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Abstract

Little is known about the experiences of parents caring for a child through long-term treatment for cleft lip and/or cleft palate. We conducted in-depth interviews with 35 parents with children between the ages of 20 weeks and 21 years to explore experiences across the treatment program. We analyzed the data using a constructivist grounded theory approach and present in detail in this article one subcategory from the analysis: managing emotions. Throughout childhood and adolescence, parents experienced conflicting emotions about their child's impairment, uncertainty about cleft treatment, and stigmatizing attitudes. Although parents attempted to manage emotional tensions by pursuing cleft treatments, the interventions could themselves be a source of conflict for them. We suggest that routine assessment of parents' emotional and social well-being should be included in cleft treatment programs, and access to psychosocial support made available.

Keywords

body image; children, disability; grounded theory; parenting; psychosocial issues

Children with clefts of the lip and/or palate¹ might undergo long-term treatment from birth to young adulthood, including surgery, orthodontics, and speech therapy to treat aspects of the condition relating to both function and appearance. Research to date on parents' emotional experiences of caring for a child with a cleft has focused on early reactions to diagnosis and the measurement of mother–infant attachment and maternal stress levels in early years. Research aiming to assess levels of maternal anxiety, depression, and “adjustment” using validated measures such as the Parenting Stress Index, Beck Depression Index, and Social Support Questionnaire (Campis, DeMaso, & Twente, 1995) suggests that by preschool years stress levels are similar among mothers of children with and without clefts (Nelson, Glenny, Kirk, & Caress, 2011). Much of this research has been informed by perspectives that emphasize notions of sorrow, loss, and stress that might be associated with caring for a child with a cleft, excluding contextual factors and any potentially positive aspects (Baker, Owens, Stern, & Willmot, 2009; Eiserman, 2001).

By contrast, qualitative studies, though much rarer in the cleft field (Nelson, 2009) have indicated that parents' emotions can be more nuanced, involving joy and delight in their child, and have also highlighted the potential

rewards of caring, such as recognizing their family's personal strengths and developing a sense of community (Bradbury & Hewison, 1994; Eiserman, 2001; Farrimond & Morris, 2004; Johansson & Ringsberg, 2004; Klein, Pope, Getahun, & Thompson, 2006). Indeed, one recent British study informed by theories of resilience found high degrees of positive coping and outlook, particularly in parents of children with more extensive clefts (Baker et al., 2009). To our knowledge, no studies have so far focused on parents' experiences of their child's cleft treatment, although there are suggestions in the literature that this might be a source of anxiety for them (Eiserman; Johansson & Ringsberg; Klein et al.; Stone et al., 2010).

The views of parents about social aspects related to their child having a cleft have also been examined, but again this research has focused mainly on mothers' views in the early stages of a child's life. In surveys across

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countries mothers have reported their child's self-confidence to have been affected by having a cleft, and that stigmatizing experiences are prevalent (Noar, 1991; Noor & Musa, 2007; Semb et al., 2005; Strauss et al., 2007; Turner, Thomas, Dowell, Rumsey, & Sandy, 1997). In qualitative studies, mothers have described their heightened sensitivity to others' reactions (Bradbury & Hewison, 1994; Farrimond & Morris, 2004; Johansson & Ringsberg, 2004; Klein et al., 2006), as well as worries about their child's encounters with social stigma outside the home environment (Cartwright & Magee, 2006; Klein et al.). Studies that have aimed to explore in depth the emotional and social experiences of parents beyond their child's early years, however, are few. We consequently aimed in this study to explore in depth the emotional and social experiences of both mothers and fathers caring for children with clefts at different ages between birth and young adulthood.

Methods

Linked to the aim of examining parents' experiences in depth, we chose a qualitative design that could help elicit and make sense of people's complex beliefs and behaviors, producing an interpretive account. Recognizing that knowledge is both socially constructed and situated, and that we come to know by constructing our understanding of reality through interactions with others, we used Charmaz's constructivist grounded theory approach to guide the study (Charmaz, 2006). In accordance with the constructivist approach, we acknowledged that our prior perspectives and existing literature would guide our research (Abrams & Curran, 2011). We also followed the guidance of Charmaz by drawing on the principles and tools of grounded theory flexibly. Although the methods documented in this article enabled us to develop an integrated explanatory framework from the data around a core category (a grounded theory), here we present in depth and detail the properties and dimensions of one fully developed subcategory to illuminate the emotional circumstances of parents in the study, how they responded to emotional challenges, and the subsequent consequences for them (Charmaz, 2006).

