

ORIGINAL ARTICLE

Parents' Perspectives of Cleft Lip and/or Palate Services: A Qualitative Interview

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The study aimed to explore in depth the perspectives of parents about their child's cleft services. Purposive and theoretical sampling produced a diverse sample of mothers and fathers with children aged 20 weeks to 21 years. Parents were recruited from a specialist cleft center in the U.K. Qualitative, in-depth, face-to-face interviews were carried out with 35 parents. Interviews were audio-recorded, transcribed, and analyzed using grounded theory to identify salient data categories. Findings revealed that parents' positive views about services rested on their perceptions of cleft-care practitioners as competent and trustworthy, possessing highly developed communication skills and the ability to provide continuity of care to families. At the same time, some mothers and fathers identified unmet support needs relating to information delivery and content as well as the coordination of services across the treatment course. More individualized information about treatment was desired; in particular, some parents had incomplete information about their child's surgical procedures, associated risks, and postsurgical recovery. Parents wanted better coordination of services with regard to communication about surgical cancellations, a child's transition to adult services, and having a key professional to link with throughout their child's treatment course. Routine assessments to gauge parents' needs could be built into cleft-care pathways so that more individualized information and support might be delivered to families in more consistent ways over long-term treatment.

KEY WORDS: *adolescents, children, cleft services, grounded theory, information, parents' perspectives, qualitative methods*

Parents of a child with a cleft of the lip and/or palate (hereafter, *cleft* will refer collectively to clefts of the lip, the palate, or both unless otherwise indicated) often face caring for them through a long-term multidisciplinary treatment program that commences at birth and continues into young adulthood. Previous research suggests that although parents hold generally positive views of services, they may also have unmet needs (Nelson et al., 2012a). However, this body of research has focused principally on the views of mothers of young children. In addition, previous findings on service support have largely been based on quantitative

studies, with a lack of qualitative research that examines parents' perspectives in depth (Nelson, 2009).

Parents' Positive Views of Services

Across several countries, surveys have previously reported positive views among parents about the organization and delivery of cleft services (Turner et al., 1997; Jeffery and Boorman, 2001; Williams et al., 2001; Semb et al., 2005; Cleft Lip and Palate Association, 2007; Kramer et al., 2007; Noor and Musa, 2007; Knapke et al., 2010). Survey research has also demonstrated that in general, parents rate positively the treatment outcomes for children's appearance, function, and well-being (Strauss et al., 1988; Broder et al., 1992; Noor, 1992; Thomas et al., 1997; Turner et al., 1997; Williams et al., 2001; Semb et al., 2005; Noor and Musa, 2007; Berger and Dalton, 2009).

Findings from these studies indicate that the characteristics of clinicians who are caring for children may be of particular importance to parents. Such characteristics include their specialism (Turner and Milward, 1988; Cleft Lip and Palate Association, 1996, 2007; Oliver and Jones, 1997; Johansson and Ringsberg, 2004; Semb et

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al., 2005; Stone et al., 2010), their communication skills (Jeffery and Boorman, 2001; Semb et al., 2005), and their sensitivity when interacting with families (Strauss et al., 1995; Byrnes et al., 2003; Cartwright and Magee, 2006; Nusbaum et al., 2008). Additionally, it has been suggested that continuity of cleft care may be highly valued by parents (Cleft Lip and Palate Association, 1996; Canady et al., 1997) because the ongoing, extended nature of relationships with practitioners instills trust in services and professionals (Johansson and Ringsberg, 2004; Semb et al., 2005; Cleft Lip and Palate Association, 2007).

Parents' Dissatisfaction With Services

Despite the generally positive views of cleft services reported by parents in the literature, some studies have also identified several sources of dissatisfaction. This research has been carried out in the U.K. prior to or in the early stages of a national reconfiguration of services at the end of the 1990s (Clinical Standards Advisory Group, 1998; Department of Health, 1998). These sources of dissatisfaction include concerns about restricted access to services and delayed referrals; poor coordination of appointments; and inadequate communication between practitioners and a lack of single point of contact for families (Martin, 1995; Cleft Lip and Palate Association, 1996, 2007; Oliver and Jones, 1997; Turner et al., 1997; Owens, 2008).

Parents' Information Needs

Studies about parents' information needs have investigated their views about both the content and provision of information, though most of this research has focused on diagnosis, birth, and early months, with little research examining information needs in childhood and adolescence.

