explore family experiences of communication with health care professionals following the diagnosis and birth of a child with cleft lip and / or palate in the United Kingdom. Twenty four interviews were conducted with families who had a child born with cleft lip and /or palate. Analysis of the data revealed that a diagnosis of cleft lip and / or palate may not be handled sensitively by the non-specialist health professionals who are providing care. Furthermore, a lack of knowledge and inadequate support may continue after the child is born as some health professionals do not provide accurate or appropriate advice relevant to this condition.

The findings have implications for current clinical practice with regard to the diagnosis and care of infants born with cleft lip and /or palate in the United Kingdom. These implications are discussed within the context of improving and developing communication in the diagnosis and care of children with cleft lip and /or palate and Experienced-Based Co Design.

Introduction

Cleft lip and / or palate (CLP) is a congenital condition that occurs in approximately 1 /700 live births (Mossey et al, 2009). The cleft may be found, unilaterally or bilaterally, in either the lip (approximately 25% of cases) or palate (around 40%), or in both (about 25% of cases). In the United Kingdom (U.K.) a cleft lip is usually diagnosed ante-natally at the 20 week scan and therefore a sonographer is the most likely health professional to break this news to parents. Evidence suggests that pre-natal diagnosis enables the parents to prepare for the unique neonatal feeding requirement of infants with cleft, allows for early planning of surgical repair and can improve overall satisfaction with cleft care (Robins et al, 2010). However, cleft diagnosis during ultrasound may sometimes be missed due to lack of attention to the face in the absence of risk factors, position of the foetus, maternal obesity, multiple pregnancies, reduced amniotic fluid and the reduced skill of the sonographer or other diagnostician (Klein et al, 2006). Consequently, an isolated cleft palate may not be diagnosed until a neonatal examination is conducted. Even then, a cleft palate may be missed if the examination is not thorough (Habel et al, 2006).

Support following a diagnosis of cleft lip and palate

The way a diagnosis of CLP is delivered can have long-term effects on how families adapt to adapt to their child's condition (Fallowfield, 1993; Krahn, Hallum & Kime, 1993). A sensitive and effective diagnosis is important for the development of cooperative relationships between families and their health care providers (Forth, 2003). Alternatively, an insensitive

diagnosis of CLP may result in high levels of anxiety and stress, possibly initiating feelings of grief due to the loss of a 'perfect' child (Forth, 2003); the associated distress may be comparable to trauma or bereavement (Aite et al, 2011; Farrimond & Morriss, 2004). Regardless of whether diagnosis occurs pre-natal or at delivery, parents may express dissatisfaction with the way it is managed (Nusbaum, et al, 2008). At this time, parents want to communicate and share information with knowledgeable and sympathetic medical staff (Robins et al, 2010) who are in control of the informing conversation, who are caring, confident and comfortable in sharing their own feelings and who enable the parents themselves to talk, show their feelings and ask questions (Byrnes et al, 2003; Fallowfield & Jenkins, 2004). They require support and accurate information, delivered in a manner that acknowledges the emotional and also the 'biographical' disruption of the pregnancy (Nelson et al, 2012; Strauss et al, 1995) and which allows them to ask questions (Strauss et al, 1995; Harrison & Walling, 2010). They require clear written information and details of how to contact support groups and others in a similar situation (Nelson et al, 2012). Delivering unwelcome news in this way provides better outcomes for parents by reducing the amount of stress and anxiety they perceive (Strauss et al, 1995).

There are a variety of guidelines for breaking bad news (Harrison & Walling, 2010; Baile et al, 2000; SCOPE, 2003; Rabow & McPhee) but there is also evidence that some healthcare professionals are unaware of them (Fallowfield & Jenkins, 2004). Furthermore, health professionals may misunderstand parental needs at this time (Berk et al, 1999; Forth, 2003) and they may have little knowledge about the treatment and prognosis of specific congenital conditions. Sonographers have reported that they are most concerned about time constraints and the unpredictability of womens' reactions when breaking bad news; however, they also note that their own perceptions of stress at this time are reduced if they

worked in an institution where disclosure guidelines are in place and followed (Hammond et al, 1999).