Recruitment and Sampling

We recruited parents through clinicians at a specialist cleft center in England. If parents expressed an interest in participating we arranged a convenient time and place for an interview and offered them the opportunity to be interviewed separately or together. We aimed to gather a varied sample of parents who could contribute a diversity of views, and began with an initial purposive sampling strategy (Murphy, Dingwall, Greatbatch, Parker, & Watson, 1998), aiming to recruit parents with children of varying ages corresponding to points when clinically significant

interventions would be taking place. At the study outset, the main ages were identified as 12 months or less and approximately 6, 9, and 15 years. Across these ages, we also aimed to sample parents of children with different cleft types and accompanying health-related conditions, of different genders, and from different socioeconomic/ethnic backgrounds. We excluded parents whom clinicians advised should not be invited to participate because of difficult family circumstances.

As the study progressed, in line with theoretical sampling, we adjusted the sample as a result of the emerging analysis (Charmaz, 2000); for example, incorporating parents of children who were having contact with services between and beyond these ages who might have had more treatment experiences, so that comparisons could be made with existing data. We continued to sample, searching for disconfirming cases, until the characteristics of our theoretical data categories were well developed at an abstract level and no new insights were apparent (Seale, Gobo, Gubrium, & Silverman, 2004). We recognized that at saturation point a particular category might still contain diverging accounts of an event, but accounts would be very similar at an abstract, thematic level (Morse, 2007). In this article we illustrate this by presenting one saturated subcategory from the analysis, fully defining its properties and dimensions.

Data Generation and Analysis

Over an 18-month period we carried out face-to-face, in-depth interviews of approximately 1.5 hours duration with parents in their homes, except in the case of one father who wished to be interviewed at his place of work. The aim was to recruit parent dyads, but when this was not possible, we interviewed one parent instead. Only one couple chose to be interviewed separately, however, to fit in with work commitments. Within parents' own time constraints, we took care not to rush the interviews, fitting in with their needs and creating time and space for discussion of sensitive issues (Stevens, Lord, Proctor, Nagy, & O'Riordan, 2010). We used a topic guide as a framework for semistructured, conversational-style interviews, covering parents' experiences of their child's diagnosis and cleft treatment, while encouraging them to discuss subjects they felt were important. We wrote field notes to record observations and any impressions about salient themes, and made reflexive notes about the assumptions we might have brought to the interview setting. We audio recorded and transcribed the interviews verbatim, and managed the study data using NVivo 7 computer software (Richards, 1999).

We used the principles and procedures of grounded theory to inform data generation and analysis (Charmaz, 2006). These included simultaneously collecting

and analyzing data, inductively developing codes and categories as data labels, applying the constant comparison method to look for similarities and differences, using theoretical sampling, and writing analytical memos throughout to develop ideas about and relationships between categories of data. We began analysis with line-by-line coding using “doing” words to focus on process and action and prevent the analysis from prematurely jumping to a conceptual level (Glaser, 1978). Through a process of comparing data with data, in focused coding, we grouped data into more selective codes and overarching categories, identifying properties and dimensions of each. We also compared categories with categories, questioning participants’ circumstances, responses, and consequences, and keeping a focus on looking for processes in the data (Charmaz, 2006). Theoretical coding was the final stage of analysis, in which we attempted to determine the relationships between categories by looking at the data for parents’ circumstances and situations, their responses to issues, and the outcomes of their actions and interactions (Charmaz, 2006).

Through writing memos we were able to think about what processes the data were revealing. Memo titles related to the titles of codes and categories, and contained ideas that occurred to us, their characteristics, and relationships to each other. We created memos for each focused code, which evolved and grew as analysis progressed. We also kept an overarching memo in the form of pencil notes in an easily transportable notebook where ideas could be jotted down as they arose. The other strategy we used for theoretical integration purposes was diagramming to sketch out potential relationships between categories of data. In tandem, memoing and diagramming enabled us to identify a core data category: “doing the ‘right’ thing.” This represented the central concept explaining much of parents’ accounts of their experiences, and comprised several subcategories related to this core conceptual category. In this article we focus on one of these subcategories—“managing emotions”—presenting its properties and dimensions in depth and detail, and defining the circumstances affecting parents as well as their responses and the ensuing consequences for them.

Rigor

First, we used the tools and principles of grounded theory described above to facilitate rigor in the conduct of the study by ensuring (a) variation in the sample via purposive and theoretical sampling; (b) depth of data through constant comparison (including the search for disconfirming cases), coding, and memo writing; and (c) a thorough, ongoing questioning of data through development of theoretical sensitivity. The critical stance encouraged by this approach helped us remain open to discovering ideas