In terms of the content of information, these studies suggest that parents need information about several issues—the implications for their child of having a cleft, what their child's future treatment program might involve, how to feed their child, and how to explain the cleft to others (Davalbhakta and Hall, 2000; Farrimond and Morris, 2004; Martin, 2005; Cartwright and Magee, 2006; Nusbaum et al., 2008). Although research focusing specifically on children's cleft surgery has been rare, indications from studies about broader issues such as quality of life and experiences of cleft lip and palate suggest that parents may find their child's cleft surgeries challenging (Eiserman, 2001; Johansson and Ringsberg, 2004; Klein et al., 2006; Stone et al., 2010; Nelson et al., 2012b; Nelson et al., 2012c).

In terms of preferences for information provision, research suggests parents value information that is accessible, individualized, and paced around each

family's needs (Turner and Milward, 1988; Martin, 1995; Cleft Lip and Palate Association, 1996, 2007; Oliver and Jones, 1997; Young et al., 2001; Farrimond and Morris, 2004; Johansson and Ringsberg, 2004; Martin, 2005; Cartwright and Magee, 2006; Nusbaum et al., 2008; Owens, 2008; Knapke et al., 2010). In addition, some studies have highlighted the importance of information provision by experienced professionals (Strauss et al., 1995; Oliver and Jones, 1997; Young et al., 2001; Byrnes et al., 2003; Johansson and Ringsberg, 2004; Cleft Lip and Palate Association, 2007). Studies have discovered that parents may prefer to receive information orally, with written information or recordings of meetings as a supplement (Semb et al., 2005; Cartwright and Magee, 2006; Knapke et al., 2010).

In conclusion, previous research investigating parents' views about their experiences of cleft services has identified both areas of satisfaction and dissatisfaction. However, it has focused largely on the views of mothers during the very early stages of their children's lives. Consequently, the experiences of both mothers and fathers during childhood and adolescence have been underresearched. Moreover, there has been a lack of qualitative research to examine in depth parents' views about the delivery and organization of cleft services, to gain fine-grained insights about what particular characteristics may be of value and what elements they may find challenging. The study reported in this article aimed to fill this gap by conducting an in-depth exploration of parents' perspectives and by including both mothers and fathers of children from birth to young adulthood.

METHODS

The study aimed to explore in depth parents' perspectives about the organization and delivery of their child's cleft services. Consequently, a qualitative approach was chosen to gather and make sense of participants' views, personal perspectives, and beliefs (Creswell, 2007). The tools and principles of grounded theory guided the study, following the recommendations of Charmaz (2006), which acknowledges the coconstruction of data and analysis by both participant and researcher.

Study Setting

The setting for the study was a tertiary specialist cleft center in the U.K., where access to health services, including for cleft lip and palate, is publicly funded (Shaw et al., 2001). At the time of the research, the center was undergoing some reconfiguration as part of national recommendations for cleft care provision (Clinical Standards Advisory Group, 1998) but was relatively long-established. Care was being provided by a multidisciplinary team of specialist clinicians serving a wide geographical area, with approximately 90 new

babies with clefts being registered per year. Children being cared for in the center were being assessed at regular intervals to monitor hearing, speech, dental status, and facial growth. Such assessments were usually carried out soon after birth, before and after an infant's primary surgeries, and at 18 months, 3, 5, 10, and 15 years of age.

Sampling Strategy

Participants in the study were sampled purposively, in preference to convenience, "snowball" (word-of-mouth), or random sampling. Purposive sampling was advantageous because it enabled inclusion of participants with specific characteristics and allowed maximum diversity in the sample to incorporate a range of views (Murphy et al., 1998). Hence, parents were purposively sampled on several criteria: age, gender, cleft type, and accompanying health-related condition of their child, as well as their own socioeconomic and ethnic background. A main aim was to sample parents with children of varying ages corresponding to points when clinically significant cleft-care interventions would be taking place. At the study outset, these were identified as 12 months or less and approximately 6, 9, and 15 years. Table 1 presents the main interventions that might be taking place in the center around these age points. Parents who could not speak English were excluded, as were parents whom clinicians advised should not participate due to particularly challenging family circumstances such as bereavement or issues of child protection or mental health problems.

As the study progressed the sample was adjusted in line with theoretical sampling (Charmaz, 2006), a second commonly used principle in qualitative studies whereby specific types of participants will be sampled to help address important questions from the emerging analysis, filling gaps in the data and developing important thematic categories. In this study, as the iterative analysis progressed, it became clear that children might be having treatment at ages other than those identified in the original sampling strategy. The strategy was consequently adjusted to incorporate theoretical sampling of parents of children at other ages to explore experiences between and beyond those

originally identified and to more fully develop the analysis.

