



'Doing the "Right" Thing': How parents experience and manage decision-making for children's 'Normalising' surgeries

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ABSTRACT

Using cleft lip and palate as an exemplar, this article examines parents' decision-making for children in the context of elective treatments which aim to 'normalise' a child's function, appearance, communication or identity. Using purposive and theoretical sampling, 35 parents with children from infancy to young adulthood were recruited through a specialist cleft centre in England. Parents were interviewed in-depth between 2006 and 2008 about their beliefs and motivations in relation to treatment decision-making in this context. A grounded theory approach was used to analyse the data. Findings revealed a core category, 'doing the "right" thing', that encapsulated parents' main concern in relation to their children's treatment and highlighted several emotional, social and cultural considerations underpinning their decision-making stance. Parents fulfilled a perceived 'moral' obligation to be 'good' parents by pursuing the 'normalising' treatments, particularly surgeries, made available to their children. Such treatments were viewed as a way of facilitating their child's social inclusion and helping them reach their full potential. In order to enable their continued pursuit of treatments over the long-term, parents also constructed specialist practitioners as highly competent and particularly trustworthy. This article captures the complexities involved in parents' decision-making for children's elective 'normalising' treatments, where both functional and appearance-related concerns are involved. It suggests that social norms about parenting, physical appearance and healthcare practitioner power may significantly shape decision-making in this context, so that such choices may be viewed primarily as 'moral' rather than social. Services could support parents with such challenges, by gauging their needs for information about surgery and its likely outcomes and providing emotional/decisional support to consider all available options.

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Introduction

For over a decade in the United Kingdom's (UK) health care setting, patients' involvement in treatment decision-making has been advocated for its potential to positively affect health outcomes as well as demonstrating respect for patient autonomy and responding to consumer demand for increased involvement (Wirtz, Cribb, & Barber, 2006). The 'shared' decision-making model proposes that patients and clinicians decide about treatment together rather than control being held by doctors alone (Charles, Gafni, & Whelan, 1999). However, the extent to which shared decision-making occurs in practice, whether patients desire such involvement and professionals possess the requisite skills, is unclear (Coulter, 1999). Conceptual models of how people make decisions are commonly either normative (concerned with how decisions *should* be made), or descriptive

(how decisions are *actually* made), with most existing studies of parental decision-making for children's healthcare associated with the latter model (Beresford & Sloper, 2008).

Most research to date on parents' decision-making for children's healthcare has focused on life-threatening conditions or 'non-elective' treatments (Daniel, Kent, Binney, & Pagdin, 2005) in Western countries. Using interviews, observational methods and surveys, this research has examined the experiences and preferences of parents about involvement in decision-making across a range of childhood long-term conditions. Findings suggest that parents differ widely in their ability and desire to be involved in making decisions and report different perceptions of the extent of their involvement (Brinchmann, Forde, & Nortvedt, 2002; Gore, Johnson, Caress, Woodcock, & Custovic, 2005). Demographics appear to be unable to accurately predict decision-making styles because preferences often differ according to context, including the type of decision being made and parents' relationship with health professionals (Knopf, Hornung, Slap, DeVellis, & Britto, 2008). Current models and

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measures of ‘involvement’ in decision-making have therefore been acknowledged to be too narrowly focused, because the concept is highly complex and context-bound (Wirtz et al., 2006).

One context in which particularly complex factors may be at play for parents in treatment decision-making is that of elective surgery. While diverse in their individual characteristics and consequences, conditions such as spinal scoliosis, ambiguous/incomplete genitalia, restricted growth, profound deafness and cleft lip and/or palate, share a common decisional context. Cleft lip and palate is the focus of this paper, however the context in which decisions are made for all these conditions shares three main characteristics: 1) threats to a child’s health status may be relatively reduced; 2) time pressures may be less important; 3) emotional, social and cultural considerations may take precedence over medical factors, because the goals of treatment relate primarily to ‘normalising’ a child’s function, appearance, communication or identity (Daniel et al., 2005). Parents’ motivations in this context may consequently involve a mixture of beliefs, values and emotional judgments (Bradbury, Kay, Tighe, & Hewison, 1994) such as a strong desire to protect their child from social exclusion (Sanders, Carter, & Goodacre, 2007). They may also be influenced by the interpersonal skills of practitioners providing care, or feel compelled to comply with their recommendations (Li, Bain, & Steinberg, 2004). This paper focuses on cleft lip and palate as an exemplar of such a context and examines how parents experience making decisions about their children’s surgical treatment.