in the data while also using our existing knowledge to inform analysis and go beyond the taken-for-granted. In addition to the conduct of the study, using grounded theory principles and tools enabled us to extend rigor to the outcomes of our research, allowing us to produce findings that might be judged to fulfill the criteria set by Charmaz for high-quality grounded theory research: originality, credibility, intelligibility, and usefulness (Charmaz, 2006). Second, with regard to rigor, we acknowledged that research data and analysis are coconstructed by participants and researchers, both of whom bring views, ideas, knowledge, and interactions to research, shaping the subsequent process and product (Charmaz, 1990, 2006). We consequently took a reflexive stance by thinking critically throughout the study about our backgrounds and assumptions (a mixture of clinical and nonclinical expertise, with some knowledge of policy, methods, and clinical research in the cleft field) and how these might have shaped the research (Mason, 2002). We met regularly as a team, bringing our different perspectives to the review of transcripts, coding, memos, field notes, and the study sampling strategy, thereby enhancing the study’s rigor through an ongoing and collective questioning of its design and analysis.

Ethical Issues

Our conduct of the study was governed by the key principles of informed consent and voluntary participation. We obtained ethical approval from a local National Health Service ethics committee, as well as a university research ethics committee, both comprising clinicians, academics, managers, and service users. We treated voluntary participation as emergent and subject to change, paying attention to participants’ body language or circumstances during interviews (Charmaz, 2008). We arranged support for any parent who might become distressed as a result of the interviews, and took particular care to remove identifying information in data extracts to protect families’ identities (Stevens et al., 2010).

Results

In this article, by presenting in depth and detail the subcategory “managing emotions,” we focus on fully illuminating the emotional tensions that parents experienced during their child’s long-term cleft treatment, and how they attempted to manage these tensions, using data extracts to illustrate our analysis and interpretation. Specifically, we define three properties—conflicting emotions, uncertainty, and stigmatizing reactions—that characterized parents’ experiences of managing emotions over an extended period of time. In Figure 1 we show the conditions parents experienced in caring for a child with a cleft

Figure 1. Diagrammatic representation of the subcategory "managing emotions"

(circumstances), characterized by prolonged emotional tensions (properties), as well as the reasons for such tensions (dimensions). We also demonstrate in Figure 1 that parents' common reaction to each one of these emotional tensions was to adhere firmly to the treatment protocols offered by cleft services (responses), with the result that interventions for their child, particularly surgery, could themselves be experienced as a constant source of tension (consequences).

These three major emotional tensions characterized parents' experiences across their child's treatment course. Whereas parents' emotions were similar across time from the prenatal period, through birth, infancy, childhood,

adolescence, and young adulthood, the reasons for such emotions were different as a child became older. However, for parents, these tensions were always in some way present in the backdrop of family life. Consequently, in this article we illustrate the properties and dimensions of each emotional tension with data from parents of children across different ages and stages of treatment.

Characteristics of the Sample

Of 33 families approached, 27 agreed to take part in the study. Of the 27 participating families, 8 couples elected to be interviewed together, with a further 3 fathers and 16

Table 1. Characteristics of Participating Parents

Characteristics	Mothers ^a	Fathers ^b	Totals
Number of participants	24	11	35
Ethnicity			
White	22	9	31
Pakistani	1	1	2
Indian	1	1	2
Highest educational level			
Secondary school	13	2	15
Further education ^c	5	3	8
Higher education ^d	6	6	12

^aAged 21 to 54 years^bAged 31 to 55 years^cAn elective course of advanced-level study for students aged 16 years and over (usually 16 to 18)^dAn elective course of degree-level study for students aged 18 years and over (usually 18 to 21)**Table 2.** Characteristics of the Children of Participating Parents

Type of Cleft	Girls ^a	Boys ^b	Total
Cleft lip	3	1	4
Cleft palate only	6	2	8
Unilateral cleft lip and palate	4	6	10
Bilateral cleft lip and palate	2	3	5
Total	15	12	27

^aAged 20 weeks to 20 years^bAged 5 months to 21 years

mothers interviewed separately. We consequently interviewed 35 parents in total. We present characteristics of the participating parents in Table 1, and details of their children in Table 2. Eight children had additional health-related conditions as well as their clefts, including other craniofacial conditions, and genital, renal, gastric, and eye conditions.

Conflicting Emotions

Parents' feelings were complex, and conflicting emotions could be common prenatally, at birth, and throughout childhood and adolescence. At diagnosis either prenatally or at birth, for parents the news of a child's cleft brought a simultaneous mixture of grief about the impairment and delight about having a newborn. Several experienced confusion around simplistic categorizations of "normality," "perfection," and "difference." Parents expressed disappointment about the imperfection associated with their child having a cleft, but also ambivalence about simply labeling a child as "normal" or "abnormal." As a child became older, emotional conflict could also be present

for parents who had come to see beyond the impairment to a vision of their child as the "same" as other children. Exceptions often arose at times, when parents' perceptions were filtered through a different lens, such as catching sight of a child's facial appearance in a mirror, or from the standpoint of strangers. Several conceded with sadness that outside the structure of the parent-child relationship and in the absence of knowing the "whole" person, their child's "different" appearance or function might be judged harshly:

