

# Sexual function in women with complete androgen insensitivity syndrome

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**Objective:** To investigate sexual function in women with complete androgen insensitivity syndrome (CAIS) and to investigate the prevalence of factors that might contribute to sexual difficulties.

**Design:** Cross sectional survey and clinical examination.

**Setting:** Tertiary hospital multidisciplinary intersex clinic and an international peer support group for CAIS.

**Patient(s):** Sixty-six adult women with CAIS.

**Intervention(s):** Self-completed survey of sexual function, genital normality perceptions, and compliance and satisfaction with vaginal hypoplasia treatments. Hospital case notes review, and genital examination for prevalence of vaginal and clitoral hypoplasia.

**Main Outcome Measure(s):** Golombok-Rust Inventory of Sexual Satisfaction (GRISS) scores of study participants were compared against the scores of the test validation population (as control). In physical examination participants, anatomical dimensions were assessed against published normal values for clitoral and vaginal sizes.

**Result(s):** We found that 90% of women with CAIS in this study had sexual difficulties when compared with the general female population, most commonly sexual infrequency and vaginal penetration difficulty; 77% perceived their vagina as small, but on genital examination only 35% had vaginal hypoplasia.

**Conclusion(s):** Androgen deficiency leads to sexual problems. Vaginal hypoplasia and negative psychological adaptation to living with an intersex condition are likely to have contributed to the high rates of sexual problems found in this study. Treatments for vaginal hypoplasia need to be evaluated with outcome studies of long-term sexual function, quality of life, and satisfaction. Clinical services for the management of intersex conditions need to be multidisciplinary and aim to optimize the patient's physical and psychological health. (*Fertil Steril*® 2003;80:157–64. ©2003 by American Society for Reproductive Medicine.)

**Key Words:** Androgen insensitivity, intersex, female sexual function, long-term outcomes, vaginal hypoplasia, intersex management, androgen deficiency

Sexuality is an integral part of health and well-being. Androgens are believed to play an important role in female sexual function (1); however, data on androgen effects in female sexual function are difficult to interpret because of the complexity of physical and psychological factors affecting sexual function. A recent international conference on androgen insufficiency in women identified the relationship between testosterone and sexual dysfunction as among the key areas needing further research (2).

We have investigated sexual function in a cohort of women with complete androgen insensitivity syndrome (CAIS), an intersex condition with an estimated incidence of between

1 in 13,158 to 40,800 live births (3, 4). Complete androgen insensitivity syndrome occurs early in XY fetal development when the androgen receptors completely fail to function, leading to the birth of a female infant. In adult life CAIS women have a female gender identity and standard phenotype, along with a total inability to respond to androgens. In this group of women any effects on sexual function due to androgen deficiency should be apparent.

Assessing the prevalence of sexual difficulties in CAIS is important at both an academic level, for increasing the understanding of the role of androgens in female sexual function, and also at a clinical level, for improving the clinical service provision for intersex patients

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(currently under national review in the United Kingdom). Existing data for all outcomes in intersex conditions are currently poor (5). The available literature suggests that women with CAIS have normal sexual function (6–9), but these reports were based on small sample sizes without employing validated measures of sexual function that would enable comparison with the general population. Our cross-sectional study employed a self-administered questionnaire incorporating a validated sexual function assessment instrument.

Women with CAIS may also have vaginal hypoplasia, clitoral hypoplasia, and psychological factors that might contribute to sexual dysfunction; there is no published data on the prevalence of these factors in CAIS. We used a structured genital examination to assess the prevalence of clitoral and vaginal hypoplasia, and investigated abnormal genital perceptions via the questionnaire.