After receiving a diagnosis of CLP, families should be referred to the cleft service and contacted or visited by the Clinical Nurse Specialist (CNS) within 24 hours. The role of the CNS is to provide support to parents following diagnosis and after the child's birth, helping them to understand prognostic and treatment implications as well as more specific issues such as feeding (Bannister, 2008; Beaumont, 2012; Bessell et al, 2010).

Post-natal support

Breastfeeding support is an integral part of post-natal care for all mothers and should comprise appropriate advice, support and encouragement (Beaumont, 2012; Lindberg & Berglund, 2011). Unfortunately this is not always provided and parents of children born with a cleft have, historically, expressed dissatisfaction with the way that breastfeeding support and information is provided, often because staff lack knowledge and expertise (Nelson et al, 2012a; Nelson et al, 2012b; Lindberg & Berglund, 2011). Infants may experience difficulties in latching on and creating an effective seal on the breast and co-ordinating sucking, swallowing and breathing (Beaumont, 2012; Bessell et al, 2010; Lindberg & Berglund, 2011)

While the CNS are trained to assess the infant's oral skills after birth and provide advice about appropriate and effective feeding methods, they may not always be able to attend in the immediate period after the birth (Beaumont, 2012). In such situations, mothers have reported receiving little or no support, being given inaccurate advice and being discouraged from even trying to breastfeed by the non-specialist health care professionals who are

present (Bessell et al, 2010). This is likely to result in added stress, confusion, uncertainty and anxiety for parents and health professionals at a time that is already difficult (Lindberg & Berglund, 2011). Parental concerns about poor communication and lack of knowledge in HCPs who provide cleft care services, both pre- and post-natally, were also reported in the 1998 Clinical Standards Advisory Group (CSAG) report which has been widely circulated among HCPs providing cleft care (CSAG, 2012; Farrimond & Morriss, 2004).

Given the documented dissatisfaction of parents of children born with CLP, at the time of diagnosis and after the child is born, the aim of this paper is to explore more recent family experiences of communication with health professionals at the time of diagnosis and caring for an infant born with CLP.

Method

Procedure

This study is nested within a programme of qualitative research undertaken in the development of the Cleft Lip and Palate module for Healthtalk.org Health Experiences Research Group. Researchers Handbook, 2012) Participants were recruited through a variety of methods including personal networking, social media including the Facebook pages of organisations such as CLAPA (Cleft Lip and Palate Association) and Healthtalk.org. All potential participants were sent an information sheet via email by AS. Participants were given a period of 1-2 weeks before they were re-contacted by AS for their agreement to be interviewed either by video or audio only. Those agreeing to participate signed a consent form prior to interview.

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

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

Participants

Twenty-four parents who have a child born with CLP were interviewed by AS (see Table.1). Fifteen mothers and two fathers were interviewed alone, seven people took part as couples. Twenty-two interviews were conducted face-to-face in video or audio format in family homes and two were telephone based interviews.

Analysis of interview data

All transcripts were transcribed verbatim and were returned to participants for them to confirm if all recorded data could be used for the purposes of the wider research programme. Following confirmation an inductive 'thematic' analysis was undertaken.

Transcripts were read and re-read by AS and SR to gain familiarity with the data. An initial coding frame was developed and tested on a sub-sample of four interviews. Discrepancies in codes were discussed until consensus was achieved and a definitive coding frame was developed. The data were organised using NVivo qualitative data analysis. (QSR International Ltd. Version 9, 2010). Interpretation of the coded transcripts was undertaken by AS, AW, and SR and emerging themes were identified.

Results

Data pertaining to the themes; 'diagnosis', 'feeding', 'information seeking' and 'communication with health professionals' are represented in the results in the following sections: Antenatal diagnosis of cleft, Care of a baby born with cleft, and Delayed diagnosis of cleft.