It's difficult. You've got to have "normal" and "abnormal," because that's the way you've got to categorize it but . . . it's very difficult to take in that the child you thought was "perfect" in inverted commas [quotation marks], turns out that they're not perfect as defined by the medical professionals. I understand why she's described as abnormal, but to me she was perfect, she wasn't abnormal. (Mother of an infant [MI])

Obviously you perceive things differently, don't you, as parents? I think to myself that my son's lip's lovely and it's fine, but some people must look at it and think it's quite a big scar. . . . I think I notice that with other children, whereas the parents say, "No scars. Look how it's lovely and clear, and he's got no scars!" I think it's very different. You perceive things and you see things differently when it's your own child. (MI)

Conflicting emotions were also experienced because of a child's cleft treatment, which could last from infancy through to young adulthood. Although eager for their children to undergo all treatment offered by specialist teams, parents' feelings around surgery in particular were mixed. They often reflected on the clash of interests presented by sanctioning multiple surgeries on their child. Pragmatically, surgery offered the possibility to improve a child's function or "normalize" his or her appearance, but a simultaneous emotional urge to protect their child from discomfort or distress was strong—this conflict appearing particularly intense at the time of "surrendering" their child to the surgical team:

At the end of the day we knew at the back of our minds we needed to do something. You always know, don't you, that what is best, what your heart tells you or your head tells you, are two different things? (Father of school-aged child [FSAC])

I actually carried him down to the anesthetics room and held him while he was put to sleep, and that for me is something I'll never forget. I didn't realize what a limp body felt like, and it's not like they're

asleep. To go and hold him and feel him go was a moment I'll certainly never forget. (Father of young adult [FYA])

Parents wrestled to control their own emotions at these times, to bury their feelings and present a strong outward demeanor to relinquish their child to the control of practitioners. Surgery was seen as something of a paradox, a "necessary evil" (Father of adolescent [FA]). Parents were acutely aware, in the interests of obtaining perceived long-term gains in appearance or function, of letting go of a vulnerable child to the possibility of harm or even death. A sense of parents' conflict about sanctioning surgeries on a loved child remained apparent, even in adolescent years: "I just wish they'd [surgeons] leave him alone, but make him perfect" (Mother of adolescent [MA]). Experiences of treatment became more arduous for both children and their parents as children became older. Parents often described the attempts both of themselves and their children to mask distress around surgery from each other:

Young kids can have an operation and they bounce back as if nothing's happened, and of course as you get older the impact of having something done to you becomes a bit more traumatic, and you see that in your child. As he gets older he's more conscious of what's going on around him, and what's going to happen. (FA)

When I went and picked her up [from theatre] she was fine, showing me her mouth inside, going, "Look Mum [Mother], I've got this [points to mouth and laughs]. Look!" And then the tears start. She got really upset, and then Dad started crying as well. Your emotions are everywhere. (Mother of school-aged child [MSAC])

The physical toll that treatments took on children was distressing for parents, including postsurgical discomfort, bleeding, swelling, infection, or nausea. Pursuing repeated surgical treatments sometimes brought for parents a profound sense of guilt. Several suggested that they would experience less distress if they were able to undergo surgery in place of their child. Additionally, parents did not underestimate the emotional toll that treatments might take on a child, not just at the time of surgery, but in the preceding months, and this, too, was a source of anxiety. One mother described feelings of having betrayed her son's trust after a set of surgeries that turned out to be particularly traumatic:

He was very cross with me because he trusted me, and I felt very much as if I'd let him down. He kept

smacking my hand away and he couldn't speak, and had tears in his eyes. It was hugely traumatic. (MA)

A sense of parents' vulnerability as they wrestled with mixed emotions about their child's surgery can be heard in these accounts. The key way parents attempted to resolve feelings of anxiety about cleft treatment, however, was to place their trust in the specialist clinicians providing children's care. The mother of an infant emphasized that parents like her had "got to put . . . faith in the care that's there, and take the advice of the medical professionals." There seemed little choice for parents but to repeatedly surrender themselves and their child to the care of practitioners if they wanted to access the cleft treatment that was available.

The Uncertainty of Long-Term Treatment

A sense of uncertainty was a second emotional tension that could be present for parents over an extended period, in relation to the extent and cause of their child's cleft, as well as the type, amount, and outcomes of their treatment. Parents expressed a sense of being on a lengthy course of treatment, describing it variously as "a journey" (FSAC), "a long haul," and "a quarter of a life" (FA). The pathway progressed for parents as a series of peaks and troughs in which intense bouts of surgery and other treatments would be performed, followed by periods of little or no treatment, waiting for the child to grow and to see results. Several described these troughs as a relief, as welcome "gaps" when they were "left alone" and felt "free" (MA). However, a child's treatment course, "this hospital thing running alongside of you" (MA), remained ever present in the background of family life, and feelings of uncertainty defined parents' experiences of long-term treatment.

