

The effect of clitoral surgery on sexual outcome in individuals who have intersex conditions with ambiguous genitalia: a cross-sectional study

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Summary

Background The effects on sexual function of surgical removal of parts of the clitoris are unknown. For infants with intersex conditions and ambiguous genitalia being raised female, this surgery is often undertaken in early childhood. Our aim was to assess the effects of surgery on sexual outcome in this population.

Method We did a cross-sectional study to which we recruited 39 adults who had intersex conditions with ambiguous genitalia who were living as female from clinical (n=15) and peer-support (n=24) settings. We obtained data by use of a postal questionnaire, incorporating a validated sexual function assessment inventory. We also obtained hospital notes of 36 respondents who did not want to remain anonymous, and did genital examinations of 19 women. We assessed sexual problems in relation to surgical history and compared the results for our population to those of a healthy control group.

Findings Of the 39 individuals enrolled, 28 had been sexually active and all had sexual difficulties. The 18 women who had undergone clitoral surgery had higher rates of non-sensuality (78%) and of inability to achieve orgasm (39%) than did the ten who had not had surgery (20% [p=0.002] and 0% [p=0.03], respectively).

Interpretation Sexual function could be compromised by clitoral surgery. Debate on the ethics of the use of this surgery in children should be promoted and further multicentre research is needed to ensure representative samples and comprehensive outcome assessment. Meanwhile, parents and patients who consent to clitoral surgery should be fully informed of the potential risks to sexual function.

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Introduction

The prevalence of intersex conditions is estimated at one in 2000 livebirths.¹ Many affected individuals present with ambiguous genitalia in the neonatal period or in childhood. Clitoral surgery for intersex conditions was first promoted in the late 1930s by Hugh Hampton Young, a surgeon at Johns Hopkins University, USA.² Later, psychologists at Johns Hopkins developed an intersex management protocol based on the notion that all infants are gender-neutral at birth, and that if unambiguous sex of rearing and unambiguous genitalia were made congruent in the early years, the desired adult gender identity and partner orientation would ensue.^{3–5} The theory of psychosexual neutrality at birth has now been replaced by a model of complex interaction between prenatal and postnatal factors that lead to the development of gender and, later, sexual identity.^{6–9} For parents, the realisation that their child has an intersex condition invariably results in emotional distress. In the midst of confusion, they have to decide on their child's sex of rearing with the help of health-care providers. In the USA and most western European societies, a female sex of rearing is the most likely clinical recommendation to parents.¹⁰ Once a decision of female rearing is made, surgery is often undertaken to remove any incongruent gonadal tissue and to feminise the appearance of the genitalia—usually through the removal of parts of the clitoris or phallus to reduce its size.¹¹ This surgery is done because it is thought to result in better psychological outcomes for the child than leaving the genitalia unaltered.^{12–15}

The practice of feminising genitoplasty has created considerable controversy, and is associated with many ethical dilemmas.¹⁰ First, there is no evidence that feminising genital surgery leads to better psychosocial outcomes than leaving the genitalia unaltered.⁸ Second, there is no guarantee that adult gender identity will develop as assigned.^{7,9} Finally, future sexual function might be altered by removal of clitoral or phallic tissue. Until the late 1970s or early 1980s, clitorrectomy—the removal of both the corpora and the glans—was the usual procedure. With greater acknowledgment of the vital role of the clitoris in female sexual function, clitorrectomy is no longer undertaken in the UK. Clitoroplasty, which involves dissection of the clitoral skin and removal of most of the paired clitoral corpora with preservation of the glans and dorsal neurovascular bundle, has become the usual procedure.¹¹

Cosmetic alteration of the clitoris is often assumed to have no great long-term effect on sexual function.^{12–14} Previous studies^{15–18} have reported paediatric surgical follow up of various cohorts of intersex patients who had undergone genital surgery in infancy, but all had small numbers and most did not assess sexual function in detail. The results of two psychological studies,^{19,20} which used standardised assessment of adult sexual function after

childhood clitoral surgery, suggest that sexual difficulties are more common for adults with intersex conditions than for the general population, with high rates of anorgasmia in intersex women.

Our aim was assess the effects of feminising intersex surgery on adult sexual function in individuals with ambiguous genitalia.