Recruitment

Parents were recruited via clinicians from the specialist cleft center. If parents expressed an interest in participating, the researcher arranged a convenient time and place for an interview. Parents were given the opportunity to be interviewed together or separately.

Data Collection and Analysis

Face-to-face, in-depth interviews were conducted with parents in their homes by one researcher (the first author) who was not a clinician or part of the cleft team. A topic guide was used as a framework for semi-structured, conversational-style interviews with parents. The guide was initially developed from the cleft literature and feedback from members of an independent advisory group (comprising cleft care clinicians, parents of a child with a cleft, and a specialist in qualitative research methods) and evolved in response to the emerging data analysis to incorporate additional issues. Questions focused on parents' experiences of their child's diagnosis and cleft treatment, while also encouraging discussion of topics important to them. Interviews were audio recorded, transcribed verbatim, and the data managed using an NVivo 7 database (Richards, 1999).

In accordance with the guidance of Charmaz (2006), the core principles and procedures of grounded theory originally established by Glaser and Strauss (Glaser and Strauss, 1967; Glaser, 1978; Strauss and Corbin, 1998) were used as a guide to inform the study's data generation and analysis. These principles and procedures were:

- purposive and theoretical sampling;
- simultaneous data collection and analysis;
- coding of data and memo writing to identify salient data categories;
- constant comparison of data to look for similarities and differences until data categories were well developed and saturated.

TABLE 1 Clinically Significant Ages in the Management of Clefts

<i>Approximate Ages</i>	<i>Clinical Speciality</i>	<i>Procedure</i>
Up to 12 mo Up to 6 y	Primary surgery Secondary surgery	Lip closure; closure of hard and soft palate; placement of ventilation tubes Revision of lip and/or nose; re-repair/lengthening of palate/repair of palatal fistulae; velopharyngeal surgery
Approximately 9 y	Orthodontics Bone graft	Preoperative and postoperative preparation for bone graft Closure of the cleft in alveolar bone
From 15 y	Preparation for orthognathic surgery Preparation for surgical revisions	Realignment of jaws Lip/nose revisions

Analysis was based on the grounded theory principle of starting with data rather than a preset hypothesis and moving inductively through stages of coding where segments of interview transcripts were labeled with identifying descriptors. Throughout the coding process, participants' accounts were questioned to identify patterns related to the circumstances, actions, interactions, and consequences they described (Charmaz, 2006).

In the first stage of coding, labels were applied to transcripts line by line to fracture them into smaller data segments. These initial codes were compared and contrasted with those of other interview transcripts that were being generated concurrently to look for similarities and differences between interview accounts. The second stage of analysis was focused coding, in which initial codes were grouped into more overarching categories of data reflecting salient themes emerging from participants' accounts. As part of data analysis, analytical memos were written simultaneously to note ideas about the comparison and contrast of emerging codes and categories and identify gaps in the data that could be explored in further interviews. These memos helped the researchers to maintain a questioning stance in relation to the developing analysis and to fully identify the characteristics and dimensions of main data categories. The final stage of analysis was theoretical coding, in which the focus was on interpreting relationships between categories of data to map links between them and to produce an overall explanation of the interview accounts.

Rigor

Rigor in the conduct of this study refers to actions taken by the researchers to elicit rich participant accounts, demonstrate flexibility with regard to the social context of the research and transparency in methods of data collection/analysis, and maintain a critical, open stance in questioning the data to go beyond the taken-for-granted (Popay et al., 1998). First, the tools and principles of grounded theory described in the previous sections were used to ensure variation in the sample through appropriate sampling, depth of data through constant comparison (including the search for disconfirming cases), and a thorough, ongoing questioning of the data.

Because this study also acknowledges data collection and analysis to be coconstructed by both researchers and participants (Charmaz, 2006), to enhance rigor a reflexive stance was taken to think critically about how the researchers' backgrounds (a mixture of clinical and nonclinical expertise with some knowledge of policy, methods, and clinical research in the cleft field) might have shaped the study by bringing views, ideas, knowledge, and assumptions to the process and product

of the research (Mason, 2002). Additionally, throughout data collection and analysis, the second author independently coded interview transcripts, reviewing the coding scheme, categories, and memos to confirm or refute the emerging interpretation of the data. The researchers met regularly to discuss the analysis, seeking rival explanations in the data and in particular looking at negative cases (accounts that did not fit the emerging pattern of analysis) to discuss how they added to the interpretation. In this way, analysis was subject to a process of collective questioning from different perspectives to enhance its credibility.