This uncertainty commenced prenatally, when the limitations of prenatal scanning techniques prevented an accurate assessment of the extent of a child's cleft, and continued through childhood and adolescence. Parents were frustrated by professionals being unable to provide a definitive cause for their child's cleft, or a clear picture of the type and amount of treatment that children might undergo along her or his potentially long-term treatment:

You just want to be able to say, "It's happened because of XYZ," and that's the hardest part for me. Nobody can tell you why this thing has happened. So what you do is look on the Internet trying to find out why it has happened, and you can't find it. I think that took me quite a while to come to terms with, although people had told us there isn't a reason. (Mother of toddler [MT])

I keep on saying to [speech and language therapist], “Do you think she needs another operation?” and she says, “Let’s just see how we go. She’s doing fine now and has made great progress.” But does she need another operation is all I want to know, and that’s all I seem to ever get: “Let’s see how she goes.” (MSAC)

Parents also had to contend with doubts about the interim and final outcomes of their child’s treatment, comparing it to “a guessing game” (FA), or a “suck-it-and-see [try out something untested and unknown] type of situation” (FSAC). Parents were therefore subject to long-term feelings of uncertainty in relation to the outcomes of their child’s treatment, which were often far in the future and difficult for them to imagine. One father expressed the intangible nature of treatment goals, expressing the desire for more concrete ways of helping families grasp their implications and possible end points:

Well ultimately we’ll end up with a solution, that’s the sort of thing that plants in your mind. A solution where it [child’s cleft] just won’t be seen, it’ll all look right. But in essence it probably won’t be. You’ve got a rough idea, but you don’t have a clear picture. You’re very much left to your own imagination. They will describe to you what they’re going to do, but what you don’t see is anything tangible in terms of what they did for other people so you get an idea. There are no photographs; it’s just words. (FA)

Faced with uncertainties over a child’s long-term treatment, parents often attempted to resolve the emotional tension they experienced by adhering closely to interventions recommended by the specialist clinicians providing cleft care. Sticking to treatment protocols that were “mapped out” (MSAC) engendered feelings of security and a sense of relief that “everything is just put into place for you” (Mother of preschool child [MPSC]), or “the whole of his life was planned out practically from Day One” (FYA).

Stigmatizing Reactions to a Child’s Impairment

A feeling of social exclusion was a third long-term emotional tension with which parents were contending. This could be experienced particularly in a child’s preschool years as exclusion of the family unit, but also of a child him- or herself as he or she became older and faced new experiences. In their child’s infancy, parents frequently encountered negative reactions to their impairment from friends, family, health professionals, and the public, often leading them to feel stigmatized as a family. Soon after

their child’s birth, for example, they had to contend with social responses from friends and family who often appeared unsure how to act. The reactions and interest of some health practitioners could be experienced as an invasion of privacy:

He [husband] didn’t quite know what to say to his friends, and when we said a cleft, they just looked at us as though to say, “Oh, it’s one of those.” I think their reactions shocked him a little, because they didn’t know what to say. (MI)

You just felt like everybody who came in was saying, “Oh, this is the baby with the cleft palate?” as if he was some sort of—and that really niggled me, because I was there 24/7 [24 hours a day, 7 days a week], and by the end of it I was sick and tired of a new shift coming on asking, “Oh, is this the little boy with—?” I thought, “Yes but—leave us alone!” (MT)

Coming on top of the ambivalent feelings that parents were experiencing about their child’s “normality” and “difference,” such reactions only added to their emotional strain. For mothers who wanted to feel part of a group of other mothers, interactions with professionals often left them feeling apart because their child was seen as “different” from other infants. Responses from the general public could also be experienced as negative or distressing. Mothers in particular recalled painful memories of stigmatizing public reactions, which stayed with them years later:

You’d walk past people and they used to look and say, “Oh, can I have a look at your baby?” What used to upset me was hearing them talking behind your back as you’re going away. I used to get really annoyed and dead upset, and I used to bottle it in a lot; I wouldn’t say naught to nobody, I’d just walk away, and it was all within my mind. (Mother of young adult [MYA])

Although several fathers expressed forgiving views about public attitudes, describing encounters with people’s shock or curiosity as understandable and seeing strangers as essentially benevolent but lacking in awareness, mothers described the heated and defensive feelings that such reactions could provoke. Mothers often managed the threat of social stigma by concealing their child’s cleft in various ways. Some chose not to disclose the diagnosis to friends and/or family; however, many responded to anticipated stigma by withdrawing socially, or making efforts to cover or hide the visible or functional effects of their child’s cleft that others might find disturbing:

When I used to go up into the town I'd drop the pram [stroller] all the way back and pull the cover up. I know now that I shouldn't have to do that, but at that point in time I didn't want people sticking their heads into the pram and going [makes disgusted face]. (MI)

As a child became older parents were also concerned about the potential emotional and social consequences for them of having a cleft, anticipating that they might be socially excluded. Some described children struggling with serious emotional difficulties, including suicidal thoughts, which were attributed to distress about appearance and worries about how they were perceived by others. One mother expressed anxiety about the potential significance of paintings her daughter had produced for an art course:

There's another one [painting], and it was half a face hanging off, but it's always her bad side. So to me I think that's how she's felt, and if she sees herself like that, that's how she must think the world sees her. (MYA)

Starting at the time of their child's birth and continuing throughout childhood and adolescence, parents anticipated almost as a given that family, friends, peers, and new acquaintances might not accept their child because of appearing to look or sound "different" from the "norm":

There was the whole, how will people interact with him, will he be rejected by family? You worry about it. (MI)

I mean kids can be cruel. When I was younger, taking the mickey out of [mocking] kids with hearing aids and built-up shoes and all that kind of stuff—it's what you do when you're little, isn't it? (Father of infant [FI])

Several parents were particularly apprehensive about their child's transitions, such as the move to primary or secondary school, to college, university, or the world of work, and from children's to adult health services. Balancing a desire to protect their child with the need to facilitate their independence was a particular emotional challenge that parents were continuously contending with. As expectations grew for children to form peer groups, several parents described their children as socially unconfident, experiencing difficulties in making friends and forming relationships. According to parents, children often avoided group situations. Additionally, parents often perceived their children to be contending with social stigma from peers, both in and out of school. Stories of name

calling, teasing, and bullying were common and particularly distressing for parents:

Names like "fish lips," "mong" [idiot, fool], it was horrific. He put up with it but used to come home saying, "They're calling me names!" and I'd say, "Just ignore them, they've got nothing better to do. You're better, they're nothing." When he was 10, the lads [boys] were still bullying him, and he came out of school absolutely broken hearted saying, "Just let me die, Mum." (MA)

Some parents described their own attempts to manage the emotions of their child, which they found challenging. One mother explained that she and her husband had felt isolated in their attempts to support their daughter through her adolescence because of a perceived lack of support for emotional and social issues from professional services:

I don't think there's a particular priority given to that side of things; it's more the clinical treatment based on medical need. We could have done with a bit more help in terms of helping her to deal with that—more support for the psychological and social effects, because I think she has been affected socially. We've managed to somehow sort of get her over it, but it was difficult to deal with, and we were pretty much left alone. (MYA)

Faced with worries about stigmatization from birth to young adulthood, in consequence parents largely attempted to help their children by ensuring they took advantage of everything possible that could be done by clinical services in terms of cleft treatment. For most parents, encouraging their child to engage with any interventions offered was perceived to be in the child's best interests:

I said, "You're going to go to uni [university]—have it done now [jaw surgery], before you go!" I just felt I had to convince him—even though I didn't really know what I was talking about. I felt for his sake, I didn't want him to leave it until he was in his 20s, because I was really concerned about the fact he was very insular at 18. (MYA)

The study findings highlight several emotional tensions parents were managing along the course of their child's cleft treatment. In essence, these were conflicts around their child's "normality" and "difference," mixed emotions about their child undergoing multiple cleft treatments—particularly surgery, and worries about the social exclusion of both their family and their child. The study findings demonstrate that similar emotional tensions

underpinned the context of family life as children became older, although the reasons for such tensions varied through different ages and stages of treatment. Paradoxically, even though parents saw surgery to correct their child's impairment as the main way of managing the emotional and social consequences of having a cleft, as noted earlier, pursuing cleft treatment could in itself be a source of ongoing conflict for them.

Discussion

Through presenting in depth and detail one subcategory from our larger study, we have for the first time illuminated the emotional conflicts parents experience about their child having a cleft, emphasizing in contrast to much of the prior literature in this area the conflicting and dual nature of their feelings along the treatment course, and adding the perspective of fathers. Our study contributes to knowledge by adding a contextual and sociological perspective to the existing biomedical and psychological understandings that underpin research to date with the parents of children with clefts (Moola, Fusco, & Kirsh, 2011).