Cleft lip and palate is a congenital condition affecting a child’s facial structures which has functional consequences for feeding, chewing and breathing as well as for impaired dental, facial, speech and language development (Hunt, Burden, Hepper, & Johnston, 2005). Since the face is highly visible and core to social interaction (Rumsey & Harcourt, 2005), effects on the emotional and social well-being of a child and their family may also be common due to stigmatisation associated with perceived ‘difference’ (Goffman, 1963). Treatment for clefts in Western countries is generally provided in a long-term programme of surgery, orthodontics and speech therapy that aims to improve function in relation to speech, chewing, breathing and hearing and achieve a more ‘normal’ appearance of the lip, nose and teeth (Hodgkinson et al., 2005). The type of treatment provided depends on the extent of a child’s cleft, however children and their parents may be faced with a long and complex course through treatments from birth to young adulthood. A key feature of this treatment programme is the elective nature of some elements, with parents having a key role in decision-making. Interventions that are generally common to core clinical management programmes are presented briefly in Table 1, though nursing, counselling, speech therapy, dentistry, audiology, psychology and genetics services may also be available to families across the treatment course.

Ethics and decision-making

Western ethical perspectives in the literature have informed debates about decision-making for children’s ‘normalising’

treatments, including for clefts. These perspectives have identified three ‘moral’ considerations particular to treatment decision-making in this context (Parens, 2006): firstly, that treatments are to a greater or lesser extent elective; secondly, that decision-making is influenced primarily by social considerations when children may be very young; and thirdly that parents may pursue such surgeries as a way of coping, while children themselves face the life-long consequences of such decisions.

Ethicists have recommended that professionals help parents deliberate on decisions about ‘normalising’ surgeries for children, by examining their own motivations for treatment, balancing medical information with their own values and identifying what surgeries their children need for medical and social reasons (Shakespeare, 2006). They have also suggested that practitioners could support families to help children themselves deliberate about whether surgical change fits with their developing sense of identity (Aspinall, 2006). These perspectives have fully acknowledged such issues to be challenging for both families and practitioners because they are complex, difficult to broach and may reveal unspoken values and beliefs about surgically altering a child.

Parents and decision-making in cleft lip and palate

Research examining parents’ decision-making in relation to cleft treatment is relatively rare and hails from the UK or North America. Existing research comprises surveys largely with mothers, that are either comparatively small-scale (Pannbacker & Scheuerle, 1993) or lacking in depth in their focus on decision-making (Jeffery & Boorman, 2001; Turner, Thomas, Dowell, Rumsey, & Sandy, 1997). These limited surveys suggest however that many parents feel relatively uninvolved in their child’s treatment planning. The few existing qualitative studies in the field suggest that parents may experience emotional tensions about their child undergoing surgical procedures (Eiserman, 2001; Farrimond & Morris, 2004; Klein, Pope, Getahun, & Thompson, 2006; Nelson, Kirk, Caress, & Glenny, 2011) and that motivations remain largely unspoken in consultations about elective cleft surgeries between young people, their parents and practitioners (Silverman, 1983). Little is consequently known about the beliefs and motivations that may influence parents’ decisions in this context. This study aimed to fill the gap in knowledge by exploring in depth with both mothers and fathers how they experience and manage decision-making during their child’s cleft treatment.

Research methods

Sampling and recruitment

Participants were recruited through a specialist cleft centre in England. Here, as in the rest of the UK, access to health services including those for cleft lip and palate treatment, is available free at the point of need, regardless of a patient’s financial or insurance status (Shaw et al., 2001). An initial purposive sampling strategy aimed to gather a varied sample of parents (Murphy, Dingwall,

Table 1
Core interventions in the clinical management of clefts.

Approximate ages	Clinical speciality	Purpose
Up to 12 months	Primary surgery (plastic) Primary surgery (plastic/maxillo-facial/ear nose and throat)	Lip closure to improve function/alter appearance Closure of hard and soft palate to improve function/promote speech development; placement of ventilation tubes to improve hearing loss
From 6 years	Orthodontics	Pre- and post-operative preparation (eg. preparation of gap in gum for bone graft) and straightening of teeth to improve function, oral health and alter appearance
Approximately 9 years	Bone graft surgery (maxillo-facial)	Closure of gap in bone of upper gum to allow stable eruption of secondary teeth in line of cleft
From 15 years	Surgical revision (plastic) Orthognathic surgery (maxillo-facial)	Lip/nose revision to alter appearance and improve breathing function Re-alignment of jaws to improve function and alter appearance

Table 2
Characteristics of participating parents ($n = 35$).

Characteristic	Mothers (aged 21–54 years)	Fathers (aged 31–55 years)	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

Greatbatch, Parker, & Watson, 1998). Sampling was planned to incorporate parents of children with a range of cleft types and accompanying health-related conditions, of different genders and from different socio-economic and ethnic backgrounds, in four main age groups. These groups reflected ages when clinically significant interventions would be taking place for children – 12 months or less and around six, nine and 15 years (see Table 1). As the study progressed, 'theoretical' sampling enabled the sample to be adjusted according to the emerging analysis, by incorporating parents of children who were having treatment between and beyond these ages to explore experiences as a child moved through their treatment course. As part of theoretical sampling, efforts were made to recruit parents who had decided against their child undergoing interventions, however practitioners were unable to identify any such parents.

