

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 just 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 other studies state the frequency to be 1 in 4,500 (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 resecting 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 life 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 aligns with the population statistics for these variations. A further 10 participants listed "ambiguous genitalia". PIV, MKRH 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 how they felt about the status of their surgical intervention, a total of 95.5% of participants (n=64) stated they felt the surgery was inappropriate with only 3 stating they felt that the surgery was appropriate.

Do you feel that surgery was appropriate or inappropriate?

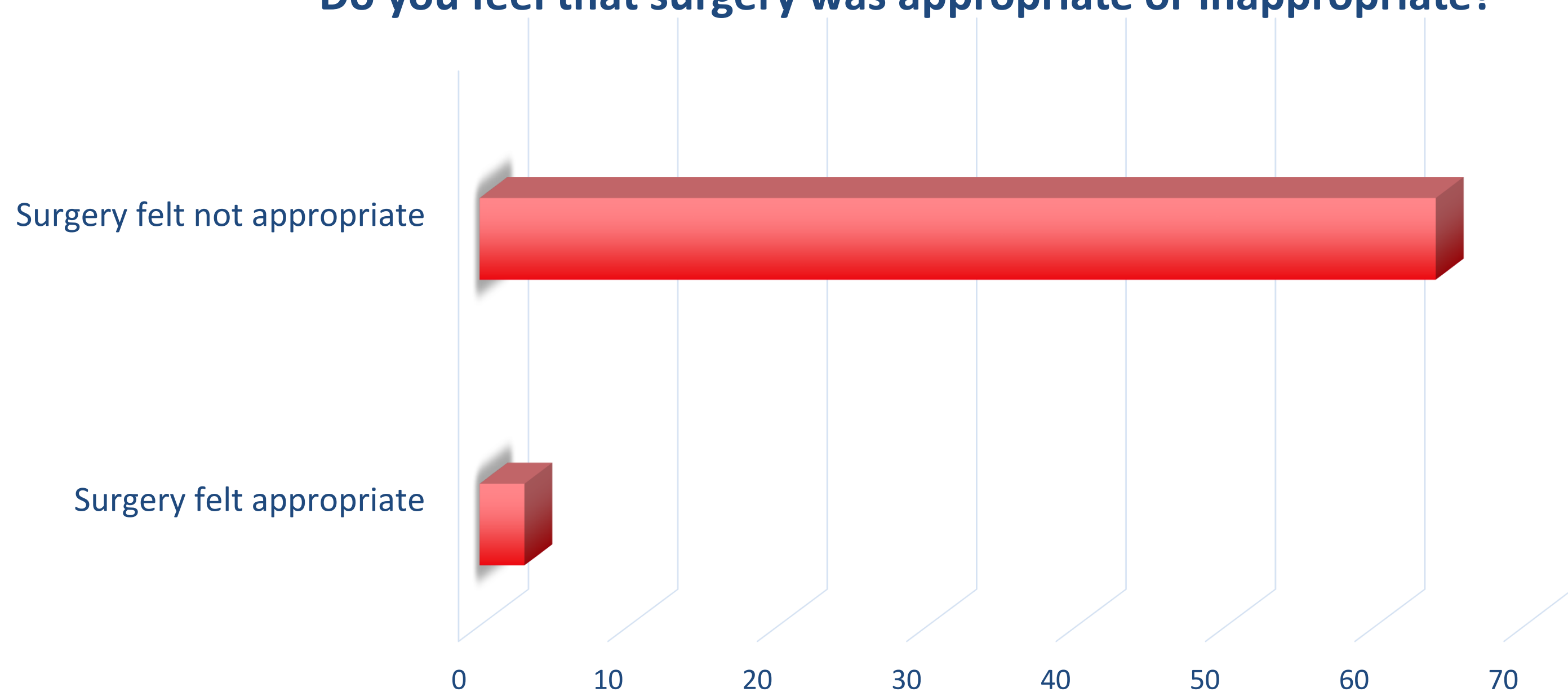


Figure 3

Some Commonly Recognised Intersex Variations	
Congenital Adrenal Hyperplasia (CAH) (complete) Androgen Insensitivity Syndrome (cAIS)	Klinefelter's Syndrome Turner's Syndrome
(partial) Androgen Insensitivity Syndrome (pAIS)	Turner Mosaic
5 alpha reductase deficiency	Turner/Klinefelter mosaic
Leydig Cell Hypoplasia	Swyer's Syndrome

Figure 1

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)

Sex assigned at birth	Total
Female	43
Male	31
Ambiguous	1
Not assigned	2
Did not disclose	3
Grand Total	80

Figure 2

Gender Appropriateness

Age group identifying a want for a different gender identity	Gender appropriate	Gender not appropriate
Ages 3-5	3	15
Ages 6-10	1	8
Ages 11-15	0	3
Ages 16-20	0	2
Ages 20+	1	5

