Cut it Out: The long term repercussions of surgical intervention on intersex infants

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What is intersex?

Intersex is an umbrella term for atypical congenital variations in one’s sex characteristics (chromosomal, hormonal and/or anatomical). In some clinical literature, the term “DSD” is used. Not all variations are considered “intersex” by all health professionals or researchers, as not all of these present with physical differences. Figure 1 lists some of the more commonly recognised, intersex variations.

Some authors claim the prevalence of intersex variations is as common as 1.7% (Blackless et al., 2000), whereas others state the frequency to be in 1 in 5,500 (Hughes, Houk, Ahmed, & Lee, 2006) or 0.018% (Sax, 2002).

Intersex people are as common as redheads!

Why is surgical intervention worth investigating?

Whilst sometimes surgical intervention is argued as required in order to enhance genital (or other) function, surgeries are often conducted on people with intersex variations to “fix” or create “typical” genitals (Warne & Raza, 2008). This approach aims to uphold social ideals of what males and females “should” look like at the cost of sexual pleasure and function which is disregarded (Lev, 2006). In some cases, surgical intervention can involve repositioning the clitoris which strips the organ of many pleasure nerves due to the accumulation of scar tissue (Creighton & Liao, 2004; Lev, 2006).

Methodology

The aim of the study was to conduct a retrospective investigation into the long term effects of surgical intervention on intersex infants in order to see how surgical intervention has impacted various aspects of life through all stages. This included investigating people with intersex variations’ perspective on the appropriateness of surgeries and gender rearing they experienced, their family relationships, and sex and relationships. A quantitative and qualitative survey was developed based on a needs analysis via a literature review. The survey was delivered online. Recruitment occurred via nine intersex support groups and word of mouth through the intersex community. Analysis was conducted via a grounded theory approach. After ineligible participants were removed, a total of 80 participants globally responded to the study. Quantitative data was then analysed using SPSS. Qualitative data is under analysis.

Results

Participants were also asked to state their current gender identity in an open-ended question. This enabled the researchers to encapsulate the range of subjective identities. A total of 60 participants responded to the question, with 31 participants (52%) currently identified as women, 10 identified as men (17%), 3 stated they were gender fluid (5%), only 2 identified as genderless (4%), and 7 had a combination of identities (11.5%). When compared with figure 2, there are clear differences between assigned sex and current gender identity for some participants.

Intersex status

Of those who did know their diagnosis at birth, AIS (n=16) and CAH (n=8) were the most common intersex variations diagnosed which align with the population statistics for these variations. A further 10 participants listed ‘ambiguous genitalia’, PIV, MKKH and Swyer’s Syndrome were all the least common variations stated by participants, with only 1 participant in each respective category.

Surgical intervention

A total of 49 participants stated they did receive surgical intervention in infancy or childhood and a further 30 stated they did not receive surgery. When participants were asked if they felt about the status of their surgical intervention, a total of 95.5% of participants (n=46) stated they felt the surgery was inappropriate with only 3 stating they felt that the surgery was appropriate.

The literature suggested surgical intervention may result in:

- Incorrect sex and subsequent gender assignments (24% reverse their gender assignment; Preves, 2003)
- Body image issues
- Resentment towards family/doctors
- Anxiety and depression
- Psychosexual harm or trauma
- Sexual dysfunction
- Shame (as a result of secrecy; Beh & Diamond, 2005)

Figure 1

Age group identifying a sex for different gender identity Male Gender not appropriate Female

<table>
<thead>
<tr>
<th>Age group</th>
<th>Gender appropriate</th>
<th>Gender not appropriate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ages 3-5</td>
<td>15</td>
<td>5</td>
</tr>
<tr>
<td>Ages 6-10</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Ages 11-15</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Ages 16-20</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Ages 20+</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

Figure 4

Those who were assigned male at birth and raised as boys were more likely to feel that their gender was inappropriate.

Gender appropriateness and family relationships

85% (n=27) of people with intersex variations who found their reared gender inappropriate had poor relationships with family.

<table>
<thead>
<tr>
<th>Gender appropriateness</th>
<th>Good relationships with family</th>
<th>Poor relationships with family</th>
<th>Pearson Chi-square</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reared gender appropriate</td>
<td>10</td>
<td>14</td>
<td>4.743</td>
</tr>
<tr>
<td>Reared gender not appropriate*</td>
<td>5</td>
<td>27</td>
<td>1</td>
</tr>
</tbody>
</table>

Figure 6

Sex and Relationships

A total of 71% (n=17) of those who found their reared gender appropriate experienced enjoyable sex; only 43% (n=12) of those who found their reared gender inappropriate experienced enjoyable sex.

It is statistically significant (p <0.04) that individuals who found their reared gender inappropriate were more likely to experience unenjoyable sex.

Conclusions

Whilst this study is ongoing, the quantitative data analysed thus far indicated that the long term impacts of surgical intervention on intersex infants had problematic outcomes for participants’ satisfaction, identity, family relationship and sex life.

- When they grew to adulthood the people with intersex variations in this study mainly felt the surgeries they experienced as infants were inappropriate.
- Around a third felt their gender of rearing was inappropriate from a young age, and the majority of those who felt their gender of rearing was inappropriate had negative impacts on family relationships.
- Over half felt their surgical intervention had a negative impact on their sex life. This challenges the idea surgery improves sexual function.

Therefore, it is imperative to reconsider the value of cosmetic interventions, and “function” ideals for infants with intersex variations.

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