Generalizability of Study Findings

In accordance with the qualitative research approach, the study was not seeking to produce findings that were generalizable to the wider population in a statistical sense, but rather to provide understanding and insights about participants' experiences that might be transferable to those of parents in other, similar settings (Flick, 2006).

Ethical Issues

The key principles of informed consent and voluntary participation governed the conduct of the study. Ethical permission was obtained from a local research ethics committee in accordance with the U.K.'s National Health Service Research Governance Framework (Department of Health, 2005). Information that could identify people or places was removed from the interview transcripts at the earliest opportunity. Transcripts were held on a password-protected database.

Characteristics of the Sample

Of 33 families approached, 27 families (comprising one or both parents) agreed to take part. Of the 27 participating families, eight couples elected to be interviewed together, with three fathers and 16 mothers choosing to be interviewed separately. Consequently, 35 parents in total were interviewed. Characteristics of participating parents appear in Table 2, and those of their children in Table 3. There were 15 girls and 12 boys; nine were aged under 1 year, nine between 5 and 11 years, and nine between 12 and 21 years. The children had a variety of clefts: four with clefts affecting the lip and/or alveolus, eight the palate only, 10 with unilateral clefts of the lip and palate, and five with bilateral clefts of the lip and palate. Eight children had additional health-related conditions as well as their clefts, including other craniofacial conditions, or genital, renal, gastric, and eye conditions. To protect the identity of individual parents and children, data were anonymized and demographic information in the tables is summarized.

TABLE 2 Characteristics of Participating Parents

Characteristic	Mothers (Aged 21–54 y)	Fathers (Aged 31–55 y)	Totals
No. of participants	24	11	35
Ethnicity			
White	22	9	31
Pakistani	1	1	2
Asian other	1	1	2
Highest educational level			
Secondary school	13	2	15
Further education	5	3	8
Higher education	6	6	12

In total, 16 families were sampled according to the original purposive sampling strategy and an additional 11 using theoretical sampling.

RESULTS

Findings revealed the positive views that parents held about cleft services, which rested on their perceptions of cleft-care practitioners as competent and trustworthy, with good interpersonal skills when dealing with families and the ability to provide continuity of care.

Findings also suggested, however, that both mothers and fathers had a number of unmet, common needs from services relating to some aspects of information and support. Parents' needs were similar across each of their child's interventions, at different stages of treatment.

Elements of Value to Parents

Parents' perspectives brought to light in detail several valued elements that contributed to a largely positive view of cleft services. These elements related to the characteristics of professionals providing cleft care and helped engender trust in cleft services.

Professionals' Knowledge and Technical Competence

Both mothers and fathers judged cleft-care practitioners as competent and trustworthy due to their perceived technical skills, which included specialist knowledge and expertise, as well as surgical proficiency. Clinicians were seen to be knowledgeable about the

nature of clefts, how a cleft might affect a child's function and appearance, and most important, what could be done to help a child. For example, perceiving practitioners as knowledgeable helped John's father to diminish his sense of worry about an imminent surgical procedure in infancy:

Sometimes you meet people in walks of life and say I'm not confident that you know what you're doing—but we never, ever felt that from anybody—either in their knowledge or ability. Father of John, aged 13 months

Confidence in cleft-team clinicians was also instilled by their perceived expertise, acquired through immersion in the field and often seen as a quality that nonspecialist practitioners lacked:

On the hospital side [neonatal care unit] they wouldn't give much information because they didn't know themselves, but the cleft team sees a lot of cleft problems, and so it's not something unusual there. They get involved in clefts and there are so many children. Father of Rana, aged 12 months

They're specialized in the situation, they're specialized in clefts, and they deal with it all the time, so they know how to deal with it and treat it. Mother of Shelley, aged 11 years

The perception that cleft specialists had built up a "bank" of expertise from treating many similar children and that the procedures performed were not unusual but routine helped parents to feel secure that their child's care was in the hands of experienced and competent individuals and helped to establish trust in them. Though the skills of orthodontists and speech and language therapists were acknowledged, in particular parents highlighted the skills of specialist nurses (SNs) and cleft surgeons. In a child's infancy SNs were particularly valued for their expertise in feeding babies with clefts using special techniques and equipment—expertise that they passed on to mothers:

*It was the feeding...she **did** help...she actually came in and spent time with us, held him, showed us how to feed him, how to listen for his noises, do you know what I mean? She actually **sat** with me and **watched** me and she did help a lot...it took time...it didn't click with me. Mother of Tom, aged 13 months*

Both mothers and fathers used strongly expressive terms to describe SNs. Parents described them as an "absolute godsend," a "star," and a "lifesaver." However, surgical skill was a technical ability that appeared to be of foremost value to parents. Expressions of awe were common in relation to a surgeon's abilities, particularly with regard to early surgeries:

*What [the surgeon] did was **amazing** with his lip—to look at him [son] now I can't believe it—so it gives me confidence in him [surgeon]. I couldn't believe it, I was amazed. Mother of James, aged 7 months*

TABLE 3 Characteristics of the Children of Participating Parents

Type of Cleft	Girls (Aged 20 w–20 y)	Boys (Aged 5 mo–21 y)	Total
CL±A*	3	1	4
CP	6	2	8
UCLP	4	6	10
BCLP	2	3	5
Total	15	12	27

* CL±A = cleft lip with or without alveolus; CP = cleft palate; UCLP = unilateral cleft lip and palate; BCLP = bilateral cleft lip and palate.

Parents frequently used superlatives such as “brilliant,” “fantastic,” “amazing,” and “wonderful” to describe the surgeon’s skill. It was important for parents to see professionals, particularly surgeons, as competent to care for their child because this contributed to the development of trust in practitioners in a context involving risks to their child.

Professionals’ Interpersonal Skills

Cleft-care clinicians were seen as possessing not only technical abilities but good interpersonal skills, comprising an ability to communicate with parents and to convey a sense of care and concern for children and their families. For parents, such skills also contributed to perceptions of professionals as competent and trustworthy. Where clinicians communicated information clearly to parents, this was particularly valued. Several parents, such as Sean’s father, had been particularly reassured by the timely sharing of specialized information by practitioners at the time of their child’s diagnosis:

*Really they were **very** good, the information that was imparted was very quick and very detailed, and **very** good, and it sort of put you at ease.* Father of Sean, aged 21 years

Others, such as Neela’s mother, commented positively on the listening skills of clinicians on the team:

They’re always willing to listen...and they’re just there when you need them...so that gave me the confidence as a mum with Neela and dealing with things on a daily basis. Mother of Neela, aged 9 years

Furthermore, parents perceived that through their warm interpersonal manner, practitioners were able to convey a much-appreciated sense of caring about them as well as their children:

*Well, you feel very much that you’re kind of a **family** in the system rather than a **number** in the system...we’d always felt very much like a family with a daughter who had a specific issue.* Mother of Sara, aged 20 weeks

Just by greeting you and just making you feel as though you’re not the only person in the world that this has happened to—just being informal—he [surgeon] just makes you feel at ease—just being friendly. Mother of Scott, aged 5 years

In particular, mothers and fathers were watchful about whether practitioners showed caring attitudes toward their children, highly valuing instances when clinicians invested time and effort in building trust with children who might be reluctant or frightened:

*What she [dentist] did was, she built up a **relationship** with him [son] and slowly but surely she coaxed him into building confidence in her. I thought that was very, very good, **very** professional, and she just handled it so well, because he was very nervous. Dentists are never the best friends, are they? [laughs] *We don’t like dentists!* Father of Lee, aged 14 years*

In addition, however, some mothers particularly appreciated when SNs showed concern not only about the child but about the mothers’ own emotional well-being. For example, an SN who had picked up on the low mood of Michelle’s mother was perceived as close to the family and trusted, because, in her words, “outsiders wouldn’t have ever known I was low.” Both technical and interpersonal skills were, consequently, important elements for parents in judging practitioners as competent and trustworthy.

Continuity of Care

A final valued element for parents was the constancy of the relationships they had established with members of the cleft team over time as their child moved through different stages of treatment and that enhanced a sense of trust in practitioners:

*I’ve known them for years now and built a trust up with them and they know how **I** am, they know how **Luke** is, and it’s like they’re part of the family anyway because they’ve seen Luke growing up, they’ve known him since he was a baby.* Mother of Luke, aged 16 years

The maintenance of such established relationships with particular practitioners over a child’s long-term treatment course was significant for parents, and it was not unusual for team clinicians to be referred to as friends or part of a child’s family. There was a sense of familiarity with practitioners who had provided care for children as they grew up.