Figure 4

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

Assigned sex at birth	Gender appropriate	Gender not appropriate	Pearson Chi-square	df
Female	21	15	7.633	1
Male*	6	20		
Ambiguous	0	1		
Not assigned	1	1		
Did not disclose	2	1		

Figure 5

Gender appropriateness and family relationships

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

Gender appropriateness	Good relationships with family	Poor relationships with family	Pearson Chi-square	df
Reared gender appropriate	10	14	4.743	1
Reared gender not appropriate*	5	27		

Figure 6

It is noteworthy that 91% (n=19) of those who identified wanting to be another gender under the ages of 10 also stated they had poor relationships with their families.

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.

DO YOU FEEL THAT SURGICAL INTERVENTION HAS IMPACTED YOUR SEX LIFE?

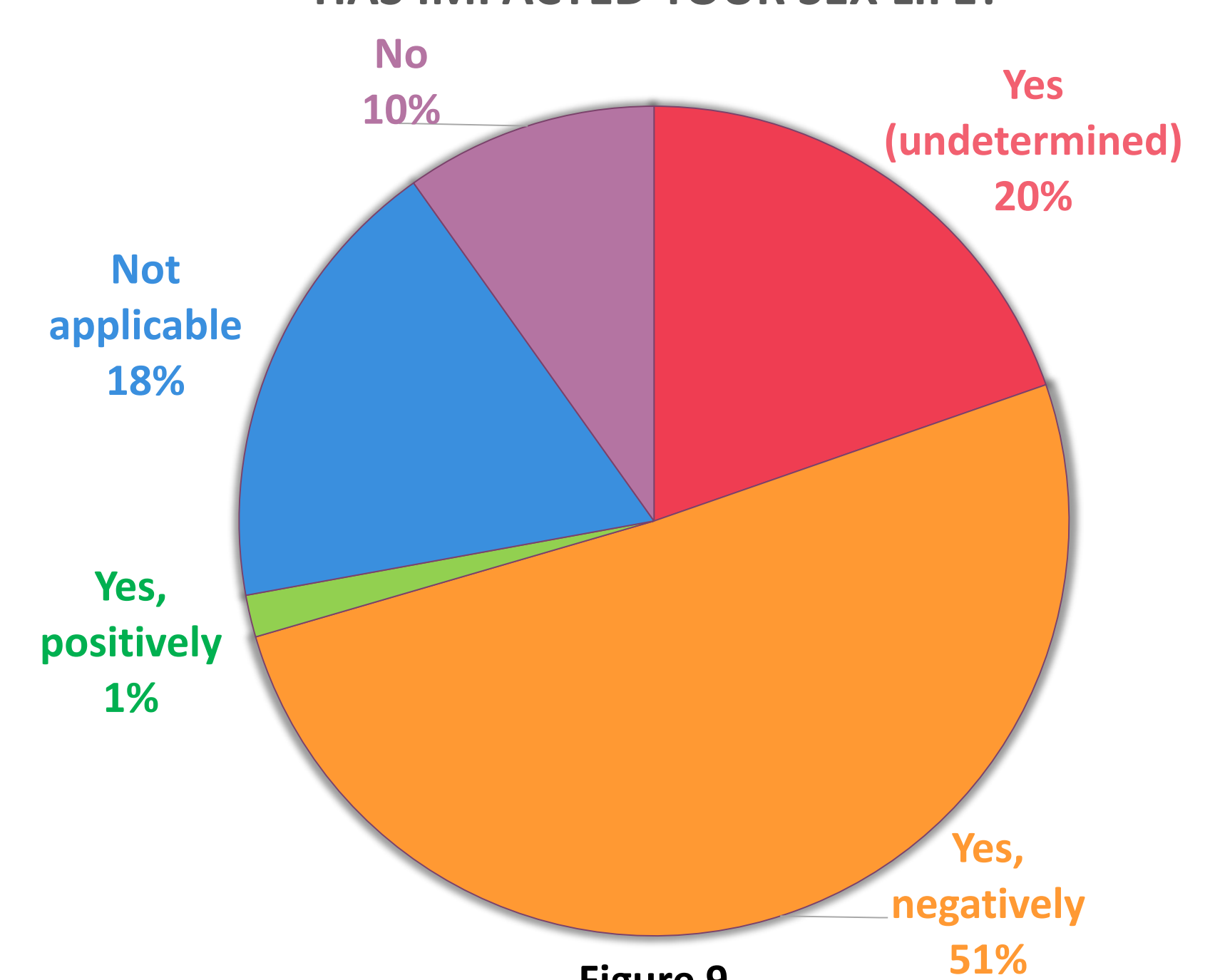


Figure 9

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.