Methods

Participants

Between Aug 1, 1999, and Jan 1, 2001, we did a cross-sectional study to which we recruited individuals aged 18 years or older with an intersex condition incorporating ambiguous genitalia and who were living as female, from the University College London Hospital adult intersex clinic (<http://www.uclh.org/services/reprodev/>) and from two UK intersex peer-support groups—the Androgen Insensitivity Syndrome Support Group (AISSG; <http://www.medhelp.org/www/ais/>) and the Adrenal Hyperplasia Network (AHN; <http://www.ahn.org.uk>).

The study was approved by the Joint University College London/University College London Hospital committee on the ethics of human research.

Protocol

We obtained data by sending potential participants a questionnaire, incorporating a validated sexual function inventory; by examining hospital notes; and by genital examination.

We posted a study pack to all individuals who fulfilled the study criteria and who had been seen for follow-up at the University College London Hospital clinic within the past 2 years, and to all members of AHN and AISSG. The pack contained an information sheet, a consent form requesting consent for hospital-notes retrieval and genital examination, a self-complete questionnaire, an invitation to attend a genital assessment, and a postage-paid reply envelope. We sent reminder study packs to all clinic patients who had not responded within 3 months. We also enclosed packs with AISSG newsletter mailings and

distributed them at three AISSG meetings and one AHN meeting.

The self-administered questionnaire could be completed anonymously or with identifiable details. The questionnaire has been previously used in a study on sexual function outcomes in complete androgen insensitivity syndrome.²¹ We assessed sexual function with the Golombok-Rust inventory of sexual satisfaction (GRISS) for women.²² The GRISS is a multidimensional questionnaire that has been validated in the UK and allows a comparison of the sexual functioning of this study population with a UK female control population. The GRISS comprises 28 questions each with five possible answers, ranging from never to always. These 28 items are scored and converted to provide eight discrete scores, one for overall sexual function and seven for each specific area of sexual function—ie, frequency of intercourse, communication, degree of satisfaction, avoidance, sensuality, vaginal penetration, and orgasm.^{22–24} The final scores on each of the GRISS subscales range from 1 to 9, and have been validated within the female UK population; scores of 1–4 indicate normal sexual functioning and scores of 5–9 indicate increasing degrees of sexual dysfunction. We entered all correctly completed questionnaires into the study. CLM, who was unaware of the diagnosis or the past history of participants, scored the GRISS questionnaires. The control group for the sexual function data were the individuals, drawn from the UK female population, used in devising, standardising, and validating the GRISS sexual function questionnaire.^{23,24}

For respondents who did not want to remain anonymous, we requested consent to retrieve medical records (paediatric and adult) to confirm diagnostic and treatment information, and contacted all the hospitals previously attended for a copy of the patient's medical file. If case notes were unavailable or data were missing, we contacted the family practitioner to request copies of all correspondence from the hospital. Data were subsequently extracted on: mode of presentation, results of all investigations, results of clinical examination, interventions, surgery, and histopathological results. We

	AHN (n=14)	AISSG (n=10)	Clinic (n=15)	Total (n=39)
Demographic details				
Median (range) age (years)	30 (21–65)	34 (18–70)	29 (19–60)	31 (18–70)
Ethnic origin				
White	13 (93%)	10 (100%)	14 (93%)	37 (95%)
Other	0	0	1 (7%)	1 (2.5%)
Unknown	1 (7%)	0	0	1 (2.5%)
Diagnosis				
Congenital adrenal hyperplasia	14 (100%)	0	8 (53%)	22 (56%)
Partial androgen insensitivity syndrome	0	7 (70%)	2 (13%)	9 (23%)
Mixed gonadal dysgenesis	0	3 (30%)	0	3 (8%)
17keto-steroid-reductase deficiency	0	0	2 (13%)	2 (5%)
5- α reductase deficiency	0	0	2 (13%)	2 (5%)
True hermaphrodite	0	0	1 (7%)	1 (3%)
Clitoral surgery group (n=28; number having vaginal surgery/total [%])				
Ambiguous genitalia at birth and early childhood clitoral surgery (age <5 years)	6/10 (60%)	0	6/7 (86%)	12/17 (71%)
Ambiguous genitalia at birth and late childhood clitoral surgery (age 5–14 years)	2/2 (100%)	1/1 (100%)	1/2 (50%)	4/5 (80%)
Ambiguous genitalia at birth, no childhood surgery, and clitoral surgery after puberty (age >14 years)	1/1 (100%)	0/1	0	1/2 (50%)
Ambiguous genitalia developed around puberty and clitoral surgery	0	1/3 (33%)	0/1	1/4 (25%)
No clitoral surgery group (n=11; number/total [%])				
Ambiguous genitalia at birth or puberty and never undergoing clitoral surgery	0/1	1/5 (20%)	2/5 (40%)	3/11 (27%)

Data are number (%) unless otherwise indicated.