Data collection

A National Health Service (NHS) Research Ethics Committee had approved the study and informed consent was obtained from all parents prior to any data collection. Between 2006 and 2008, data were collected in face-to-face, in-depth interviews with parents in their homes. Parents were given the choice of being interviewed separately or together. Using a semi-structured topic guide, interviews explored how parents experienced and managed making decisions for their child's cleft treatment and the motivations and beliefs that influenced their actions. In total 27 interviews lasting approximately 90 min each were recorded and transcribed verbatim. Field notes were also written to document information about the context of the interviews.

Data analysis

Transcripts from the interview and field notes were imported to NVivo 7 (Richards, 1999) to organise the study data. A grounded theory approach (Charmaz, 2006) was used to compare and contrast data through an evolving process of line-by-line, selective and theoretical coding to identify important categories. Informal memos and 'cluster' diagrams were drawn throughout to develop ideas about the data and chart connections between categories. Sampling continued until the characteristics of theoretical data categories were well developed at an abstract level and no new insights were apparent.

Findings

Sample characteristics

Twenty seven families (35 parents) with children between the ages of 20 weeks and 21 years participated in the study (Table 2). Eight couples elected to be interviewed together, with a further

Table 3
Characteristics of the children of participating parents.

Type of cleft	Girls (aged 20 weeks–20 years)	Boys (aged 5 months–21 years)	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

three fathers and 16 mothers interviewed separately. The characteristics of the children are presented in Table 3. Eight children had additional health-related conditions as well as their clefts, including other craniofacial conditions, genital, renal, gastric or eye conditions.

Explanatory framework

A core category 'doing the "right" thing' encapsulated the main concern of parents in connection with treatment decision-making for their child's cleft, a concern which was common to parents across the study, regardless of background or age of child. This core category and its three sub-categories ('doing something', 'fitting in' and 'being in the "right" hands') formed the study's explanatory framework, illuminating the key beliefs and actions parents accounted for in the interviews and explaining how they attempted to resolve their concern. The components making up the explanatory framework are represented diagrammatically in Fig. 1.

'Doing the "right" thing': the 'moral' dimension in decisions for children's surgery

Parents with children of all ages expressed a strong sense of responsibility to ensure the 'best' was done in relation to their child's cleft treatment. This sense of obligation was apparent through the particular language parents used, with repeated phrases such as 'have to', 'got to', 'need to' 'must' and 'should' as well as frequent references to doing the 'best' or the 'right thing' for their child appearing in the accounts. Several parents explained the rationale behind sanctioning their children's past, present and future treatments, appealing to a taken-for-granted sense of parental duty:

'When it's your child you just want the best for them don't you, when you're a parent?' (Mother of Matthew aged 5 months)

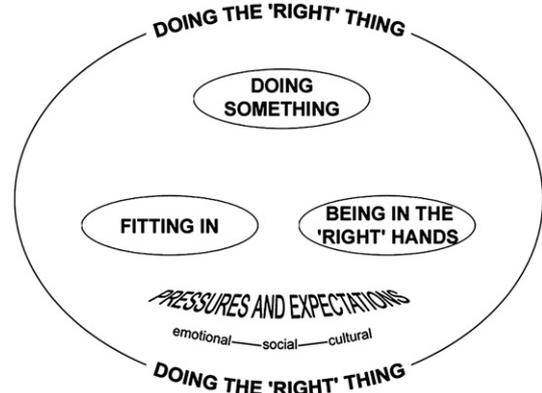


Fig. 1. The explanatory framework for the study.

'I make sure that I'm doing the right thing... I am going to do the best for her.' (Mother of Zahira aged 5 years)

'Doing the "right" thing' for their children in terms of treatment was consequently seen as a marker of being 'good' parents. This emerged as parents' main concern and thus the core data category in accounts spanning infancy and childhood through to young adulthood. Parents were often keen to stress that their intention in relation to treatments was not to do the 'best' for themselves, but rather for their child. A sense of 'moral' obligation in putting a child's perceived needs before their own was apparent:

'We've come to the same point – this isn't about me, this isn't about my wants, needs or anything else.' (Mother of Jade aged 7 years)

'It's not a personal thing for us, it's for him isn't it? We're doing the best for him.' (Father of Lee aged 14 years)

While parents themselves did not use the term 'moral' to label aspects they talked about in terms of 'doing the "right" thing', the marked sense of obligation in their accounts suggested that relationships with their children were characterised by a strongly 'moral' dimension. This expressed sense of obligation explained parents' drive to prioritise their child's needs, but suggests also that parents may have been eager to protect themselves from negative judgments (from friends, family, clinicians and possibly also the researcher) of their parenting competence, that might arise if they decided not to pursue treatment. The 'moral' dimension consequently underpinned parents' vigilance with regard to cleft treatment, but also served to legitimise their pro-treatment approach to decision-making. 'Doing something', the sub-category presented in the next section, was the key way parents fulfilled their perceived obligations of 'doing the "right" thing'.

