

“They did not have a word”: The parental quest to locate a ‘true sex’ for their intersex children

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ABSTRACT

Given the paucity of research in this area, the primary aim of this study was to explore how parents of infants with unclear sex at birth made sense of ‘intersex’. Qualitative methods were used (semi-structured interviews, interpretative phenomenological analysis) with 10 parents to generate pertinent themes and provide ideas for further research. Our analysis highlights the fundamental shock engendered by the uncertain sex status of children, and documents parental struggles to negotiate a coherent sex identity for their children. Findings are discussed in light of the rigid two-sex system which pervades medicine and everyday life, and we argue that greater understanding of the complexity of sex and gender is required in order to facilitate better service provision and, ultimately, greater informed consent and parental participation regarding decisions about their children’s status.

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When parents are told that their child’s sex is ambiguous, they are likely to find it difficult to accept, since sex of child is the first and perhaps most fundamental signifier of identity. When a new baby is born, friends and family universally enquire ‘Is it a boy or a girl?’, and this holds for intersex babies too (Intons-Peterson & Reddel, 1984; cited in Zucker, 2002). To date, only a few small studies have actually explored parents’ experiences when confronted with their children being diagnosed with ambiguous genitalia. These qualitative studies (Slijper, Frets, Boehmer, Drop & Niermeijer, 2000; Le Maréchal, 2001) have concentrated on the emotional reactions of parents, whereas the present paper examines how parents make sense of their child’s uncertain status. Specifically, we consider how prevailing assumptions about sex and gender influence negotiations about the children’s care and identity.

Intersex conditions

Preves (2003) describes intersex children as 'born with ambiguous genitalia, sexual organs or sex chromosomes' (p.2). The incidence of intersex conditions is reported at 2% of children when one considers chromosome, gonad, genital or hormone features (Preves, 2003). In addition, not all intersex conditions are identified at birth, and some may not be identified until puberty or later. This complicates the task of calculating numbers affected, and it may not be unreasonable to cite an incidence figure as high as 4%. This study will focus on infants born with ambiguous genitalia, a key early indicator of intersex. Ambiguous genitalia can arise through a variety of underlying conditions.

In cases of Congenital Adrenal Hyperplasia (CAH), the individual will have a 46, XX karyotype, but the body produces more androgens than normal due to an enlarged adrenal gland (see Gordon & Speroff, 2002). This leads to masculinisation of the external genitalia, ranging from an enlarged clitoris to a normally sized penis. Female internal organs such as ovaries, the fallopian tube and the uterus are formed, however. In cases of Androgen Insensitivity Syndrome (AIS), the insensitivity can be partial or complete (again, see Gordon & Speroff, 2002). Individuals have typical male pattern chromosomes (46, XY) and are gonadally male (they have immature, fully or partially undescended testicles), but they lack an androgen receptor. This means they are partially or completely insensitive to the normal levels of androgens produced by the testes. Hence male genitals may be only partially developed or do not develop at all. In complete AIS cases, more 'female' changes take place at puberty; for example, breasts develop and rudimentary female structures are formed (vagina, labia, clitoris). With partial AIS, future virilisation can occur.

There is a strong emphasis in the medical literature that both appearance of the genitalia as normal, and being raised consistently as male or female, are necessary for a child to develop a clear gender identity and achieve psychological well-being (see Carmichael & Alderson, 2004). This means that non-lifesaving surgical 'correction' of the genitals is often carried out in the first two years of a child's life. Arguably, normalising surgery is both unethical and serves to create a culture of secrecy and shame (Preves, 1998, 2003). Although the purpose of surgery is to de-stigmatise the child and to free her/him from feelings of difference it would encounter should she/he live on with ambiguous genitalia, Preves argues it actually serves to reinforce the stigma through degradation and shame.