Table 1: Baseline characteristics

	Number of participants	Clitoral size	Median (range) vaginal length (cm)
Clitoral surgery group (n=13)			
Ambiguous genitalia at birth and early childhood clitoral surgery (age <5 years)			9.5 (1.5–13.0)
Clitorectomy	6	Absent (n=1) Small (n=2)* Normal (n=2)* Large (n=1)*	
Reduction	1	Very large	
Recession	1	Small	
Ambiguous genitalia at birth and late childhood clitoral surgery (age 5–14 years)			8.5†
Unknown	1	Large	
Ambiguous genitalia at birth, no childhood surgery, and clitoral surgery after puberty (age >14 years old)			5.25 (0–10.5)
Clitorectomy	2	Absent (n=2)	
Ambiguous genitalia developed around puberty and clitoral surgery			
Clitorectomy	1	Absent	2.5†
Reduction	1	Large	2.0†
No clitoral surgery group (n=6)			
Ambiguous genitalia at birth and never undergoing clitoral surgery	6	Normal (n=1) Large (n=3) Very large (n=2)	10.5 (1.5–12.0)

*No glans or hood seen, but a subcutaneous mass in the place of the clitoris was present. †Actual size.

Table 2: Results of genital examinations

constructed a clinical history for each respondent, which we used to assign an accurate intersex diagnosis, a complete surgical history, and a Prader score²⁵ to define genital appearance at presentation.

We sent all respondents who had indicated an interest in attending the research clinic for clinical examination a more detailed information sheet and choice of clinic appointment times. At the examination, data were obtained on the appearance and dimensions of the genitalia, by previously described methods.²¹ We excluded participants from the study if they had not had genital ambiguity, if the constructed clinical history led to doubt over the diagnosis of an intersex condition, or if they had coexisting conditions that could affect sexual function, such as major psychiatric or neurological impairment.

Statistical analysis

We did statistical analyses with SPSS (version 11.0.0), with Pearson's χ^2 statistic, Fisher's exact test, and Kendall's rank correlation test, as appropriate. We judged a p value of <0.05 to be significant.

Role of the funding source

The sponsors had no role in the study design, data collection, data analysis, data interpretation, or writing of the report.

Results

81 potential respondents received a study pack (21 patients, 39 AHN members, and 21 AISSG members). 44 (54%) of 81 questionnaires were returned (15 from clinic patients, 14 from members of AISSG, and 15 from members of AHN). We excluded two because of inadequate completion. Of the remaining 42 questionnaires, three respondents had chosen to remain anonymous (two from AHN, one from AISSG). Of the 39 participants who consented to retrieval of hospital records, a clinical history was constructed. However, in two cases the exact technique of childhood surgery remained unknown. Three further respondents were excluded after construction of the clinical history because of an additional diagnosis of multiple sclerosis (one) and doubt over the diagnosis of an intersex condition (two).

Table 1 shows the baseline characteristics of the final sample (n=39). Of these, 19 (49%) attended for genital examination (table 2).

The range of diagnoses in our study group covered most intersex conditions that present in childhood with ambiguous genitalia, with the most common being congenital adrenal hyperplasia and partial androgen insensitivity syndrome (figure 1). Most participants (27 [69%] of 39) had presented at birth or before age 5 years with ambiguous genitalia (mean Prader score 3.29, SD 0.9, range 2–5). Two individuals with congenital adrenal hyperplasia presented at age 7 years with ambiguous genitalia and pubic hair growth (Prader score 2). Of the remaining ten who did not present at birth or in early childhood, four presented with primary amenorrhoea and ambiguous genitalia were noted, four presented with ambiguous genitalia alone, one had vaginal hypoplasia, and one who was raised as male did not undergo pubertal virilisation in addition to gender dysphoria. All participants were aware of their diagnosis.