'Doing something': pursuing solutions

A key strategy that parents used to ensure they met the perceived 'moral' obligation of 'doing the "right" thing' was in accepting any available cleft treatments. As there were no financial implications for families in choosing treatments, parents were not constrained by insurance or money in making decisions. Consequently, the costs associated with their child undergoing unpleasant procedures – such as a sense of inner conflict, anxiety and even distress – were primarily emotional.

Pursuing solutions began soon after a child's birth, when 'doing something' involved sanctioning early surgeries to close the cleft in their child's lip and/or palate. Recalling the early months of a child's life, parents' accounts held little sense of choice or deliberation about whether or not to proceed with these early interventions, being characterised more by what they described as instinctive decisions to take action:

'It's fairly simplistic, the choices we had were to do something about it or not and you can't not do anything, so you have to do something.' (Father of Tom aged 11 months)

'Doing something' in the early days of a child's life appeared to set the tone for parents' decision-making stance in relation to future treatment. Across childhood and adolescence, parents were actively concerned to access surgery, orthodontics and therapy for their child's speech problems, hearing loss, facial/dental appearance or breathing/eating difficulties. Although some of these treatments may have been elective in nature, parents' accounts often suggested a sense of 'mission' rather than choice:

'However far we need to go, if it takes till she's 18 and leaves home, that's how far we'll go.' (Mother of Neela aged 9 years)

An explicit sense of deliberation was rare in parents' accounts. The father of 14-year-old Lee was the only parent to report having declined a recommended intervention (a grommet operation for suspected hearing loss that he described as merely 'fashionable' and 'in vogue'), though he had accepted all subsequent surgeries that had been made available to his son. Michelle's mother was the only parent in the accounts who overtly expressed doubts about treatment, questioning whether repeated operations could be justified for her daughter on the basis of their costs and benefits:

'It's not that I want to go against them [cleft care practitioners], it's just, how far do we take it? I feel like Michelle speaks well and can communicate with people, I just don't feel like it's necessary any more now. I've never gone against them...but...how far do you take it?' (Mother of Michelle aged 6 years)

More commonly, parents were anxious about the potential consequences of *not* accepting treatment. While some parents were aware that surgery may or may not work, knowing that even specialist practitioners might hold divergent views about efficacy, they were concerned not to miss the offer of treatment:

'Whether it's the right thing or not, you don't know – so you just go ahead with it. It [palate re-repair] was to correct her speech – make it better. It might not work, it might work – they're not 100% [sure about efficacy], but my main concern was to have that done.' (Mother of Shelley aged 11 years)

At times however, the surgical 'mission' failed to bring imagined gains for children, bringing emotional costs for parents. Some, such as 13-year-old Emily's mother, were disappointed when the expected benefits of surgery were not immediately obvious or when professionals expressed dissatisfaction with results. Other parents were surprised and anxious to discover that their child's surgery may need to be repeated, appearing unprepared for such an eventuality:

'They've [cleft team] always warned us that there may be further surgery, but it was never about the lip, it was always about his nose... nobody's warned me about that! So that was a shock, because we thought – one lot of surgery and that was going to be it.' (Mother of Matthew aged 5 months)

Unsurprisingly, emotional costs were particularly involved for parents when adverse events occurred as a result of their child's surgery. Parents' anxiety was often compounded by not understanding why or how such complications may have arisen and feeling compelled to undergo more surgery to put right the harm. Although parents avoided overtly blaming themselves for such outcomes, a sense of emotional conflict was perceptible in their stories. Daniel's parents had agreed to multiple simultaneous surgical procedures in an effort to reduce the number of repeated anaesthetics he would undergo, but felt that this decision had brought significant negative physical and emotional consequences for both Daniel and themselves:

'I would never, **ever** recommend to any parent to be tempted to have the two operations together – it was a big mistake, because he couldn't cope with it, **and** me – nobody could. I don't think the nurses could either, they were upset as well...because he was tragic ...such a poorly little boy.' (Mother of Daniel aged 12 years)

While pursuing solutions through surgical intervention may have enabled parents to fulfil their perceived 'moral' obligation of 'doing the "right" thing' for children, it is clear that such intervention often brought with it significant emotional costs. In this way parents traded what they perceived as short-term discomfort for longer-term emotional and social gains.

'Fitting in': surgical 'normalisation'

So far it has been suggested that despite the emotional costs involved, parents attempted to do the best for their children by pursuing cleft treatments out of a sense of parental duty. Two key factors appeared to drive parents' pursuit of treatment, the first of which was a desire for their child's social acceptance or 'fitting in'. Having a cleft threatened 'fitting in' and created worries for parents, which were evident right from birth:

'When she was first born I'd wait for people's opinion, when they looked in the pram and looked at her face – and wait for them to react and see what they would do...thinking "oh-oh let's just see how they react."' (Mother of Shelley aged 11 years)

Parents worried that their child (and by extension, their family) would be socially isolated because of a cleft's consequences in three main domains: firstly, functional aspects such as speech and communication, with related effects on making friends and learning; secondly, visible appearance with effects on a child's self-esteem and own emotional well-being; and thirdly, how these functional and appearance-related consequences might influence others' perceptions of their child. In the back-drop of family life, such worries could be present from the prenatal period, through birth, infancy, childhood, adolescence and young adulthood, although no particular pattern of prominence could be identified over time.