The Intersex Society of North America (ISNA) has been a vocal and political group in outright disagreement with many surgical procedures. Some ISNA members who have undergone feminising genitoplasty perceive themselves to be 'mutilated' and deprived of normal sexual opportunities. Conversely, some members who have grown up without having had surgery say that they are happy with their bodies as they are and have "assertively reclaimed the word 'intersex'" (Warne, 1998, p.82). It is also worth pointing out that the birth of intersex children is treated more positively in some non-Western cultures (Kipnis & Diamond, 1998). Parents in Western societies, however, are likely to construe an intersex child as problematic at best and abnormal at worst.

Parents' perspectives

The understandings and experiences of parents of children with ambiguous genitalia are under-researched. However it is likely that a number of 'parent factors' contribute to the overall outcome for the child. For example, Howe (1998) argues that parents communicate a sense of shame to their children as they grow up, which makes for a fraught relationship plagued by issues such as rejection and guilt. Carmichael and Alderson (2004) also note the importance of parental adaptation to the child's health condition for the subsequent adaptation of children (Thompson, Gustafson, Hamlett & Spock, 1992; cited in Carmichael & Alderson, 2004). In addition, Liao and Boyle (2004) state that from their clinical experience of working with intersex adults, parents need to come to terms with intersex first in order to enable their children to accept their status. These authors highlight the probable importance of sustained support of parents for coping with losses and fears, which are engendered by prevailing ideologies of 'normal sexuality' and 'normal life'. The present study may help to clarify difficulties faced by parents of intersex infants, particularly in relation to commonly held understandings of sex and gender.

There are only two known studies which consider the experiences of parents whose child has been diagnosed with an intersex condition. Slijper, Frets, Boehmer, Drop & Niermeijer (2000) looked at the emotional reactions of 18 parents and 10 adult patients to the clinical diagnosis of AIS. They found that for the majority of parents and adult patients, early reactions to diagnosis were ones of shock, grief, anger and shame. Mothers identified current feelings of guilt significantly more than fathers and emotional reactions were more long-lasting in mothers and adult patients than in fathers. However, it is not absolutely clear how the categories of emotional reactions were arrived at and analysed in this study.

The second study, an unpublished thesis by Le Maréchal (2001), is summarised by Carmichael and Alderson (2004). In this qualitative study, 20 parents were interviewed, including seven couples. The 17 children whom the parents represented all had AIS. It was found that parents commonly reported devastation, disbelief and confusion. Almost all of the parents talked about their experience of grief on finding out about their child's condition. This was most often directly related to the discovery that their child was infertile and hence linked to a loss of possible grandchildren. In Le Maréchal's study, the grief was also reported to be linked to fears around their child's future relationships and capacity for sexual intimacy.

The present paper builds on these studies by adopting an explicit focus on how parents construe intersex in terms of assumptions made about sex and gender. We report on a qualitative interview study with parents of children under six, born with unclear sex, and concentrate mainly on the process of diagnosis and decisions made about intervention. It is possible that the study may have implications for raising the awareness of health professionals and parents alike about the complexity and variability of sex and gender.

The two dedicated studies cited above focused solely on children born with AIS. The current study involves parents whose children had a variety of diagnoses leading to ambiguous genitalia. Also, both previous studies spoke to parents of very young children right through to parents whose children were in late adolescence or their early twenties. The current study will only investigate the accounts of parents whose

children were born in the last five years. In this way we will be in a good position to examine the impact of current treatments and services from the perspective of parents.

METHOD

As our focus is on parents' perspectives, and because little research on this topic has so far been conducted, we adopted a qualitative approach. Qualitative methodologies enable parents' meanings to be elicited. Specifically, we used semi-structured interviews to facilitate rich, participant-centred accounts. Smith and Dunworth (2003) state that 'qualitative approaches...are generally engaged with exploring, describing and understanding the personal and social experiences of participants and trying to capture the meanings that particular phenomena hold for them' (p.604).

Semi-structured interviews are democratic and flexible, in that a rigid structure is not imposed (Smith, 1995). The researcher is guided by the schedule rather than dictated by it. It is acknowledged that the researcher has ideas about areas of interest for the interview and will have composed some questions to reflect these, but from the phenomenological position, the participant is the expert on the position. The researcher's aim is to enter the social and psychological world of the respondent as much as possible. Thus the researcher has the flexibility to follow the concerns and interests of the respondent, and to probe new areas of interest which arise in the interview. Smith et al (1995) highlight other benefits of semi-structured over structured interviews as the facilitation of rapport and the production of 'richer' data.