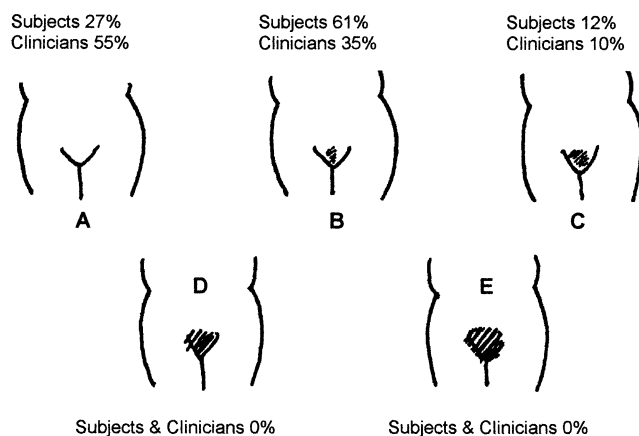
## MATERIALS AND METHODS

Our study was designed to recruit patients from both a clinical and a nonclinical setting. Approval was obtained from the joint University College London (UCL)/University College London Hospital (UCLH) committee on the ethics of human research. Recruitment for this study included all CAIS patients aged 18 or over who had attended the UCLH adult intersex clinic (10) for a follow-up appointment in the previous 2 years ( $n = 24$ ); each woman was sent a study pack comprising a postage-paid reply envelope, an information sheet, a self-complete questionnaire with consent form, and an invitation to attend the research clinic for genital assessment. The same study pack was shipped with the biannual postal newsletter distributed to all members of the Androgen Insensitivity Syndrome Support Group (AISSG) (11), an international peer support organization for CAIS and other intersex conditions. Reminder study packs were sent to the patients who did not respond and were also enclosed with subsequent AISSG newsletter mailings and distributed at three AISSG meetings. Total number of questionnaires distributed via the AISSG was 111 for members over 18 with a diagnosis of CAIS.

The self-administered questionnaire could be completed anonymously or with identifiable details. For respondents who did not prefer to be anonymous, consent was requested for retrieval of all medical records (pediatric and adult) to confirm diagnostic and treatment information. For respondents who consented to medical notes retrieval, we contacted all hospitals they could recall attending, requesting copies of their entire medical files. The medical files were analyzed and data were extracted on the patient's mode of presentation, and all investigation results, clinical examination findings, interventions, surgery, and histopathologic results. After a clinical history was constructed for each respondent, we used this to assign an accurate intersex diagnosis.

**FIGURE 1**

Participants' self-rating of amount of pubic hair ( $n = 66$ ) and clinicians' rating at genital examination ( $n = 20$ ). Women were asked on the questionnaire to circle the picture that best represented the amount of pubic hair that they have.



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All respondents who had indicated an interest in attending the research clinic were sent a more detailed information sheet and choice of clinic appointment times.

Participants were excluded from the study if they were under 18 years of age, if the constructed clinical history led to doubt over the accuracy of their CAIS diagnosis, or if they were assigned a diagnosis other than CAIS. Participants were also excluded if they had coexisting conditions that could affect sexual function, such as major psychiatric or neurological impairment.

### Questionnaire Details

The questionnaire was designed to collect a wide variety of data, including knowledge of condition and past medical history, drug history, satisfaction and compliance with all treatments, and perceptions of pubic hair appearance (Fig. 1) and vaginal normality (Table 1). It also included the Golombok-Rust Inventory of Sexual Satisfaction (GRISS) for females, a multidimensional sexual function questionnaire designed to assess the existence and severity of sexual problems (12).

The GRISS has been shown to be reliable and has been validated in UK populations (13, 14), thus allowing a comparison of sexual function in the study sample with that of the UK female population. The GRISS comprises 28 items that yield 8 discrete sexual function scores: a global score for overall sexual function and seven subscale scores for sexual frequency, communication, satisfaction, avoidance, sensuality, vaginal penetration problems, and orgasm. This allowed a breakdown of specific areas of sexual dysfunction. Scores on each of the GRISS subscales range from 1 to 9, and have

**TABLE 1**

Participants' current perceptions of their vagina.