Our findings mirror those in the wider children's long-term-conditions literature, which has often identified the nuanced views of parents about notions of their child's "normality" and "difference" (Ablon, 1990; Daniel, Kent, Binney, & Pagdin, 2005; Kearney & Griffen, 2001; Larson, 1998; Nelson, 2002). Although previous qualitative studies in the cleft field have identified parents' feelings of anxiety in relation to their child's surgery (Eiserman, 2001; Johansson & Ringsberg, 2004; Klein et al., 2006; Stone et al., 2010), in this article we highlight the sense of ongoing conflict that characterizes parents' experiences of cleft treatment. It is likely that the validated quantitative measures previously used with mothers have not been sufficiently sensitive to reveal the everyday tensions they might experience, and have also largely excluded fathers. Such tensions have only been mooted in prior ethical debates suggesting parents might be "quietly conflicted" about their child's elective surgeries (Domurat Dreger, 2006, p. 255), but not until now examined empirically.

Our findings are supported by the wider literature in which children's surgery and/or pain has been shown to have an intense emotional impact for both mothers and fathers, often challenging their role as the protector of their child (Amin, Harrison, & Weinstein, 2006; Callery, 1997; Jordan, Eccleston, & Osborn, 2007; Maciver, Jones, & Nicol, 2010; MacLaren & Kain, 2008; Salisbury, LaMontagne, Hepworth, & Cohen, 2007; Sanders, Carter, & Goodacre, 2007; Sobo, 2005). The theory of stress and coping (Lazarus & Folkman, 1984) explains how individuals might appraise and respond to stressful life events. Sloper (1999) concluded that when their child has a

long-term condition, parents will draw on personal, material, or social resources by taking action (problem-focused coping) and/or cognitively reframing their circumstances (emotion-focused coping). Our study findings suggest that parents of children with clefts primarily employed problem-focused coping strategies to manage their emotional tensions by turning continually to cleft treatments to help their child.

Goffman's sociological work in the 1950s and 60s first described the social phenomenon of "stigmatization," explaining how individuals perceived as "different" could be excluded from full acceptance into society (Goffman, 1963), although stigma is conceptualized not as an attribute of an individual but rather as a culturally and historically determined social perspective (Gabe, Bury, & Elston, 2004). Parents' desire to protect their children from physical discomfort as well as the emotional and social pain that might result from anticipating or encountering stigmatizing attitudes has been previously highlighted as a common theme in both the cleft and wider children's long-term-conditions literatures (Ablon, 1990; Cartwright & Magee, 2006; Daniel et al., 2005; Kerr & McIntosh, 2000; Klein et al., 2006; Maciver et al., 2010; Robinson, 1993; Sach & Whynes, 2005; Tluczek, Murphy Orland, & Cavanagh, 2011). The accounts we have gathered in this study support this previous research. However, prior to this study only research outside the cleft field, across a range of children's conditions, has highlighted the uncertainty that parents might be managing throughout their child's treatment, including frustrations about intangible future outcomes (Brinchmann, Forde, & Nortvedt, 2002; Kearney & Griffen, 2001; Tanner, Dechert, & Frieden, 1998; Tluczek et al., 2011; Vehkakoski, 2007). We have therefore brought new knowledge on these issues to the cleft field in conducting this study.

Implications for Future Research and Practice

In this study we have for the first time explored parents' experiences of caring for a child through cleft treatment, and more research is required to build on and extend our qualitative work. Further in-depth research is needed to elicit the views and experiences of children and young people along the course of their treatment for a cleft, which are likely to be distinct from those of their parents. Research could also focus on the development and evaluation of therapies to promote the emotional and social well-being of families that might be offered as an adjunct or alternative alongside the program of surgical and other clinical treatments, such as support for confidence building and/or the development of social skills.

Implications for policy and clinical practice arise from our study, relating to family support for emotional and

social well-being throughout a child's treatment course. We have highlighted some of the common emotional and social challenges parents faced, which might be less visible to the providers of services. These challenges were not pathological states, but common, everyday parental worries that extended along the treatment pathway. We consequently suggest that, in line with the United Kingdom's policy on "family-centered" care (Department of Health & Department of Education and Skills, 2004) and theoretical perspectives which emphasize the idea of "partnership" between families and professionals (Coleman, 2002; Coyne & Cowley, 2007; Dale, 1996; Franck & Callery, 2004; King, Rosenbaum, & King, 1997; Mitchell & Sloper, 2001; Mittler, 1994), that routine family assessments which incorporate aspects related to emotional and social well-being for both children and parents could be built in as part of regular screening along the care pathway (Rumsey & Harcourt, 2007). Access to support could then be provided to parents on an individual or family basis when desired. Making emotional support an integrated and regular part of care could help to reduce the potential stigma of using such services that parents might experience (Hodgkinson et al., 2005).