To analyse participant accounts, we opted for Interpretative Phenomenological Analysis (IPA - Smith, 2004), an increasingly influential method used mainly by health psychologists and suitable for relatively under-researched topics (for recent examples of health-related IPA research see Ogden, Clementi & Aylwin, 2006; Bramley & Eatough, 2005; Howes, Benton & Edwards, 2005). The constituent parts of IPA are summarised by Smith (2004). IPA is phenomenological in that it is concerned with individuals' perceptions of events. Meaning is central: 'the aim is to try to understand the content and complexity of...meanings rather than measure their frequency' (Smith, 2003, p.64). IPA is clearly grounded in the text but also moves beyond the text to a more interpretative and psychological level. The interpretative part of IPA recognises that the researcher has an integral role in making sense of the participant's account. Smith (2004) calls this aspect a 'double hermeneutic': 'the participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world' (p.40). For the present study, IPA is appropriate as we focus particularly on the meanings parents attribute to intersex, and sex and gender more broadly. In addition, IPA allows us to attend to both unique themes within an interview transcript and to highlight common themes across cases.

Recruitment

Before the study began, ethical approval was sought and gained from the Local Research Ethics Committee. The participants were parents of children born in the last five years with unclear sex, and were all under the care of a regional paediatric endocrinology team and were recruited by the specialist nurses working in this team. The second author interviewed each parent at a time and place convenient to them.

The aim was to recruit a sample of parents whose children were born with unclear sex. It was intended to try to recruit mother-father pairs. This was to enable the role of gender to be explored where appropriate, as the views of fathers have been relatively neglected in the past, leading to a literature dominated by mothers' perspectives. The final group of participants included three couples, two mothers from partnerships where the father chose not to participate, and two single mothers. Thus there were three male and seven female participants in the study and the participants were parents of seven children. The children were all two years old or younger, apart from one child who was five years old.

Regarding ethnicity, eight participants were white British, one participant was British-Asian, and the other participant was British-African. Of the seven children, four were being raised as girls, and three as boys. The conditions which the children had been diagnosed with are reported here as stated by the participants. Of the girls, three of the four were diagnosed with CAH, a masculinising condition affecting external genitalia and caused by excessive androgens in the body. The other girl was diagnosed with pure gonadal dysgenesis. Any specific diagnoses of the boys did not emerge during interviews.

Interviews

Eight interviews were conducted in family homes, one was conducted in a participant's work office, and the other was carried out in a room in the university. Interviews lasted roughly between 45 minutes and 90 minutes, and transcript lengths varied from 5,264 to 13,204 words. Interviews were conducted individually, other than for two participants. One mother's partner was present for the interview (he had already been interviewed on his own), and another mother's own mother was present.

Before the interviewing process, we developed a topic guide of relevant areas to be covered:

- the time prior to receiving a diagnosis,
- the process of finding out about their child's status,
- decisions and medical interventions,
- parents' understanding of conditions (then and now),
- how they coped emotionally (then and now),
- support systems and their uses,
- effects on their feelings about their child,
- things they would change about the process, and
- ideas about their child's future

For the present paper, we concentrate mainly on parent's responses to questions around diagnosis and treatment, and how these are informed by assumptions about sex and gender. Under each topic we had actual questions formulated using a broadly narrative style ('Can you tell me about...'). All interviews were audio-taped with parents' consent, and the tapes were transcribed verbatim.