Antenatal diagnosis of cleft

The sonographer is likely to identify the presence of a cleft lip on an ultrasound scan and the person who informs the family of the diagnosis. Parents who received a diagnosis of cleft during their scan often reported a lack of empathy and awareness about the diagnosis and its implications:

"She'd [sonographer] showed us all his limbs and his heart and all his organs, so we knew that everything was OK. And then she said that, "Yeah unfortunately, I've seen that your son has a cleft lip. And it was just kind of like that really. They told us to basically expect the worst case scenario." (Kerrey, son born with cleft lip)

One mother was given a brochure about CLP by the sonographer to read at home after receiving the diagnosis for her child, suggesting a difference in parent and sonographer perceptions about this condition:

“She said, ‘Yeah cleft lip, I’m pretty sure I saw a line just in the middle here. But you will be referred for an in-depth scan soon, after a week or ten days. Wait here for five minutes,’ she went somewhere and came back with the brochure, and she said, “You will be called by a nurse, a specialist cleft nurse in the next few days. She will come and show you pictures. Don’t worry. Actually you have nothing to worry about because I told you your son is absolutely healthy. This is something cosmetic; it will be repaired. Don’t worry.’ But I was, nothing could help in that moment really, I was just crying and crying and crying.” (Iva, son born with cleft lip)

A few families were asked by their sonographer to consider termination without an opportunity to understand the diagnosis and its consequences:

“I think the way it was delivered was blunt.... it was like, ‘Carry on with the pregnancy,’ it was you know, ‘If it’s born there is a team around to help,’ that was it. It wasn’t, there was no there was no further information, you know, ‘This is what they can do, this is what happens,’ blah, blah, etc. It was that, and then it was just like, ‘Or you can terminate.’ And then it was, ‘Go away for the weekend and think about it.’ And that was, that was literally how it was delivered, you know.” (Andy, son born with cleft lip and palate)

Some families also had the opportunity to meet specialist health professionals from their regional cleft teams and usually co-ordinated by Clinical Nurse Specialist (CNS):

I had so many questions, and she (CNS) just offered us, she said, "Would you like to come and meet, you know, the cleft surgeon? You've got a lot of issues, a lot of questions," and she said, you know, "we can, you can, we can book in to come and see him." **(Rebecca, son born with cleft lip and palate)**

Care of a baby born with a cleft

Following the birth of a child with CLP a feeding assessment should be undertaken prior to the introduction of assisted feeding and a feeding plan that supports the mothers' preference for feeding should be devised and documented (Bannister, 2008). Most parents are told about feeding by the CNS when he or she visits the family shortly after the birth. However, when a CNS is not available midwives are often responsible for offering feeding support and advice even if they have no expert training:

"I mean the midwives in the hospital, I was so surprised how little most of them knew, because they'd never seen a cleft baby, which is quite extraordinary really I think, with the incidence being what it is." **(Natalie, son born with cleft lip and palate)**

Some parents reported that they were given inappropriate advice by maternity ward staff that left them confused or felt pressurised to breastfeed:

"The midwives weren't cleft specialist, they really wanted me to try with having him feeding on the breast, and I was sort of hand expressing into his mouth, which was just pants frankly, did not work, it was ridiculously difficult. And the specialist cleft nurse turned up

with a hand pump and a big industrial kind of breast pump. And she was the one who said, "Look, you know, this is not going to work, he's not going to be able to feed on the breast, you know, but if you express and use the squeezable bottles he'll be able to, you know, you'll be able to do it that way." And so, and that did work. And I felt that there was not really out and out disagreement but contradictions in the advice I was getting from the specialist cleft nurse and the maternity nurses, I think that all of their stuff is around trying to support mothers to do breast, natural breastfeeding, feeding on the breast and they were pushing that line. And I think that it's also there's some, I had heard this as well, that sometimes it's possible for cleft babies to feed on the breast, and they were kind of, you know, hoping that you know, all best intentions, just yeah, not helpful." (Christie, son born with cleft lip and palate)