In addition to perceptions of practitioners as competent based both on their technical and interpersonal skills, the continuity of care they provided as children became older was also reassuring for mothers and fathers. All three elements contributed to a view of cleft-care professionals and the services they provided as worthy of parents’ trust.

Parents’ Unmet Service Needs

Although parents commonly praised the technical and interpersonal skills of cleft-care practitioners, highly valuing the continuity of care provided, they also identified areas where support from professionals might be improved. Parents suggested that improvements could be made to the ways in which practitioners sometimes delivered information, the detail of information provided, particularly about surgery, and the way in which services were coordinated. Such needs could apply across the treatment course, not being confined to one particular period or treatment intervention.

Ways of Delivering Information

Although parents valued clinicians’ depth of knowledge and clear communication of such knowledge, they

nonetheless identified ways in which information provision could be more consistently good. Parents admitted, for example, that assimilating information over their child's treatment course could be challenging at times and suggested that the pace and content of the information-giving process might be adjusted for families according to their needs. Looking back on her teenage daughter's treatment course, Kelly's mother identified that professionals might explore the information needs of particular parents and children in more depth at each stage of treatment and match their information-giving accordingly:

Every person is different, every child is different. . . you have to get to know the person and try and gauge how much they need to know and that is difficult. It's getting the balance right. . . it is about listening and trying to gauge from parents and from their children how much is right. Mother of Kelly, aged 17 years

Furthermore, although parents valued the standardized leaflets/general information that might be made available to them about cleft care, several suggested that a written plan of care, more individualized to their particular child over time, could better prepare them for what interventions lay ahead and when they might take place. This would help them keep track of their child's past and possible future treatments:

It would be nice to have something we could easily refer to. . . a little booklet you could keep, something that is a guide to the treatment for your child, in other words a strategy—this is how we're going. . . but there's nothing that you can walk away with and keep so that you've got an idea of timescales as to what's likely to happen. . . you don't get anything like that. Father of Lee, aged 14 years

Although parents stressed their appreciation of the wealth of information that could be provided by specialist practitioners, it was suggested that enhancing the ways in which information was delivered by pacing or developing individualized, parent and child-appropriate information to supplement standardized leaflets could improve their experiences of cleft care.

Information About Children's Surgery

One area in which parents suggested there may be gaps in their knowledge and understanding was about the process of their child's surgeries, from the presurgical to the postsurgical phases. For example, more in-depth explanations of what would happen during their child's procedures were needed by some parents, who described accessing the Internet to fill gaps in their knowledge and look at pictures to aid understanding. Whereas John's mother conceded that not all parents would desire such information, she was particularly keen to know the details of her baby's palate operation:

I suddenly thought before he had his surgery I'd really like to see what they do when they do a cleft repair, and my

sister said to me, "No you don't want to see, you won't want to see" and I said, "No I really would." I presume not all parents would, but a video or something—I would've liked to have seen how they were going to do it, how it was actually going to be put back together again. Mother of John, aged 13 months

Additionally, some parents' understanding of the possible risks involved in each of their child's procedures appeared incomplete, in particular with regard to the likelihood of needing repeat surgery. Some parents of older children with greater treatment experience suggested that, in hindsight, more information on risks, as part of preoperative discussions, would have been beneficial. Shelley's mother described her uncertainty and worry about her daughter's multiple hearing operations:

*You hear different stories where people have said no more than three lots of grommets—and she's had **four**. Whether it was the right thing to do or not, I don't know, and whether that's why she's got what she's got with her ear [perforated eardrum], I don't know. . . I didn't really understand the terminology [the ear, nose, and throat consultant] said and she needs it repaired straight away, or else she'll end up deaf in that ear. Mother of Shelley, aged 11 years*

As well as a better understanding of risk, several parents needed more preparation about what to expect in the postoperative period so that they could better support their child and themselves at an emotionally demanding time. Several were unclear about the immediate consequences of surgery, for example, knowing the difference between signs that were a normal part of the recovery process and signs about which they should be concerned. Lee's mother had been alarmed by swelling to his face following a bone graft:

*His face swelled up, and oh it was lopsided for a bit and you think, "Is it all right?" It was **fine**, but we weren't made aware of that. If they just said, "This could happen," but surgeons don't, they just tell you that it's being done, "Have this after-care, it's fine, everything went well, it's been a good operation." [The surgeon] was lovely, but if somebody would have just said, "Oh it might be this thing," you wouldn't be worried. Mother of Lee, aged 14 years*