Analytic procedures

To begin with, each transcript was read several times. Next, each transcript was examined systematically and descriptive codes noted in the margin. Following descriptive coding, transcripts were re-read and coded at a more abstract or psychological level to obtain higher-level codes (e.g. 'need for knowledge',

'emotional rollercoaster'). The next stage was to group these codes into related themes (e.g. 'struggle for clarity', 'emotional responses'). Themes were then arranged into possible hierarchies. For example, much of the data related to the experience of uncertainty; this theme seemed to subsume many of the other themes. A table of themes was devised for each participant, which denoted the relationships between overarching themes and subthemes. However, there were also great similarities between these separate analyses and in this paper we present the common themes. The validity of the analysis was established through independent analyses of select transcripts by the team followed by discussion and agreement about key themes. As well, an external colleague coded two transcripts and discussed convergence with the second author (NW). In this way purely subjective interpretations were avoided and complexity in the data recognised.

ANALYSIS

The two core themes presented below were expressed by all parents, in one form or another. The analysis suggests a core theme pertaining to parental (and staff) bewilderment upon detection of a 'problem', and an ensuing climate of pervasive uncertainty about the sex status of the child. In turn, the second core theme refers to the parents' desperate (and in some cases ongoing) quest to discover the 'true sex' of their child.

Intersex as unfathomable 'otherness'

This theme concerns parents' (and staff) difficulty in comprehending 'intersex', and comprises early confusion and disbelief, a profound absence of knowledge, and a lack of language with which to categorise their child's (non-) status. Parents' experiences of uncertainty started from the point where it was identified that there was something wrong or different with their baby due to ambiguous genitalia. A basic, natural 'truth' was shattered, that is, that all humans are either male or female. A sense of bewilderment was common:

we were just (.) confused obviously, what don't, why don't they know what he is? (Paul)

It is as if the sex of child should be self-evident and utterly unambiguous. But when external genitalia, a quintessential marker of sex, are found to be indistinct, then serious doubts arise about sex status, as one father describes:

The midwife said 'congratulations you've had a girl' and from that, that minute I were just waiting for her to say you know, 'we've made a mistake', you know, 'it's a boy', 'cos I saw straight away what [daughter] were made up of. { } I knew straight away that there was sommat wrong (Rick)

The uncertainty engendered as a result of this discovery seemed to rock parents' fundamental sense of the world. It appeared that somehow having a child that was not clearly male or female, who did not fit neatly into the 'truth' of the 2-sex system, was akin to their child having no status. One mother was told at first that her child was a boy, she was then told it was a girl, and then she was told that they weren't sure. She described feeling left in limbo with this uncertainty. She seemed to

imply that her child was somehow something other than human, or possibly even less than human:

As I remember it, we were told she was a boy, we were told she was a girl, and then we were told they didn't know. And that's kind of where I remember being left, as 'we don't know'. So having this baby that was a nothing so to speak, and then going to the ward, and just being left in this state of not knowing really (Anna)

The quote implies that sex itself humanises a person; sex is so fundamental, that without it, a human seems to have no status and is a 'no-thing'. Similarly, one couple talked about not knowing what their child was. On the surface, it would appear that they were referring to their baby's sex, but perhaps their language hinted at deeper concerns about their infant's ontological status:

As soon as she was born, nobody knew what, what, what (.) what she was as such (Rick)

I just felt numb you know and, I didn't, I couldn't register with, with her anyway, 'cos I didn't even know what she was! (Naomi)

One mother implied she saw her child as something sub-human:

I thought he's just like a (.) half man and half lady. Exactly what shall I tell you, it's not even a man, it's not even a lady. I thought like that. (Baseema)

Clearly, the distressing experience of having an intersex child challenges the limits of comprehension and language – the child is defined negatively in terms of what it is not; there is no available category to confer identity. This holds for health professionals as well as parents:

I said 'is it girl or a boy?', and they didn't', they just didn't say anything. They did not have a word. (Baseema)

For parents, this silence among health professionals about intersex conditions was particularly shocking. One enduring lay view of doctors is as all-knowing and god-like. This illusion was shattered for a number of participants, and this seemed to contribute to their overall confusion. Parents were confronted with the fact that yet more of their ideas were being challenged; this time, their fundamental beliefs about doctors and medicine. For example, one father expected all doctors to understand the nature of ambiguous genitalia:

There was something wrong somewhere down the line and no-one could just pin point what it was. It's, erm, you expect these things to all, you know, be, be, everybody to be aware of the situation of everything but, you know, it's obviously not like that (Rick)