In parallel, parents strongly invested hope in the power of cleft treatments, particularly surgeries, to enable their child to fit in by 'normalising' their function and appearance. It was hoped that initial surgical closures would aid feeding, growth, speech and language development as well as enhancing their child's emotional well-being in the longer term. Parents often claimed to understand their child's inner emotions, making direct connections between a child's negative self-image and the power of transforming surgeries to enhance their confidence and sense of well-being:

'He [son] said "why do I have to look like this – why me?" so I think he's pretty looking forward to it [jaw surgery], because he says "I'm going to be a **new** person when I come out of here the next time".' (Mother of Luke aged 16 years)

By extension, there was an assumption that these surgeries which aimed to 'normalise' a child's function/appearance and enhance their self-esteem would enable them to more easily fit in with peer groups, achieving social acceptance and avoiding potentially stigmatising experiences:

'He needs to be looking like the rest of them [at college] to be able to socialise with the rest of them and not be worrying about what he looks like, because he can then think – I just look like the rest of you.' (Mother of Sean aged 21 years)

Parents' accounts were notable for the ways in which they described the re-shaping of their children's appearance. References to 'fixing' and 'repairing' a child's cleft were common:

'Well I knew that he could have it fixed so I weren't worried.' (Mother of Jack aged 11 months).

Such 'fixing' was often portrayed by parents as relatively minor, presenting a somewhat unproblematic view of surgery which conceivably assimilated the more technical stance and terminology of practitioners. Perhaps this can be understood as a coping strategy that parents used to help manage feelings of distress. Notions of shaping, 'correcting' and re-fashioning were also evident:

'They explained [surgical team] that because the infection had set in they're dealing with used and second hand material. They

said it's trying to make a dress out of an old dress – it's not usually as good as the start from fresh – but you can usually make a good dress out of an old dress, providing you stick to the rules.' (Mother of Liz aged 21 years)

While parents justified surgeries because of benefits to a child's feeding, hearing and general health, changes to their 'normalised' appearance were presented as particularly advantageous:

'Now she looks like a normal little girl who's full of life. No-one else will ever know any different when she goes to school, so no one will be able to tease or taunt her.' (Mother of Emma aged 7 months)

It was comforting for parents that such 'normalising' could provide their children with a degree of protection from anticipated social stigma and this belief sustained them during the treatment course. When reflecting on previous treatments, parents stressed their belief that the end results justified the costs involved and that they had done the 'right' thing in sanctioning surgeries for their child:

'I don't regret any of the treatment that she's had done. I think that it's difficult to deal with at the time, but I do think it's been the right thing to do. I don't regret any of them.' (Mother of Kelly aged 17 years)

Seeking to enable a child's 'fitting in' through surgeries meant that parents could have been vulnerable to seeing such treatments as a 'cure-all'. Physical cleft treatments held primacy in parents' accounts as key ways for them of 'doing the "right" thing', while non-physical ways of helping a child reach their full potential were much less present. This suggested a constant dilemma for parents:

'It's only with the other kids bullying her and saying things that got her thinking can you have this done, would it make any difference? We can only say we don't think you need it - you're beautiful as you are - it's other people that haven't seen what you've gone through, or experienced what you've come through.' (Father of Kelly aged 17 years)

Such a paradox (feeling duty-bound to pursue surgeries to alter a child they loved so that others might also accept them) reflected the underlying feelings of conflict that parents in this study experienced in decisions about cleft treatment. Parents therefore primarily managed the functional, emotional and social challenges of their child's cleft by pursuing surgical solutions to 'fix' and re-shape its effects.

'Being in the "right" hands': parents' trust in cleft care practitioners

In addition to enabling their child's 'fitting in', the second key factor influencing parents' decisions to pursue cleft treatment was their deep-seated trust in the specialists providing cleft care. This enabled parents to construct a sense of 'being in the "right" hands', encouraging them to pursue treatment and thereby fulfil their objective of 'doing the "right" thing' for their children. Practitioners were trusted for their perceived specialist knowledge and expertise, but also for their interpersonal skill:

'We'd sit with him [surgeon] and he was very good and he had a lovely manner. It only filled you with confidence that you were with the **right** people doing the **right** thing for him [son].' (Father of Lee aged 14 years)

Seeing practitioners in such a positive light allowed parents to more easily entrust to them their child's care and pursue the treatment offered. While parents' trust could be based on

perceptions of practitioner competence, parents also felt obliged to trust in practitioners by virtue of their status as healthcare professionals:

'It's a case of trusting, because you might question things and you can't change anything. All you want to know is that it's going to be done and it will come out all right. It's putting your faith in the professionals. If they say it's going to happen then why question it – they know far more than I do and you've just got to put your confidence in them.' (Father of Simon aged 20 years)

In addition, a somewhat fatalistic sense of trust was sometimes evident in parents' accounts, where they downplayed the risks or adverse consequences of surgeries. Several parents explained these as 'just one of those things', attributing future possible risks or past post-operative complications to chance rather than human error. Shelley's mother was aware that an operation to revise her daughter's palate surgery had only a 50:50 chance of being effective. Although this last operation had brought the total of Shelley's surgeries to 13, her mother presented a fatalistic view:

'Well I hope it does work, but if it doesn't, it doesn't. At the end of the day it's been done. It's one of those things.' (Mother of Shelley aged 11 years)

Referring to fate in instances when trust might be threatened was a way to preserve trust in the practitioners on whom parents relied for their child's long-term care. They expressed forgiving attitudes towards practitioners when adverse events occurred or surgeries turned out to be particularly traumatic, often accentuating the challenging nature of the surgery and the heroism of the surgeon:

'They decided that they'd do an all-in-one and see how it went. He [surgeon] immediately put her on the right antibiotics and the infection cleared up – everything was fine. She still had this great big gap...but it also come out the other end, because they managed to save her, because this infection is quite a serious one – many people died of it in hospitals about five years ago.' (Mother of Liz aged 20 years)

Appealing to this surgical heroism even where treatment had failed enabled parents to maintain their vision of practitioners as competent and trustworthy, legitimise decisions to pursue their child's treatments and continue with future treatments over a long-term pathway. However, such accounts suggest a sense of the power imbalance in parent-professional relationships arising from parents' dependence on practitioners for children's treatment.

Indeed, a main consequence of investing such deep-seated trust in practitioners was the strong expectation that clinicians could resolve the challenges associated with a child's cleft. Among both mothers and fathers, feelings of reliance and expectation in relation to specialist nurses were strong in the first year of a child's life. Parents often stated they 'could not have managed' in the nurse's absence and relied strongly on them for help with feeding, information and emotional support. However, such feelings of reliance also extended to the wider team along a child's treatment course, throughout childhood and adolescence:

'I've never lost confidence in [surgeon] or the people that he has, from the beginning I suppose because I don't **know** anything else and I don't know anybody else. I trust the people that I've got. I think that's a **very** big part. I suppose if they said she's got to have another 16 operations, then I'd be right behind her – if it's for her good.' (Mother of Jade aged 7 years)

Parents were consequently vulnerable in their dependence on practitioners, on whom they had no option but to rely in order to

continue with their child's treatment. Needing to maintain their belief in 'being in the "right" hands', parents constructed the practitioners providing cleft treatment as the main source of solutions to the problems they faced.

A second consequence of this deep-seated trust was that parents chose to follow the lead of clinicians for their child's treatment decisions. Although some cleft treatment might be seen as elective in nature, parents in the study described decision-making for such treatments as a 'no choice' or 'automatic' scenario, maintaining that they had no alternative but to defer to professional recommendations for intervention, because of their expertise. Such attitudes were common at the beginning of a child's initial treatment course, but continued throughout. Parents appeared to be grateful for the opportunity to 'go along with' the decisions of professionals:

'At the end of the day, if he [orthodontist] thinks that's the right thing, then who am I to judge it...if they think it's the right way to go, then who are we to disagree?' (Father of Kelly aged 17 years)

Parents' accounts suggested an absence of perceived explicit choice for them in decisions about treatment. Further, their accounts held little sense that children themselves took an active role in decision-making (though it should be noted that children did not take part in the study and their perspectives may have differed significantly from those of their parents). One exception however, was the case of decisions relating to orthognathic surgery to re-align jaws in late teenage years:

'But that is not down to me – that will be up to Scott whether he wants the surgery done or not – if he needs it, that's his choice. I've already been told that – that will be his choice.' (Mother of Scott aged 5 years)

While parents at least perceived an explicit choice about orthognathic surgery, they did not expect to be part of the decision-making process, perceiving professionals to have deemed the young person as the decision-maker in this instance. Thus, parents' decisional stance even here, appeared to rest on the guidance of professionals.

Parents explained their compulsion to delegate power for decision-making to professionals with reference both to feelings of responsibility to their children and perceptions of practitioners as experts. By leaving decisions to professionals, parents could avoid the emotional burden of feeling responsible for a 'wrong' decision. Feeling they lacked the requisite knowledge to make decisions that would have long-term consequences for children, parents deferred to experts who 'knew best' and satisfied their goal of 'doing the "right" thing':

'Well it was easier [leaving decision to clinicians]. I've not had to make a decision where I've thought am I going to feel in 'x' years time that I've let her down or I've made the wrong decision, 'cause that's the worse thing – you don't want that for your children, you don't want to think – did I make the wrong decision? So it's better [for practitioners to take the lead] 'cause you're reassured.' (Mother of Sara aged 20 weeks)