"I was asked by a midwife about whether I was going to breastfeed. You know, she kind of looked at me after I'd explained everything to her, and shown her a squeezable bottle, and explained what was going to happen over the next few months, and how the muscles in the mouth were formed and she still looked at me and at the end of that she kind of said, 'Oh so you're not going to try and breastfeed at all?' And I just thought, 'I'm not sure that you've listened to a word that I've said.' And, you know, these people are there to hold people's hands through a really uncertain time anyway, but when they're putting pressure onto somebody to do something that's physically impossible it's pretty, you know, it's not ideal really." (Maria Z, daughter born with cleft palate)

When a baby is suspected of having associated / and or genetic conditions they are taken to the Special Care Baby Unit (SCBU) to be fed breast milk via bottle and a naso-gastric tube.

However, staff on special care units may not have experience of feeding babies born with

CLP:

“The cleft nurse team come in within 24 hours to teach you how to use the squeeze bottles except the midwives on maternity units, they’re very cautious of doing it. I’m not sure why. Some people say they’re scared of drowning or they’re scared of not feeding the baby enough. Or whatever happens, anyway they’re quite cautious of not having the guidance from the cleft service to do it. At our hospital they have a transitional care ward, which is quite new in our hospital but it’s for mothers who have babies who may have extra needs or mothers who have had a particularly complicated labour or something like that. So we went on there because xxxxxx was, had a cleft lip and palate, he was on a feeding tube, so he was being syringe fed down the tube, and we had to squeeze the bottle as well, so we needed a little bit more care than the general ward as well.” (Tamsin, son born with bilateral cleft lip and palate)

Some babies were taken to special care at short notice and without adequate explanation of why the baby had to be nursed there:

“First of all, because it was very late at night xxxxxx got taken to special care straight away to be tube fed, and that was all that was said to me was you know, I wasn’t given any explanation to what it was or anything like that. It was just like took away and fed her with the tube. And then I had to go back to a room, so yeah. It was the midwife who was looking after me at the time. And they had actually not much experience of cleft palate or anything

like that. So that they couldn't they weren't able to feed her with a special bottle or anything because they'd never oh well they probably had come across them but they didn't have any experience of dealing with it." **(Rebecca, daughter born with cleft palate)**

A consequence of not being able to feed a new baby meant that some mothers were distressed, feeling that they had failed their child at a critical time:

He didn't have his special bottles, and I didn't know exactly how to feed him he had to go to neonatal, because I couldn't feed him from a normal bottle so he wasn't getting the milk that he should be getting. So they had to feed him through a tube for the first day. They said to me that I can go down whenever but I mean I just felt so helpless because I couldn't feed him. It was just I was just sitting there. The only thing I could do was hold this little syringe up so that it could go through the tube into him. **(Safiya, son born with cleft lip and palate)**

Delayed diagnosis of cleft

Some babies received a delayed diagnosis of cleft palate, sometimes weeks or months after they were born. In some instances this was because some health professionals, both in hospital and in the wider medical community, had little or no knowledge of cleft palate and its implications. Difficulties with feeding either on the breast or with a bottle can be a sign of an undiagnosed cleft and some families reported difficulties communicating their concerns about feeding their unsettled babies to HCPs:

“It wasn’t even noticed when she was born... by the coordinators ...The breastfeeding coordinators. They [midwives] just brushed it off because... they were just very off. And they were expecting her to drink and she just wasn’t drinking, but they still discharged us and... it just wasn’t a nice experience in the hospital anyway so....The midwife I had was very... rude. I was told to grow up by the midwife. Because she wouldn’t feed. And she didn’t offer me any help: just gave me a bottle. But if they’d have checked then for the cleft they would have found it.....” (Laura, daughter born with cleft palate)

One mother was aware that there was a breastfeeding specialist midwife on the ward and, eventually, she asked her to watch her try and feed her new baby:

“They did all the basic checks, and it was within the first 24 hours that we realised that something was wrong. I was a second time mum, trying to feed her, and she couldn’t latch on properly: lots of noises, lots of mess. But I was told to keep trying by the midwives. And I was probably seen by about three or four of them as they changed shift pattern, and each one just gave me different advice. They watched me feed her. I was offered a breast pump in the evening. And during that day I did say, ‘Please can I speak to the breastfeeding specialist midwife?’ because I knew there was one on the ward, but she was only available Monday to Friday, and it was during the day, and I asked for her about teatime, which was too late. And she came the next morning, watched me feed Xxxx and heard a clicking sound, which made her say, ‘Can I just have a look at her again?’ And then she did a mouth examination and told me that Xxxx had a cleft of the soft palate, which was a shock to me: didn’t know what a cleft of the soft palate was.” (Jenny, daughter born with cleft palate)

Discussion

A diagnosis of CLP may not be handled sensitively by the health professionals who are providing care. Following diagnosis, healthcare professionals with little or no expertise in CLP may be in the difficult position of having to care for families who are upset but demanding further information. After the child is born, a lack of knowledge and inadequate support may continue and some health professionals provide inconsistent or inappropriate advice for feeding.

In accordance with other studies parents were often dissatisfied with the delivery of diagnoses and information about looking after a child with CLP (Clinical Standards Advisory Group, 1998). Furthermore, health care professionals providing care for infants born with CLP lacked knowledge and experience in providing feeding advice and support, and the encouragement of breastfeeding (Beaumont, 2012; Bessell, 2010). Instead of perceiving this neonatal period as a time when they get to know and learn about their new baby, parents are reporting that the poor communication between them and the HCPs involved with infant care results in unwanted and unhelpful pressure to care for the baby in specific ways, guilt when these methods don't work, uncertainty in knowing what is best for the infant, and a mistrust in ongoing relationships with healthcare professionals who, ultimately, should be there to provide support.

Implications for practice

Families expressed a need for accurate and accessible sources of information away from care settings e.g. reliable written information and internet sources that provide up-to-date

and realistic detail rather relying on pictures of 'worst case scenarios' (Nusbaum et al, 2008). There are guidelines for breaking bad news (Baile et al, 2000; Rabow & McPhee, 1999; SCOPE, 2003) and there is also evidence that many healthcare professionals are unaware of them (Fallowfield, 1993; Byrnes et al, 2003). Therefore, these guidelines need to be made available to primary care providers so that they can develop good practice for working with families where pregnancy, birth and infancy / childhood are more challenging.

With regard to feeding an infant born with CLP the Academy of Breastfeeding have published a protocol for breastfeeding (Beaumont, 2012) but there seems to be less awareness of these guidelines. Actions which would support mothers of babies born with CLP include being given a feeding assessment prior to the introduction of assisted feeding (bottle or tube feeding) and agreed feeding plans to support a mothers' preference; counselling and support for those who need / require it.

Parental dissatisfaction with the diagnostic process for CLP can be avoided (Krahn et al; 1993) especially if existing differences between health professionals' perceptions of parental information needs and actual parental preferences can be reconciled (Byrnes et al, 2003; Berk et al, 1999). While we acknowledge that in-depth training on all congenital and developmental disorders is unrealistic we believe that basic training about CLP and other congenital disorders should be provided for midwives, health visitors and nurses; in addition all clinicians should have quick access to expert information and support where needed. Parents who have a child born with a cleft can act as advocates for awareness raising among non-specialist professionals, at the same time providing a service user's perspective and highlighting family concerns about the early stages of cleft care. All of the mothers in the

present study whose children had received a late diagnosis of cleft believed that their experiences should be used to raise awareness of CLP in non-specialists. Some have been involved in training health professionals such as midwives and general practitioners to become more aware of the signs and symptoms of cleft palate. Health professionals can also consult and / or direct families to the Healthtalk.org Cleft Lip and Palate module in order to gain a family-centred view of having a baby with CLP (Healthtalk.org, 2014). This online resource contains specific topic summaries including issues with diagnosis, feeding and the treatment of cleft lip and palate.