Currently in the United Kingdom's cleft services, emotional support is provided by clinical nurse specialists to parents in the first 18 months or so of a child's life. An extended, flexible program of emotional and practical support around the needs of families could be planned, to run beyond the early stages throughout a child's treatment to afford parents the opportunity to express their feelings to a trusted practitioner on an ongoing basis. Access to emotional support at different points along a child's care pathway from a "key worker" such as a nurse or counselor has been shown to promote parental coping in other long-term conditions affecting children, such as cerebral palsy and cystic fibrosis (Beecham, Sloper, Greco, & Webb, 2007; Piggot, Paterson, & Hocking, 2002; Sloper, 1999; Wong & Heriot, 2008). Such a model could have application in cleft services and would require a redistribution of the resources that currently prioritize surgical and other physical treatments.

In particular, parents might benefit from emotional and practical support from professionals in relation to their child's surgeries, which they might experience as painful or distressing (Maciver et al., 2010). We have suggested in our findings that whatever a child's age at the point of surgery, the emotional toll on parents might still be considerable. Support programs in other conditions, including video education and information pamphlets to improve parents' knowledge, as well as anxiety-reduction support to aid coping, have been shown to help them manage the process of children's anesthesia and surgeries (Franck & Spencer, 2005; Kain et al., 2007; Pinto & Hollandsworth, 1989). Such programs could be adapted for use in the cleft field, and practitioners could provide written

information to back up verbal advice about pre- and post-operative care, as well as expectations for a child's immediate recovery (Ruccione, Kramer, Moore, & Perin, 1991).

Help for parents to nurture their child's self-confidence and emotional well-being could also be beneficial. Children did not take part in the study, and the ways in which they might experience their own treatment course remain so far undocumented. However, parents commonly expressed worries about their child's appearance and self-esteem, investing great hope in the power of physical treatments as a key way of resolving associated problems. Consequently, alongside physical treatments, care plans could incorporate support for parents to focus on positive attributes and build children's confidence beyond aspects of physical appearance and function alone (Eiserman, 2001). First impressions are greatly moderated by how personal attributes other than appearance are perceived (Edwards, Topolski, Kapp-Simon, Aspinall, & Patrick, 2011). Support to develop these attributes could be particularly beneficial at times of a child's transition to new environments or groups (Hatton, Canam, Thorne, & Hughes, 1995). Helping parents to support their child in developing resilience and a sense of self-worth could consequently be an important focus of cleft services (Aspinall, 2006; Rumsey & Harcourt, 2007).

Finally, parents might gain from practical support to develop strategies to help their child in the face of stigmatizing social attitudes of negativity, fear, or curiosity. Even with surgery, encounters with individuals who have difficulty accepting a child's "difference" might still occur, and practitioners are well placed to provide support to help parents manage such challenging experiences. Programs to support and develop social skills in managing reactions to difference have already been developed, and after evaluation might be offered by practitioners as an integrated part of cleft services (Mouradian, Edwards, Topolski, Rumsey, & Patrick, 2006; Rumsey & Harcourt, 2007).

Limitations

A child's treatment for a cleft might extend over a period of 20 years, and we did not have the opportunity in this particular study to follow the same families longitudinally to examine changes in parents' experiences across the treatment trajectory. Another possible limitation of the study is that we gathered data in a mixture of joint and separate interviews with parents, generating data that might be qualitatively different. The research was not intended to be a comparative study of mothers' and fathers' views, however, and we aimed to be responsive to the wishes of participants by offering them the choice of joint or separate interviews. Moreover, it has been previously acknowledged that there might be benefits as well as

drawbacks of joint interviewing, including the potential to generate more comprehensive data (Arksey, 1996). In common with many family studies (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005), more mothers than fathers took part, however, and it is likely that mothers' views are more dominant in the findings. Finally, there is the possibility that our sample comprised only parents who were particularly eager for their child to undergo cleft treatment. The views of parents who might not have been adhering to treatment protocols were absent. We made efforts to recruit this group of parents; however, practitioners were unable to identify any families who had disengaged with treatment.

Conclusions

With this study we contribute to knowledge by exploring and presenting in depth, for the first time, the experiences of both mothers and fathers as they cared for a child with a cleft. We reveal the often conflicting feelings, emotional costs, uncertainties, and social stigma which were present for parents not only at the start of their child's life but throughout their longer-term treatment. Such issues, though debated to some extent in the ethics literature, have been relatively invisible in empirical studies to date. Additionally, we identify the need for research to build on this in-depth work, including an examination of the experiences of children and young people with clefts through the treatment course. Finally, we highlight the necessity for services to take into account not only parents' needs for physical cleft treatments but also, in line with provision for other long-term conditions affecting children, the emotional and social needs they might have as a child grows up, and how they might be better supported along the way.

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Note

1. In this article, unless otherwise indicated, we use the term *cleft* to refer collectively to clefts of the lip, clefts of the palate, or clefts of both the lip and the palate.

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