Such delegation was presented by parents however, as an active choice in which they described feeling that their views were taken account of in considerations about their child's treatment:

'At the end of the day it was mine and her Dad's decision. You wasn't expected to go along with their [clinicians'] rules, you was asked if you would like to go along with their rules. Everything was very considerate. Because I asked the team and they were in favour for it [surgery]. They said it's not their

decision, but they were in **favour** of that decision.’ (Mother of Liz aged 20 years)

Parents accepted practitioners’ recommendations to intervene with treatment rather than do nothing as being ‘right’ for their children, both because of the imagined benefits of such treatment and respect for the perceived expertise of the professionals leading the decision-making process. Although parents felt taken account of in decision-making, they chose to trust in professionals to make the ‘right’ decisions about their children’s care, and in their concern about ‘doing the “right” thing’, were often vulnerable to the power imbalance inherent in relationships with practitioners, on whom they were compelled to rely for cleft treatment over an extended period.

Discussion

This study explored in-depth how parents experience and manage treatment decisions for their child’s elective surgery. The study was conducted in a specialist centre in the UK’s NHS where families are not required pay for cleft treatment. While no financial element entered into decisions for these parents, emotional, social and cultural expectations appeared core to decision-making because the condition affects not only a child’s function but their appearance, communication and identity. It suggests that in such circumstances, emotions, beliefs and values are key influences on the motivation of parents. The findings reveal that parents appeal to ‘doing the “right” thing’ as part of a perceived ‘moral’ obligation of being a ‘good’ parent, by pursuing available treatments in attempts to ‘normalise’ the effects of their child’s cleft. In so doing parents invest hope both in the power of cleft treatments and in specialist clinicians to give their children better opportunities for social inclusion. Parents relied strongly on practitioners to lead decision-making for children’s treatment and may consequently be vulnerable not only to wider cultural pressures but also to the power imbalance inherent in relationships with them.

Notions of ‘good’ parenting are socially and culturally constructed in different ways worldwide (Lamm & Keller, 2007), however the ‘moral’ dimension characterising parents’ felt responsibility about ‘doing the “right” thing’ around decision-making in this study has also been noted in the Western literature, for example in relation to children’s general surgeries (Darbyshire, 1994) and the care of disabled children (Carnevale, Alexander, Davis, Rennick, & Troini, 2006). It is suggested however that such ‘moral tales’ (Baruch, 1981), may also be mechanisms through which parents can demonstrate they are fulfilling ideals of ‘good’ parenting, thus protecting themselves from criticism about their parenting competence (May, 2008).

Similarly in Western literature, research has previously identified parents’ concern about taking action to ensure everything possible is being done for their child (Henderson, 2008; Larson, 1998). In studies of surgery for scoliosis, cochlear implants and ambiguous genitalia, parents have similarly reported viewing children’s surgery as essential rather than a choice, even when outcomes may be uncertain (Bridewell et al., 2000; Sach & Whyne, 2005; Sanders et al., 2007), suggesting that parents are ‘trading-off’ perceived short-term discomfort and risk for longer-term emotional and social improvements. ‘Regret theory’ proposes that in conditions involving risk, people often make decisions under uncertainty by anticipating the consequences of a particular choice and comparing them with consequences that might arise from a different choice (Loomes & Sugden, 1987). It proposes that seeking to avoid feelings of regret arising from not taking action may be a strong influence on a person’s drive to do something rather than nothing. Anticipating future regretful feelings about

failing children by declining cleft treatment was evident among parents in this study and appeared to play a significant role in their pro-treatment stance. However, it should be noted that despite efforts to recruit participants who had refused cleft treatment for their children, clinicians were unable to identify any such parents, and their views are accordingly absent from this study.

It has been suggested in the decision-making literature that a more ‘spontaneous’, less ‘logical’ approach to making decisions may help the decision maker to avoid the discomfort of pre- or post-decisional conflict (Higgins & Kayser-Jones, 1996) and this may partially explain parents’ eagerness in this study for ‘doing something’. As a consequence of the understandable urge to seek solutions in this way, it may be challenging for parents to resist the offer of treatments for their child. It has been suggested before that parents may step on a ‘treadmill’ of long-term treatment which is comforting, but which may inhibit their ability to fully deliberate and make real choices in about ‘normalising’ treatments (Feder, 2006). Aspinall proposes that prior to operations, important ‘work’ is needed in the form of talking between parents, children and professionals so that a child may be part of, not an object of, the surgical change process (Aspinall, 2010).