Question: What do you think of your vagina? Please tick as many as you wish.	Number of women (%) choosing this statement
I don't know	1 (1.5)
My vagina is tiny or nonexistent	2 (3)
My vagina is normal	15 (23)
I would like my vagina wider	15 (23)
I would like my vagina bigger	16 (24)
My vagina is narrow	21 (32)
My vagina is small	21 (32)
I would like my vagina longer	30 (46)
A sexual partner would notice that it was different from other women	32 (49)
My vagina is short	39 (59)

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been validated within the female UK population such that scores of 1 to 4 reflect normal sexual functioning and scores of 5 to 9 indicate increasing levels of sexual dysfunction.

### Clinical Examination

Data were collected during the clinical examination on the appearance and dimensions of the genitalia (Table 2). Depending on vaginal size, the introital width and vaginal length measurements were taken with graded-size vaginal dilators (15) or a high vaginal swab (for vaginal length). Two of the authors (CLM and SMC) performed all the examinations, and were not blinded to the patient's past history but were blinded to the patient's sexual function scores. Anatomical dimensions were assessed against published normal values for clitoral (16, 17) and vaginal sizes (15). The vagina was defined as short if it was less than 8 cm in length, (>2 SD below mean) (15). The clitoris was defined as small if the transverse or longitudinal diameter of the glans was less than

**TABLE 2**

Genital examination outcome variables.

Item	Assessment
Pubic hair	Tanner grade (I–V), type of hair (vellus or sexual) and position of hair on pubis.
Glans clitoris	Transverse and longitudinal diameters (mm).
Clitoral body	Length (mm). Prominence.
Labia minora and majora	Size, shape, position, pigmentation, and rugosity.
Urethral meatus	Position and size.
Vagina	Introital position and width. Length of the unstretched vagina from hymenal remnants to vault.

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1.4 mm or 2.3 mm, respectively, or the body length was less than 7.4 mm (>2 SD from mean) (16, 17).

### Statistical Analysis

All statistical analysis was performed with SPSS software (SPSS, Inc., Chicago, IL), using Pearson chi-square test, Fisher's exact test, and Kendall's rank correlation test as appropriate. The control group for the sexual function data was the UK female population used to devise, standardize, and validate the GRISS sexual function questionnaire (13, 14). We did not recruit and examine a control group for the clinical examination because accurate and reproducible data and methods from adequate sample sizes are already available for genital dimensions (15–17).

## RESULTS

### Patients and Response Rates

The study consisted of 66 participants; 29% patients (19 out of 66), 68% support group members (45 out of 66), and 3% other (2 out of 66). The clinic sample (n = 24) response rate was 82.6% with 19 out of 23 questionnaires completed; one study pack was returned as undeliverable using the patient address in the hospital's records. The AISSG sample (n = 111) response rate was 41.4%, with 46 questionnaires returned; one questionnaire was excluded due to inadequate completion. Two additional study participants were neither patients nor support group members but had requested to take part in the study after having heard of it via alternative sources (from a sister who was participating, n = 1; from information on the AISSG website, n = 1). The age range of the participants was 18 to 70 years (median 34 years). Of the 66 women who participated in the questionnaire survey, 20 (30%) also took part in the genital examination.

### Self-Assessed Gender Appearance and Knowledge Regarding Condition Details

All participants identified their external appearance as female; however, one participant additionally reported a male-type gender identity and dissatisfaction with her female appearance. The majority of participants (63 out of 66) chose their condition description as "CAIS—the body is unable to recognize testosterone so XY female with internal testes." Of these 63 participants, 79% (50 out of 63) indicated their sex chromosomes were "46XY (the usual male pattern)," 16% (10 out of 63) did not know what their sex chromosomes were, 5% (3 out of 63) did not answer the question, and none of the women indicated that their sex chromosomes were "46XX (the usual female pattern)." One participant indicated her condition was partial androgen insensitivity, "the body is only partly able to recognize testosterone, variable gender and body, but XY with testes," although the constructed clinical history and genital examination confirmed a diagnosis of CAIS. Two women indicated that they did not know the type of their intersex condition or their sex chromosome

pattern; one of these women was a patient, and the other was from the peer support group.