Three individuals have not accepted the gender they were assigned in childhood. Of the two participants raised as males, the first, with partial androgen insensitivity

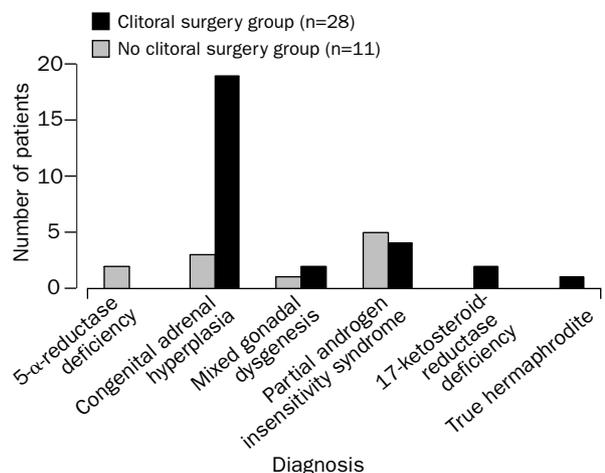


Figure 1: Type of intersex condition diagnosed



Figure 2: Age at clitoral surgery

syndrome, was initially assigned female at birth but reassigned to a male sex of rearing at around age 3 weeks. He developed a feminine physique despite some masculinisation and, although still legally male, underwent surgical genital reassignment at age 30 years and lives as a woman. The second individual raised as a male has mixed gonadal dysgenesis and now lives as a female—she underwent surgical reassignment to female at age 23 years. The only participant wishing to live as a male is a 60-year old with 5- α -reductase deficiency who was raised female and married in her early twenties and underwent vaginoplasty without being told of her intersex condition. However, her sexual orientation and gender identity developed predominantly as a male, and in her late fifties she finally decided to seek surgery to reassign as a male. This individual is legally being reassigned male and, since a gonadectomy was never done, there is the possibility of fertility with his partner.

Most participants had undergone clitoral surgery (table 1), and the median age of first clitoral surgery was 3.5 years (range 0.1–42; figure 2). The 11 individuals who did not have surgery had either been born with ambiguous genitalia (four) or ambiguous genitalia were noted at presentation (seven; mean age 14.6 years [range 7–20, SD 4.16]). There was no difference in degree of genital masculinisation at presentation between the two groups (mean Prader scores for the clitoral surgery and no clitoral surgery groups were 3.2 and 2.7, respectively). The two groups were equally distributed between clinic patients and support group recruits. All of the individuals who had undergone gonadectomy were taking hormone replacement therapy, apart from one female aged 56 years with partial androgen insensitivity syndrome. Those who had never undergone clitoral surgery were older than those who had undergone clitoral surgery (mean age 40.9 *vs* 30.7 years), possibly reflecting historical trends—genital surgery was less prevalent in the UK before the 1970s than after.

Surgical technique indicated historical trends, with most individuals seen before 1979 undergoing clitorrectomy and most of those operated on after 1980 undergoing nerve-sparing clitoral reduction with corporal excision. However, one individual had undergone clitorrectomy in 1985 and another had had clitoral reduction in 1975. Overall surgical technique remained unknown in two patients (7%), clitorrectomy had been done in 18 (64%), clitoral reduction in seven (25%), and one individual (4%) had undergone clitoral recession. Four participants (14%), all with congenital adrenal hyperplasia, had undergone more than one clitoral