For one mother it was the lack of communication which she noticed. She found she had to actively seek out information from health professionals. On asking someone, she felt that they would still not tell her what was going on. She put this down to their own lack of knowledge:

But nobody said anything to me, and then I mean I had, people had to come to me and say, well, I had to find people just to say 'well what's actually going on?', and

still nobody would say anything to me, 'cos I don't think they knew themselves either (Judy)

Because of the importance of sex in categorising babies (Intons-Peterson & Reddel, 1984), the parents interviewed also experienced difficulties regarding disclosure to friends and family. For example, as with other parents, Naomi felt uncomfortable changing her baby's nappy in front of significant others, or in a baby-changing facility:

I was scared to change her nappy in front of anybody, simply because I didn't want people peering over my shoulder (Naomi)

Implicitly perhaps, the physical mark of otherness is construed as monstrous, and likely to upset others inured to the two-sex system. The same mother, Naomi, who had to ring friends and family back with news that the sex of her baby was not clear, was concerned about the images people would conjure up of her infant:

I mean what sort of picture? I was more bothered about you know, kind of picture are they conjuring up in their mind of a, what sort of baby I'd had! You know, you're obviously getting a picture in your mind of what, what can she look like, sort of thing... (Naomi)

The use of the word 'conjure' is interesting and suggests the production of an illusion, again underlining the unreal status of intersex in the popular imagination. The focus on outward (genital) appearance ('what can she look like') reiterates the importance of 'correct' genital anatomy for human status, and implies that deviation from the norm is to be imagined as grotesque.

In sum, parents universally reported a failure of language and understanding when confronted with a child of indeterminate sex. This breakdown in comprehension extended to health professionals as well as the general public and highlights the cultural dominance of the male-female dichotomy in conferring sex status. Thus, the anterior quality of intersex children is reinforced by medical uncertainty and (projected) popular visions of bizarre mutilated creatures.

The struggle to recover a 'true sex'

In the light of the angst surrounding the ambiguous sex status of their children, all of the parents interviewed described a determined, if difficult, effort to secure an unequivocal sex category for their child as either male or female. This project entailed a series of encounters with health professionals and is framed by established biological criteria within a medical context.

It seemed difficult for parents not to attribute a sex to their child while status remained medically unresolved:

I couldn't say 'it', so we just said in our mind, you know, we'll just say 'he' until we find out (Naomi)

In the absence of medical information, parents based their judgements on superficial resemblances and physical features. One father spoke about trying to work out the sex of his child during the time that tests were being carried out:

You just want somebody to walk down corridor to you like and say 'she's a girl', you know, 'congratulations she's a girl, I know 100% she's a girl', but that just never, it never comes, it never happens, even, you know, after a week or so we still don't know what sex your baby is, that's just (.) you, you talk about basically rubbish, between, like me and [wife] did, you know, erm 'well she looks like our [son] so we think she's a boy'. That's just totally irrelevant. You, you're making your own minds up on what you think, you know, to try and probably, I don't know, ease pain, to (.) not make it sound as erm (.) serious as it is (Rick)

The desire for an unambiguous ('100%') decision is clear. When this is not delivered, parental speculation runs riot, stretching to the flimsiest of evidence ('rubbish'), underscoring the desperation to name, and so know, their child. One mother tentatively felt her baby was a boy from the appearance of his genitals, although at that stage there was still some uncertainty. However, once this path towards maleness was embarked on, it seemed harder and harder to leave it as time went on. The process of emerging clarity was 'finalized' when the results of chromosome tests were returned:

Then we got to look at his thing [penis] and obviously from seeing it then it just looked like (.) erm it didn't look like much really, (.) it mainly looked, briefly did look like a males, so I think that from then we decided that we would call him a male, do you what I mean. I mean I know they can't don't have much features, and I know they don't sometimes they don't look like boys or girls, but he felt like a boy so we just referred him as a boy anyway. But obviously then they came back to us and said, well we've found some chromosomes which he has got XY chromosomes but his X, his Y's are disfigured, so from then on we decided well yeah he's definitely a boy, do you know, even if they asked us or not, which they came to us and said 70% of him is actually male, but then they gave us that choice which way do you want to go (Judy)

Again, the importance of external genitalia are emphasised as an informal way of 'telling' sex. But here the parents' intuitive sense of maleness is also underlined, and this helps to make decisions when presented with the chromosome evidence.