A second postsurgical concern for parents was about optimal feeding to support the recovery process. Several parents identified that they would have welcomed more detailed advice, whatever the age of their child, on how to give their child nutritious food without causing discomfort or disturbing the operation site. For example, following orthognathic surgery, Sean's father felt unprepared for an extended period in which his son's chewing was heavily restricted. Sean, his father, and his mother were each reportedly distressed by the situation and, in the absence of advice, had managed to find a solution by themselves, though not without cost:

To be fair [my wife] got him through that bit, because I was a bit emotional. . . I was going to go back there [ward] and

thump somebody at one stage, because—the state they'd left him in. . .with a great deal of help from [my wife] he managed to get through the first week. Luckily, luckily, we found him that alternative [liquid meal supplement].
Father of Sean, aged 21 years

These data extracts suggest that one area where some mothers and fathers might have gaps in knowledge and understanding is in relation to their child's surgical procedures. Whether parents had past treatment experience with their child or not, it seemed they might have an incomplete understanding of each individual surgical procedure, its associated risks, and possible postoperative consequences.

Service Coordination

A last area of improvement that parents highlighted was in terms of service coordination, with regard to management of surgical cancellations, the transition from children's to adults' surgical services and having a single point of contact for support throughout a child's treatment course.

Parents recognized that surgical cancellations were inevitable at times; however, the way in which cancellations were communicated could be distressing because the practical and emotional preparation involved in the lead-up to a child undergoing surgery was challenging. Parents therefore wanted to be informed directly by an individual known to them, in a sensitive way, and with an adequate explanation and notice. James' early surgery had been cancelled following a booking oversight, and his parents had not been fully informed about the reasons:

We had both booked time off work, so for it to happen in the way that it did—that really upset us. It makes a very difficult situation a million times more difficult. You get quite emotional, because you build yourself up to it. . .so if they are going to change things they should explain, "We've changed this date because. . ." and just give us the full explanation. . .because that's not good enough when you've got a 3-month-old baby who's due to go in for an operation. Mother of James, aged 7 months

When children reached the teenage years and were undergoing orthognathic surgery, there was a reported need for improvement in the organization and coordination of a young person's transition to adult surgical services where these operations would take place. For families already familiar with the environment and procedures of the children's hospital but lacking in knowledge about the adult setting, coordination between these services was needed to help them better prepare for any differences they might encounter:

Both Sean and I, we weren't prepared for it being a male surgical ward. I know he's 18 and obviously a man, but. . .the last time he had an operation he was a young lad. . .and he'd gone to the children's hospital and everybody would want to make sure he was all right. And

he goes here [adult ward] and nobody really cared. . .it was like—nobody gives a toss about this, you know? Father of Sean, aged 21 years

Last, several parents identified the need for a single point of contact along a child's cleft treatment course, which often stretched into young adulthood, involving a number of multidisciplinary clinicians and other professionals. For parents, the lack of a single contact for help to navigate the system of care or merely to ask advice as their child grew older contrasted starkly with the intensive period of support provided to families by SNs in a child's toddlerhood:

The lack of one key person all the way through as a support [is a downside of the service]. I don't know whether that's feasible or anything, but it was at the beginning, the first 18 months or so and that was really good, but since we've just gone from whichever specialty she needed. . .I think it would have been nice to have a point of contact just to ring maybe.
Mother of Kelly, aged 17 years

Having a designated person with whom to connect throughout their child's long-term treatment for keeping track with appointments or to discuss any concerns would have been reassuring for parents and was an issue in the accounts of both mothers and fathers across children's ages.

In summary, parents held cleft-care clinicians in high esteem for their perceived qualities of technical competence, interpersonal skill, and continuity of care. Such perceived qualities engendered parents' trust in the professionals providing their child's cleft care. However, at the same time parents identified a number of areas where they felt support from services could be more consistently provided across their child's treatment course. These improvements related to aspects of information delivery, the detail of surgical information, and some elements of service coordination. Such issues were common themes in the data from both mothers and fathers, across children's ages and stages of treatment, suggesting that parents' needs for information, preparation, and support should be gauged at each phase of their child's cleft treatment, regardless of how much prior treatment experience they may have had.

DISCUSSION

This study explored how parents in a British specialist cleft center experienced services for their children's cleft care. In line with the background literature presented, it supports findings identifying that parents often view cleft services positively; yet, at the same time recognizing areas that could be improved. Far from being contradictory, it suggests that these two positions are not mutually exclusive and are perhaps unsurprising, given the long-term nature of the treatment course, involving many different procedures, clinicians, and specialties.