Potential advances in healthcare communication may be made via studies using *Experience Based Co-Design* (EBCD) methodologies which are described in detail elsewhere (Locock et al, 2014). The aim of EBCD is to empower staff and patients to make changes in clinical practice by filming individual and family experiences and stories of healthcare. Patients, their families and healthcare professionals are then brought together to prioritise identified areas for improvement and to define key actions. With respect to CLP, there is scope for health professionals to use an existing Healthtalk.org video archive as ‘triggers’ for discussion by creating ‘Scrapbooks’ of pertinent material to educate non-specialist professionals about diagnosis and feeding infants with CLP. In addition, non-specialists could use the archived videos for self and peer education and families could refer to the video clips in awareness-raising seminars with non-specialist professionals.

Conclusion

A diagnosis of CLP may not be handled sensitively by the non-specialist health professionals who are providing care. Furthermore, a lack of knowledge and inadequate support may

continue after the child is born as some health professionals. The findings have implications for the diagnosis and care of infants born with CLP in the U.K. It is suggested that the concept of Experienced-Based Co Design may be a valuable means for improving and developing communication in the diagnosis and care of children with CLP.

Abbreviations:

CLP – Cleft lip and / or palate

CNS – Clinical Nurse Specialist

CSAG – Clinical Standards Advisory Group

CLAPA – Cleft Lip And Palate Association

EBCD – Experience Based Co-Design

HCPs – Health Care Professionals

HERG – Health Experiences Research Group

SCBU – Special Care Baby Unit

U.K. – United Kingdom

Declaration of competing interests

The authors declare that they do not have any competing interests

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Table 1. Details of parents (N= 24, includes *individuals with cleft).

Interviewee	Parent	Age of Interviewee	Child / Cleft type	Ethnicity
Christie	Mother	41	Son with Cleft lip and palate	White British
Natalie	Mother	46	Son with Cleft lip and palate	White British
Mandy	Mother	29	Son with Cleft Palate	White British
Tamsin and Andrew	Mother / Father	29 /33	Son with bilateral cleft lip and palate	White British
Rhiannon	Mother	27	Daughter with cleft palate	White British
Matt	Father	29	Daughter with cleft palate	White British
Rebecca and Russell	Mother / Father	23 / 30	Daughter with cleft palate	White British
Michelle	Mother	33	Son with cleft lip and palate	White British
Paul	Father	33	Son with cleft lip and palate	White British
Milly and	Mother	20 / 23	Son with	White

Communication and diagnosis of cleft lip and palate

Michael*	/Father (cleft lip)		cleft lip and palate	British
Mally*	Father	62	Son born with cleft lip	White British
	Mother / Father	37 / 36	Son born with cleft lip and palate	White British
Alison and Chris	Mother / Father	39 /44	Son born with cleft lip and palate	White British
Iva	Mother	29	Son born with cleft lip	Bulgarian
Kerrey	Mother	27	Son born with bilateral cleft lip	White British
Safiya	Mother	21	Son born with Cleft lip and palate	Mixed White and Asian
Maria Z	Mother	32	Daughter born with cleft palate	White British
Suzi	Mother / Daughter	51	Daughter born with cleft	White British

Communication and diagnosis of cleft lip and palate

			palate	
Andy	Mother / Father	31 / 36	Son born with cleft lip and palate	White British
Della	Mother	24	Son and daughter born with Cleft palate and PRS /Sticklers Syndrome	White British
Mary Y	Mother	46	Son born with cleft lip and palate	White, Australian
Maria	Mother	41	Daughter born cleft palate / late diagnosis Stickler syndrome	White- Chinese
Jenny	Mother	36	Daughter born with cleft palate	White British
Laura	Mother	22	Daughter born with cleft palate	White British
Mary W*	Mother	53	Daughter born with cleft lip and palate	White British