

Parents feel shock, anxiety and the need to protect children with genital ambiguity

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Parents of babies born without clearly defined male or female genitals experience a roller-coaster of emotions, including shock, anxiety and the need to protect their child, according to a study in the October issue of the *Journal of Advanced Nursing*.

UK researchers who spoke to 15 parents found that they were keen to find a sense of [harmony](#) between their child's genital ambiguity and the sex they raised them as.

"The parents we spoke to went through a dynamic and evolving process, which included their [willingness](#) to engage with professionals" says Dr Caroline Sanders, a Consultant Nurse working in paediatric [urology](#) and [gynaecology](#) at Alder Hey Children's NHS Foundation Trust in Liverpool.

"They had to deal with challenges relating to their lives, emotions and beliefs and one of the mothers, Faye, experienced serious abuse because people thought her daughter was different. At the other end of the scale, Imogene was delighted when a scan showed that her [child](#), who she felt looked like a girl, was female inside."

Dr Sanders teamed up with Professor Bernie Carter and Dr Lynne Goodacre from the University of Central Lancashire to carry out the study, which involved in-depth interviews with ten mothers and five fathers over a period of 18 months. Two of their 11 children – six girls and five boys – were under four and the remainder were aged five to 11.

All the children had disorders of sex development, which include conditions where the chromosomes, testicles, ovaries or sexual anatomy are not as expected. It's estimated that one in 300 babies are born with concerns about the development of their external genitalia and in one in 5,000 births the baby's sex is unclear despite expert examination.

Parents who took part in the study said the events following their child's birth were "confusing" and "chaotic" and led to bewilderment and loss of orientation. Several parents recalled that some healthcare professionals had been vague or hesitant when discussing their child's genital uncertainty, which heightened their [anxiety](#). This was compounded when healthcare professionals referred to their genderless child as "it", inferring that their child was "wrong" or a "freak".

Many of the parents protected their child by not sharing news of their child's condition with extended family or friends. Information was kept private, but not secret, while parents tried to understand what was happening. "You couldn't explain it because you didn't really know" said Gina. Maria felt the need to be open about it, but adds that: "My husband wouldn't have told a soul...because it is genitalia and is still looked at as something that's taboo." Brian, however wanted to talk about it. "I found it easier talking to people about it" he said.

Faye found local people's interest in her baby cruel, intrusive and alarming. She recalled people stopping her in the street, pulling the covers off her baby and saying "oh you'd never know would ya?"

Early surgical decisions raised strong emotions in some parents. Sian was anxious about whether she had done "the right thing", but Anne described a documentary that suggested that parents shouldn't be allowed to make decisions about genital surgery as "ridiculous".

Some parents were concerned about whether they had made the right

decision about their child's sex and subsequent gender and worried about their children feeling different to others and experiencing uncertainty in adolescence. They wanted to protect their child, but at the same time they felt that they needed to be honest with them as they grew up.

Reconstructive genital surgery made it easier for some parents to protect and bond with their child. Medical evidence about whether the child was predominantly male or female, and how they looked, guided the parents' decisions when it came to surgery. But one mother who learnt that her child had both male and female internal organs described the news as a "double whammy".

The parents also needed healthcare professionals to use consistent and understandable language to explain what was happening to their child and how they could move forward. However, in some cases there were no clear-cut answers, particularly when the conditions were caused by chromosomal abnormalities.

"Our study revealed the serious [emotional](#) traumas and dilemmas that having a child with ambiguous genitalia creates for parents" says Dr Sanders. "It underlines the need for greater sensitivity and understanding about the issues these parents face.

"Health professionals need to be aware of the impact that medical language has on parents, particularly in the early stages, and communicate with them clearly and regularly, checking that they understand what they are being told.

"We also feel that further resources are needed to support [parents](#) and children affected by these disorders, including the development of a national network – building on the work already done in Scotland - and integrated working to improve standards of care."

More information: Searching for harmony: parents' narratives about their child's genital ambiguity and reconstructive genital surgeries in childhood. Sanders et al. Journal of Advanced Nursing. 67.10, pp2220 (October 2011). [doi: 10.1111/j.1365-2648.2011.05617.x](https://doi.org/10.1111/j.1365-2648.2011.05617.x)

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