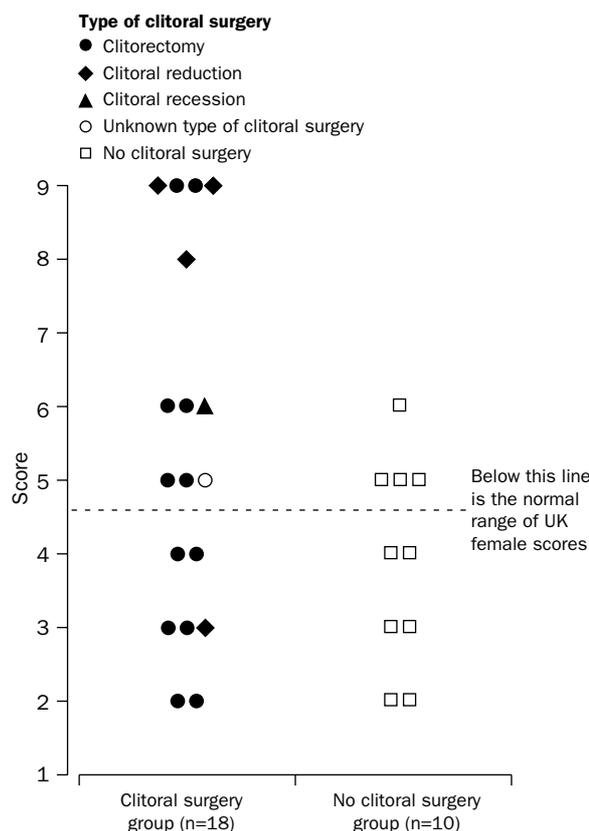


Figure 3: Orgasm GRISS subscale scores by group

operation because of regrowth of the corpora. The first of these individuals had had a clitorrectomy at age 1 month, and underwent a second reduction procedure at age 12 years. The second underwent clitoral reduction at 1.1 years, vaginoplasty at 10.1 years, and repeated clitoral reduction and removal of hair from the clitoral hood at 15.1 years. The other two patients underwent three clitoral reductions at ages 4, 14.5, 16, and 17 years, respectively. In the group that had undergone clitoral surgery, 18 (64%) of 28 had also had vaginal surgery (table 1) at a mean age of 9.2 years (range 0.1–28, SD 8.7). A second vaginal surgical procedure had to be done in seven individuals (39%) and a third in two of these (11%). Three of the 11 participants who had not undergone clitoral surgery had undergone vaginal surgery (vaginoplasty type: amnion, Williams and colovaginoplasty) aged between 21 years and 23 years.

Sexual function data were available for only 28 participants (table 3), because 11 (28%) had never been sexually active. A higher proportion of individuals in the clitoral surgery group than in the no clitoral surgery group had not been sexually active (36 *vs* 9%), although this difference was not significant ($p=0.13$). The proportion of

	Subscale scores (%)					
	Clitoral surgery group (n=18)			No clitoral surgery group (n=10)		
	Normal*	Difficulties†	Severe difficulties‡	Normal*	Difficulties†	Severe difficulties‡
Frequency	28%	72%	33%	30%	70%	30%
Communication	28%	72%	17%	20%	80%	20%
Satisfaction	61%	39%	0%	80%	20%	0%
Avoidance	28%	72%	22%	20%	80%	10%
Sensuality	22%	78%	22%	80%	20%	10%
Vaginal penetration§	33%	67%	33%	33%	67%	22%
Orgasm	39%	61%	28%	60%	40%	0%

*Score of 1–4. †Score of 5–9. ‡Score of 8 or 9. §Four individuals chose not to answer the questions on vaginal penetration.

Table 3: Sexual function of 28 participants, according to GRISS

never sexually active individuals recruited from support groups or the clinic did not differ (29 vs 27%, $p=1.00$). Additionally, we noted no difference for history of vaginal surgery (44% of individuals who had had vaginal surgery and 58% of those who had not had not been sexually active, $p=0.42$). Three participants in the clitoral surgery group and one in the non-clitoral surgery group did not answer the questions relating to vaginal penetration: one participant had no vagina and the other three are currently in homosexual relationships that do not involve penetrative sex.

Every one of the 28 sexually active individuals, irrespective of whether or not they had had clitoral surgery, had subscale scores indicating a sexual problem in at least one of the seven areas of sexual function (table 3). The mean number of areas of difficulty was higher for the clitoral surgery group than the no clitoral surgery group. Difficulties with sensuality were significantly higher in the clitoral surgery group than in the no surgery group ($p=0.002$), and were associated with communication difficulties ($r=0.54$, $p=0.01$) and avoidance ($r=0.42$, $p=0.02$). Both groups had overall difficulties with orgasm (figure 3). A complete inability to orgasm is rare in the healthy population, with only 7% of controls responding to question 14 of the GRISS that they always find it impossible to orgasm.²³ However, seven (39%) of 18 of the sample who had had clitoral surgery answered that they always found it impossible to orgasm compared with none of those who had not had clitoral surgery ($p=0.03$).

On comparison of sexual function results for individuals recruited from the support group with those recruited from the clinic, there was a slightly higher rate of difficulties in the clinical sample. However, this difference was not significant—eg, non-sensuality 47% compared with 73% ($p=0.25$). Analysis of sexual function results also showed no significant relations with intersex diagnosis.

Discussion

Our results indicate that individuals who have had clitoral surgery are more likely than those who have not to report a complete failure to achieve orgasm and higher rates of non-sensuality—in particular, a lack of enjoyment in being caressed and in caressing their partner's body. However, we are not able to rule out other factors that might account for differences in sexual difficulties between the two groups, since we did not collect data on mood, body satisfaction, sexual knowledge, and confidence, quality of life, or subjective assessment of clitoral surgeries. All individuals in this study, whether having undergone clitoral surgery or not, had difficulties with various features of sexual function. Two participants who attended for genital examination mentioned that they had answered the GRISS questions on orgasm, but that after conversations with female friends they were not sure if they had actually had an orgasm. Even after assuming that non-respondents had had no sexual difficulties whatsoever, our results indicated that half of those presenting with ambiguous genitalia report having problems in some area of sexual functioning. Clinicians involved in adult care should, therefore, assess their patients for potential sexual problems and provide health-care services accordingly.