In their struggle for clarity and acceptance, some parents talked about actively reducing ambiguity through the fulfilment of gender stereotypes. One father admitted to dressing his child in a more feminine way. He had also said that from time to time he had caught himself thinking about whether his child was a girl or a boy, thus dressing her in pink was a way of demonstrating (or reminding) himself and others that she was a girl. Perhaps he did not feel totally comfortable with dressing her like this, and this may possibly have caused him some anxiety:

I guess I probably tended to dress [daughter] more in pink to demonstrate publicly that she was a girl, than I would have worried about my older daughter, who was, who had quite long hair from quite young, she always had hair, so she always looked like a girl. [Daughter] actually has always looked a girl as well, she always had, both children had proper hair, as it were, and looked like girls from quite early on, but I probably felt that the way in which she acts could be seen as being boyish, so

I've tended to dress her more female than our other daughter, and worry about that. Not worry about it, but catch myself doing it. (Andrew)

One mother also felt she could start to accept her child as a daughter more after making her fit more strongly with gender stereotypes:

When we'd named her and she started wearing pink and just little things like that, I could start to accept it (Anna)

Fulfilling gender stereotypes can have the function of increasing parents' clarity over their child's sex of rearing – temporarily at least.

Giving birth to a child of unclear sex meant that parents had to confront their understanding of the 2-sex system and their beliefs about what actually constitutes sex. Parents had to go through a process of questioning taken-for-granted beliefs and shifting their boundaries regarding the importance of markers of sex, in order to retain some clarity about their child. Initially, as mentioned, the importance was placed on the appearance of the external genitalia for determining sex:

I actually looked down between her legs and there was... you know, there was no sort of definite girl or boy (Naomi)

However, as time went on, the importance or value of external genitalia in defining sex took less precedence. Rather, the 'clarity' of sex was offered by the presence of internal reproductive organs, and of chromosomes. For example:

But she is female, because she's got the ovaries and everything (Tracey)

This is an interesting shift, from outside (genitals) to inside (ovaries), but still upholds the notion that sex is defined biologically as something marked on (or in) the body.

One father was surprised by the health professionals' fluid ideas of sex. He felt that it was clear that his child was female due to her chromosomes:

It was suggested { } that she would make a very nice boy. They looked at her genitalia and said we could make her into a boy, and we were, I suppose a little surprised by that because we knew that if the chromosome test had been correct, then chemically or whatever, I'm not a biologist or a medical person (.) In my mind that made her a girl, irrespective of the appearance of the genitalia (Andrew)

All parents assigned greater clarity to particular medical tests in line with this idea. Chromosome tests and tests to determine the internal reproductive organs of the child were seen as giving more authority than mere genital appearance. For example, the results of a scan enable one mother to eradicate the ambiguity of her daughter's sex ('she's no mix up'). She uses the phrase 'without a shadow of a doubt', which implies an exaggerated, almost impossible degree of certainty:

Obviously the scan indicated that everything inside is female, so, without a shadow of a doubt she is a girl, she's not like, a boy on the outside or a girl, you know, she's no mix up like that (Naomi)

The 'everything inside' is signalled as the true signifier of sex, residing deep within a person rather than on the surface.

The reduction in anxiety as a result of the seeming increase in clarity regarding their children's sex was mentioned by one father, who described the 'roller coaster' of emotions, which was not resolved until clarity of her 'true sex' was discovered:

It were just an emotional roller coaster really, until [consultant] said, 'She's got CAH. She needs medicines for the rest of her life, and she's female. 100% female.' As when, it were just a sigh of relief you know it's, everything just seemed to be explained do you know, he told you what were happening. It was a roller coaster from { } when she were born to then (Rick)

All parents struggled to some extent with the experience of uncertainty relating to their child's unclear sex. Some found that they had to make their own attributions or judgements in order to reduce their anxiety. However, the relative clarity of authoritative medical tests of chromosomes and internal reproductive organs ushered in a massive relief for most parents.