A key influence on parents’ decisions to pursue cleft treatment was their desire to facilitate their child’s social ‘fitting in’. In line with other research findings in the West, parents in the study did not challenge societal notions of ‘normality’ but assumed them as a given (Sanders et al., 2007) so that surgically altering children to conceal signs of ‘difference’ was justified as ‘doing the “right” thing’ (Abelow Hedley, 2006). Parents’ urge to ‘normalise’ children to protect them from emotional and social pain has been previously documented in studies on ambiguous genitalia (Gough, Weyman, Alderson, Butler, & Stoner, 2008; Sanders et al., 2007) and restricted growth (Daniel et al., 2005), as has parents’ desire to project an image of their family unit as ‘normal’ when their child has a long-term condition (Piggot, Paterson, & Hocking, 2002). Since the pull parents feel towards the surgical ‘normalisation’ of a child is deeply influenced by their fears about social exclusion, it has been suggested that the hope for a relatively straightforward surgical ‘fix’ may be strong (Edwards, 2006). The findings of this study suggest this to be the case. Turning to surgeries in this way seems a logical response to the stigma parents feared their family would face, though there was evidence that parents lived with the ‘paradox’ (Larson, 1998: p. 870) of loving a child as they were, while simultaneously wishing to erase their impairment. Aspinall suggests that parents are often vulnerable to a need to put things ‘right’ and fulfil deeply felt parental obligations (Aspinall, 2006). Rather than making a distinction between surgeries that were essential and elective in ways that made respective connections with function and appearance, parents viewed mostly all the treatments offered as necessary. In consequence, contrary to concerns that altering children surgically might be unethical, parents saw ‘normalising’ their child as a key part of their parental ‘moral’ obligation. Surgical care for cleft lip and palate is limited however, and physical marks will almost always remain in the form of scarring or growth disturbance (Strauss, Broder, & Helms, 1988). Parents in this study may have been vulnerable then, in their concern about their child ‘fitting in’, to seeing such treatments as a complete ‘cure’.

Trust in healthcare practitioners is acknowledged as particularly important to fostering therapeutic relationships in long-term care in Western countries (Calnan & Rowe, 2005). The study findings appear to support the view that relationships in children’s conditions may often involve ‘obligatory trust’ (Carnevale, 2004: p. 240) for parents because of a natural dependence on practitioners providing care (Brinchmann et al., 2002). In other studies, parents have been reluctant to risk taking decisions that may have adverse

consequences for their child (Alderson, 1990). Indeed, families may have no option but to believe in 'being in the "right" hands' because to do otherwise would be an added emotional challenge, threatening to hinder coping (Henderson, 2008; Kraetschmer, Sharpe, Urowitz, & Deber, 2004). The UK NHS has a relatively limited 'litigation culture' (Talbot-Smith & Pollock, 2006) which might partly account for the passivity of parents in relation to practitioners in this study's setting. However, prior North American research on parents' perspectives of children's general surgeries suggests that parents' fatalistic thinking primarily arises from a need to maintain a vision of practitioners and systems (particularly surgeons) as trustworthy, even when adverse events occur (Sobo, 2005).

Conceptually, this study supports prior attempts to theorise about patient decision-making in Western healthcare settings which have suggested that existing models do not take sufficient account of context and complexity (Wirtz et al., 2006). It also broadly concurs with Gabe et al.'s theorising about decision-making in paediatric contexts (Gabe, Olumide, & Bury, 2004), as being influenced by i) the setting for the decision ii) the beliefs and agendas of the parties to the decision (parents/carers, children and professionals) and iii) the kind of coalition that might be formed between them. While studies of children's 'normalising' surgeries across the world have identified variation in parents' decision-making styles, from strongly compliant (Sach & Whyne, 2005) to reflective (Daniel et al., 2005) and cautious (Okubo, Takahashi, & Kai, 2008), this study suggests that in the 'normalising' treatment context across children's conditions, emotional, social and cultural influences are powerfully at play for parents when they are making choices about their children's care. In particular, social norms about parenting, appearance and medical authority may mean that such choices are understood and experienced by parents primarily as 'moral' in nature.

This study suggests it is important for parents to 'feel' involved in decisions about their child. The importance of achieving parental involvement through having emotional needs met and reaching shared understandings with practitioners and has long been highlighted in the literature (Alderson, 1990). Practitioners clearly have an important role in helping parents engage in decision-making, because expressing inner values and preferences may be challenging for them. Professionals have been encouraged to be aware of their personal and professional perspectives in the clinical setting so that they can help parents discuss the risks and benefits of treatment and the options available, including alternatives to surgery (Aspinall, 2010). Decisional support for parents might also be enhanced by affording them the opportunity of accessing the stories of young adults who have completed the treatment course in order to inform their decision-making.

Conclusion

The study has captured the complexities involved in parents' decision-making for children's elective surgeries in the context of their child's cleft lip and palate, where both functional and appearance-related concerns are important, 'normalising' treatments are offered and emotional, social and cultural influences are strong. It has revealed that social norms about parenting, physical appearance and healthcare practitioner power may significantly shape and influence parents' decision-making for their children's treatments. Such choices in this context may be experienced and interpreted as 'moral' rather than social. Services may have a role in helping parents manage such challenges, by establishing their needs for information on risks and benefits of treatment and its likely outcomes, including the possibility of repeat interventions and providing emotional/decisional support to consider all available options.

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