However, this study also adds to knowledge by defining more clearly the elements, which may be of value to such parents, that center on the perceived skills of cleft care professionals and the relationships they establish with families. The importance to parents of practitioner knowledge/technical competence, interpersonal skills, and continuity of care are mirrored in the literature on other long-term conditions affecting children, where they are recognized as significant contributors to the establishment and maintenance of practitioner-parent trust (Mitchell and Sloper, 2001; Law et al., 2003; Kirk and Glendinning, 2004; Graungaard and Skov, 2006; Young et al., 2006; Lalor et al., 2007; Ward, 2009). Additionally, it is recognized in the wider health care literature that these two elements are key components in the development of *trust* (Mechanic, 2000; Calnan and Rowe, 2005), defined as the belief that a person or system is acting in one's best interests (Fugelli, 2001). Furthermore, effective communication skills, conceptualized as rapport building, partnership building, question asking, attending to socioemotional aspects, and information giving (Roter, 2000), have been shown to impact positively on health outcomes, including patient satisfaction (Stewart, 1995). Such skills are also core to the "patient-centered" (and indeed, the "family-centered") process of care (Mitchell and Sloper, 2001; Stewart et al., 2003).

Although elements of family-centered care were evident in the accounts, this study also contributes more detailed knowledge about the unmet needs that some parents may have in relation to information delivery, detailed surgical information, and service coordination in this context. It adds new specific findings on the value to parents of having (1) a tangible care plan, individualized to their particular child and documenting their long-term cleft treatment; (2) more detailed understandings of the process of surgery; and (3) better coordination of services in terms of the transition from children's to adults' services and a key person to link with over time. The wider literature on children's long-term conditions has long reflected the benefits of making available to parents, where desired, child-specific, tailored general information (Pain, 1999; Mitchell and Sloper, 2002), detailed surgical information (Ben-Amitay et al., 2006; MacLaren and Kain, 2008; Nagata et al., 2008), care coordination for transition (Kirk, 2008; Tuchman et al., 2008; Department of Health, 2009), and a "key worker" to coordinate a child's care through stages of treatment (Greco and Sloper, 2004; Beecham et al., 2007).

This work has implications for future research and practice. Given that the views and experiences of children and young people about their own treatment are likely to be distinct from those of their parents, in-depth research is needed to elicit their perspectives. In terms of policy and clinical practice, the study has highlighted that some fathers and mothers have similar

needs for preparation and support in each phase of their child's treatment. In line with U.K. policy on family-centered care (Department of Health and Department of Education and Skills, 2004) routine assessments to gauge parents' information and support needs could be built into regular screening along the treatment course. Such needs could then be met on an individual or family basis, including individualized information on a child's long-term care plan, oral and written advice about preoperative and postoperative care, as well as more coordinated services across the treatment course.

Limitations and Strengths

Parents were recruited from one specialist center in the U.K., and consequently their views may not reflect those of parents using other cleft services that are different in nature and organization. Parents were recruited by clinicians and not directly by the researchers, which may have introduced an element of selection bias, either conscious or unconscious. Due to time constraints it was not possible to follow the same families longitudinally over their child's treatment course, which would have strengthened the study design. Another possible limitation is that a mixture of joint and separate interviews with parents was used and may have generated different data. However, the study was not primarily a comparison of mothers' and fathers' perspectives, and parents' wishes for joint or separate interviews were respected at recruitment stage. Moreover, it is acknowledged that joint interviewing of couples may generate more comprehensive data (Arkesey, 1996). The strengths of the study are that the use of qualitative research has enabled a deeper understanding of the elements of value to parents using services for their child's cleft care, and though recruited from one center, the study sample was diverse, drawing on both purposive and theoretical sampling techniques to incorporate maximum variation and thereby elicit the views of a wide range of parents.

CONCLUSIONS

The study illuminates how both mothers and fathers perceive cleft services for their child across infancy, childhood, and adolescence. The use of a qualitative approach extends the available knowledge on parents' views of cleft services in several ways. First it identifies that the elements of support that parents value relate specifically to their perceptions of the skills of cleft-care professionals and the parent-professional relationships established. Second, it contributes detailed knowledge about the unmet needs some parents may have around information provision and service coordination. Such needs appear to be common across children's ages and stages of treatment and may be required each time their child is facing an

intervention, regardless of a family's prior treatment experience. These issues must be taken into account in the future planning and delivery of cleft services in order to improve the support that parents receive throughout their child's long-term treatment course.

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