Surgery was also regarded as a solution to the 'problem' of intersex. One father expressed uncertainty as to whether his new-born would have to remain ambiguous ('we didn't know if she'd just stay like that for good'):

And he [surgeon] said to us { }, he says 'we can, you know, make, we can go either way with this, we can make a good boy or a girl', which was something, because we didn't know if she'd just stay like that for good or, or whatever (Paul)

Similarly, another father was less anxious about his daughter being nude in front of others following his daughter's surgery. His 'sense of relief' was related to the possibility of her having come to harm through teasing:

While previously she did look like a girl but with a penis and I think there's a sense of relief there, for me, in that yeah if she wants to run around in the garden with her clothes off like all the other children do in the summer then she's not going to be teased and people aren't going to talk (Andrew)

For some parents then, surgery was a means of increasing clarity. This seemed to be particularly pertinent when surgery was opted for at an early stage.

In sum, parents found it difficult to tolerate the ambiguity of intersex and made concerted efforts to construct and nominate sex status for their children in an information vacuum. As the quest for true sex progressed, great faith was then invested in various bio-medical indicators and tests as a means of banishing otherness and designating sex status. The implications of this analysis are now discussed.

DISCUSSION

The shock engendered by intersex babies is profound – it radically unsettles established taken-for-granted conceptions of sex and gender and marks one's child as 'other'. While existing studies have also reported parental shock and devastation in the context of intersex babies (Slijper, Frets et al, 2000; and Le Maréchal, 2001, described in Carmichael & Alderson, 2004), the above analysis moves beyond

emotional reactions to identify the meanings parents attached to intersex. Specifically, we considered how parental perspectives were shaped by adherence to the rigid two-sex system prevalent within the bio-medical hospital context and beyond.

One implication of this analysis is that a more fluid understanding of sex and gender would perhaps help parents cope with the initial impact of having an intersex baby. As Carmichael and Alderson (2004) argue, dominant cultural definitions of sex and gender need to be challenged, and health professionals should be trained to accommodate manifold permutations of sex so that parents of intersex children can be better supported. Health professionals with a greater appreciation of the difficulties faced by parents would undoubtedly facilitate better quality communication and support: 'a better understanding of the issues for parents would help health professionals to achieve the goals of consent-based, collaborative health care' (Carmichael & Ransley, 2002:7).

Clearly, there is a role for trained clinical psychologists to intervene and counsel parents of intersex children. Indeed, some parents had actively availed of psychological services and found this beneficial, although they also suggested that earlier referral would have been helpful. This suggestion makes sense in light of the profound disorienting impact of having a child with ambiguous genitalia. In particular, parents valued the psychologist's knowledge about future outcomes based on working with a range of prior cases. Routine early referral to a psychologist then could go some way to educating and reassuring parents about typical trajectories of intersex cases, and of course provide much needed emotional support. Parents also expressed a desire to talk through their experiences with other parents of intersex children. Indeed, one couple had been put in touch with other parents and were meeting regularly in informal settings, an experience they reported to be extremely rewarding. So, a combination of formal psychological help allied with unofficial parent-led support groups would seem to be important in facilitating parental coping with a challenging situation.

As the analysis has indicated, the very existence of intersex individuals may challenge scientific-medical efforts at defining and diagnosing sex status. What at first sight appears to be a simple task, the naming of sex, cannot solely rely on the make-up of external genitalia or internal organs, for this type of evidence can be far from conclusive, as our parents' stories suggest. Indeed, it is difficult to imagine sex assignment criteria to which all medical experts would subscribe, and we must accept that in certain cases the ascription of sex is simply undecidable. Perhaps then, health professionals should be encouraged towards a less biological understanding of sex status and to see sex as something which can be defined and performed in many ways. There is now a growing literature on the multiplicity of gender, which Hird (2003: 188) urges clinicians to appreciate:

'The patient's gender is always read as either male or female. There is no discussion of the possibility of both, neither, or a third gender, despite the sustained discussion of these possibilities in the intersex, transgender, feminist psychoanalytic and social psychology literatures'.