To claim that clitoral surgery has no long-term effect on sexual function is wrong. However, ours was a fairly small cross-sectional study, and we do not know how representative it is; thus, on the basis of our data we

cannot recommend a complete halt to clitoral surgery. Some clinicians have suggested that individuals who attend support groups are particularly dissatisfied with their medical care and, therefore, that a sample derived from a support group might be seen as skewed in favour of people who have worse outcomes.²⁶ Other clinicians intimate that the opposite is true, noting that individuals who attend support groups are better informed, more self-sufficient, and more likely to have found the medical care they require than those who do not. We noted a slightly higher rate of sexual difficulties in patients recruited from clinics than from support groups, although there was no significant difference between them for rate of sexual difficulties or whether or not individuals had ever been sexually active.

Because of the lack of an evidence base, some clinicians are uneasy about clitoral reduction surgery, albeit nerve sparing, especially for infants. New research has re-examined the anatomical structure and nerve supply of the clitoris, which is a triplanar erectile tissue complex made up of a root (bilateral crura), body (bilateral corpora cavernosa), and the glans covered by the prepuce or clitoral hood (formed by the anterior fusion of the labia minora).²⁷ The tip of the glans is visible but the rest of this complex organ is hidden, surrounding three quarters of the urethra and extending into the vestibule of the vagina.²⁷ The importance of the clitoris in female sexual function has been known since ancient times, and scientific information to that effect has been available for decades. What remains unclear is the contribution of different parts of the clitoral complex to sexual sensitivity, arousal, and orgasm. Clitoral reduction surgery could damage nerves that pass to the glans clitoris,¹¹ and how far damaged nerves might regrow and to what degree the sensory innervation of the clitoral hood and glans clitoris are important in sexual function is unknown. The most prevalent technique of clitoral reduction also removes the paired clitoral corpora that fill with blood during arousal and lead to clitoral erection. To what extent this part of the clitoral complex is involved in orgasm, and what implications corporal removal might have on sexual function, is unknown.

Parents and clinicians often consider the alteration of ambiguous genitalia to achieve a more normative female appearance a logical and obvious course of action. But the outcomes of these procedures have not been systematically examined or compared with non-intervention. Feminising genitoplasty remains the standard management for intersex infants because of clinicians' beliefs that it improves psychological outcomes. The alternative of leaving the genitalia unaltered might predispose the child to various difficulties, including difficulties with body image and gender development, bullying, and embarrassing erections. Counter arguments are that surgery can be done later in childhood if difficulties do arise—when the child is older and can contribute to the discussion—and that with time the genital appearance frequently changes, with the obviously ambiguous neonatal genitalia often changing spontaneously to a more feminine appearance through the phallus becoming proportionately smaller in relation to the growing labia and fat deposition, and also because of treatment to reduce androgen production.

Our findings suggest that adult sexual function could be compromised by feminising clitoral surgery. Infants and young children are powerless to oppose any procedures, so genital surgery for them is not just a medical issue but also a moral one. Debate over ethics with interested parties should be encouraged and clinicians should

advance the debate and help individuals and families to make the best possible decisions by producing reliable information. Many surgeons will undoubtedly feel justified in doubting the findings of this study, and will fall back on the traditional response of claiming that current techniques are more advanced than the surgical procedures we assessed.²⁸ Although surgery has advanced in many ways, this is not a valid reason for complacency. In this study surgery was done 8–40 years ago, and most individuals had undergone clitorectomy. Of the three sexually active participants who had undergone the newer technique of nerve-sparing clitoral reduction, however, two had the worst possible score for orgasm difficulties (orgasm subscale score of 9). Detailed, multicentre studies that explore the potentially varied effect of timing and technique of clitoral surgery on psychological, sexual, and quality of life outcomes are needed. Until such data are available, individuals consenting to cosmetic clitoral surgery should be counselled on the risks of the procedure.

Contributors

S Creighton and C Minto conceived and devised the study, agreed overall study design, and undertook genital examinations. C Minto collected data, analysed, and interpreted data, and wrote the report. S Creighton and L Liao contributed to discussion and interpretation of the data and to writing the paper. C Woodhouse, L Liao, and P Ransley were involved in the conception and design of the study and contributed to the final version of the paper.

Conflict of interest statement

None declared.

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