Moreover, Hester (2004: 218-9) makes the point that medical science, despite attempts to uphold the two-sex system, has produced a proliferation of sexed bodies by virtue of devising multiple markers of sex, such as genetics, chromosomes, gonads, hormones, internal phenotype, external phenotype and sex of rearing:

'Beneath the disciplinary gaze of the doctor, and despite concerted medical effort not only to eliminate the causes of variation and to intervene with surgical, endocrine and psychosocial methods to control the bodies of intersexed people, it is the fluidity of the sexed form of the human body that confronts us. Given the wide variety of combinations, it is no exaggeration to suggest that there are not two sexes, not even five sexes, but literally hundreds of possible sexes that humans can inhabit'.

Theoretically, the notion that sex as well as gender is constructed and multi-faceted leads to a necessary re-evaluation of the status of bodies within feminist and gender studies, since the social constructionist idea of the body as a tabula rasa upon which culture (including gender) is ascribed is disrupted. As Hester (2004) and others (e.g. Butler, 1993; Fausto-Sterling, 2000) suggest, bodies are active rather than passive, and may undermine attempts to fix gender in culturally sanctioned ways.

As mentioned earlier, there is also considerable cultural variation in constructions of intersex outside Western medicine, and movements such as the ISNA present powerful arguments against an exclusive two-sex system (see Warne, 1998). As well, there is also increasing media coverage of intersex conditions (e.g. 'Secret Intersex'; 'Middle Sex', both Channel 4, UK, 2005), which in theory could help deconstruct traditional notions of sex and gender. Despite these instances where intersexed people are depicted positively, it remains largely the case that to inhabit bodies which fall outside conventionally male or female prescriptions is to live on the margins of society (e.g. Grosz, 1994). A sustained rethinking of sex and gender is therefore required so that intersex can be discussed more openly in health contexts and more generally (see Hird, 2003).

Of course, the present analysis rests on a particular sample, and it would be useful to interview parents of children with a greater range of intersex conditions. Clearly, life-threatening and hereditary conditions, for example, might engender a different set of concerns in parents. Nonetheless, we have managed to interview quite a diverse sample and encountered very similar concerns. As well, the sample size was sufficient to enable saturation of core themes so that we would be confident of findings being applicable to parents in similar situations.

Another issue of note was the small numbers of fathers who opted to take part. In order to compare the experiences and understandings between the sexes, the number of participating fathers would have to have been larger and comparable to the number of mothers. The fathers (and mothers) who chose to participate in the study are likely to be those who were more open about how they felt. It could be hypothesised that some fathers may have thought it would be too difficult for them to talk in depth about their feelings. Even with the small numbers of fathers who took part, there was still a leaning towards a more avoidant style of coping, although this theme would need to be investigated with further research.

As this area is generally under-researched, there are many ways in which future research could expand on the preliminary findings of this study. For example, a longitudinal study looking at how parents' struggles change over time may give insight into the points in time which are particularly difficult for parents. In addition, there may be ways in which parents' experiences can be researched further using other qualitative methods. For example, the use of interviews plus diaries may help

people to express things that they feel embarrassed talking about. Using focus groups or observing support groups may give rise to information relating to how people gain support from others, or how people make sense of information in dialogue with others. It would also be very interesting to follow families in which the decision to delay or reject surgical interventions had been made. Due to the lack of information on outcome for patients without surgery, a detailed and rigorous longitudinal case study would be of high value. It may serve to challenge and/or confirm some ideas which exist about the effects of growing up without surgery.

In sum, more research is required into the perspectives of parents' when their child is born with ambiguous genitalia. It is interesting that intersex is receiving more critical attention and we suggest that both staff and parents would benefit from education and training to promote more fluid and dynamic understandings of sex and gender.

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