## Clinical Interventions

Most of women (62 out of 66) were taking hormone therapy. Of the four women not taking hormone therapy, two had functioning gonadal tissue in situ and two chose not to take hormone therapy despite gonadectomy. Of the two women who were deficient in sex steroid hormones, one was not sexually active and the other had GRISS scores indicating sexual dysfunction.

Data from the constructed clinical histories suggested that 56% (37 out of 66) of the women had been offered treatment for vaginal hypoplasia; 45.5% (30 out of 66) had chosen to undergo this treatment and 54.5% (36 out of 66) did not undergo any form of vaginal intervention. Most of the women (24 out of 30) had used vaginal dilators to increase vaginal length by pressure. Compliance with dilation treatment was poor; 37.5% of the women indicated that their compliance was bad or very bad. Only 33% of the women expressed satisfaction with dilation treatment, and 42% indicated they were "unsatisfied or very unsatisfied" with dilation treatment. Treatment satisfaction was strongly correlated with compliance ( $r = 0.64, P = .001$ ). There was no relationship between age at dilator treatment and either compliance or satisfaction with treatment.

Six women had undergone vaginal surgery for hypoplasia, and one of these women had undergone two plastic surgery procedures on the vagina. The procedures were amnion vaginoplasty ( $n = 1$ ), McIndoe vaginoplasty ( $n = 3$ ), Williams vaginoplasty ( $n = 1$ ), and Fenton's procedure ( $n = 2$ ). From the hospital records, four of these women had severe vaginal hypoplasia (<3cm vaginal length) before treatment. Satisfaction with vaginal surgery was slightly higher than dilator treatment, with 50% expressing satisfaction. Of all those undergoing treatment for vaginal hypoplasia only 10% (3 out of 30) of the women felt that they had achieved a normal size vagina. Additionally, one woman felt that, although her vaginal size was "normal," she was self-conscious about her genitalia because of the scars from abdominal surgery.

## Perceptions of Vaginal Characteristics

Table 1 provides a summary of the participants' current perceptions of their own vaginal characteristics. In total, 79% (52 out of 66) of the women indicated that they perceived their vagina as being abnormal in some way. Looking specifically at vaginal length, as opposed to overall volume (incorporating introital width) which can be influenced by many factors, 62% (41 out of 66) felt that they had a short or nonexistent vagina and/or wished for a longer vagina. There was no difference in prevalence of abnormal vaginal perceptions between the women from the clinical setting and those from the peer support setting (74% vs. 73%,  $\chi^2 = 0.002, P = .97$ ). There were also no differences between these

two groups with regard to indicated wish for the vagina to be bigger, wider, or longer ( $\chi^2 = 0.23, P = .63$ ), and the perception that a sexual partner would notice that the vagina was different ( $\chi^2 = 0.94, P = .76$ ).

## Sexual Function Results

Because 7.5% (5 out of 66) of the participants had never been sexually active with a partner (age range: 19 to 40 years, mean 27.8 years  $\pm$  SD), they did not complete the GRISS. Two additional participants did not complete the GRISS; one had not been sexually active for over 20 years, and the other chose not to answer the relevant questions. Data on sexual function therefore came from 59 participants, of whom one was in a lesbian relationship and did not answer the four questions contributing to the score for vaginal penetration.

Most of the women (53 out of 59; 90%) had one or more subscale scores reflecting sexual problems (score of 5 or above). The most prevalent areas of sexual difficulty (Fig. 2) were sexual infrequency (39 out of 59; 66%), vaginal penetration problems (34 out of 58; 59%), lack of communication (30 out of 59; 51%), and avoidance of sexual intercourse (29 out of 59; 49%). Satisfaction scores were high, with only 14% of the participants having a score indicating dissatisfaction.

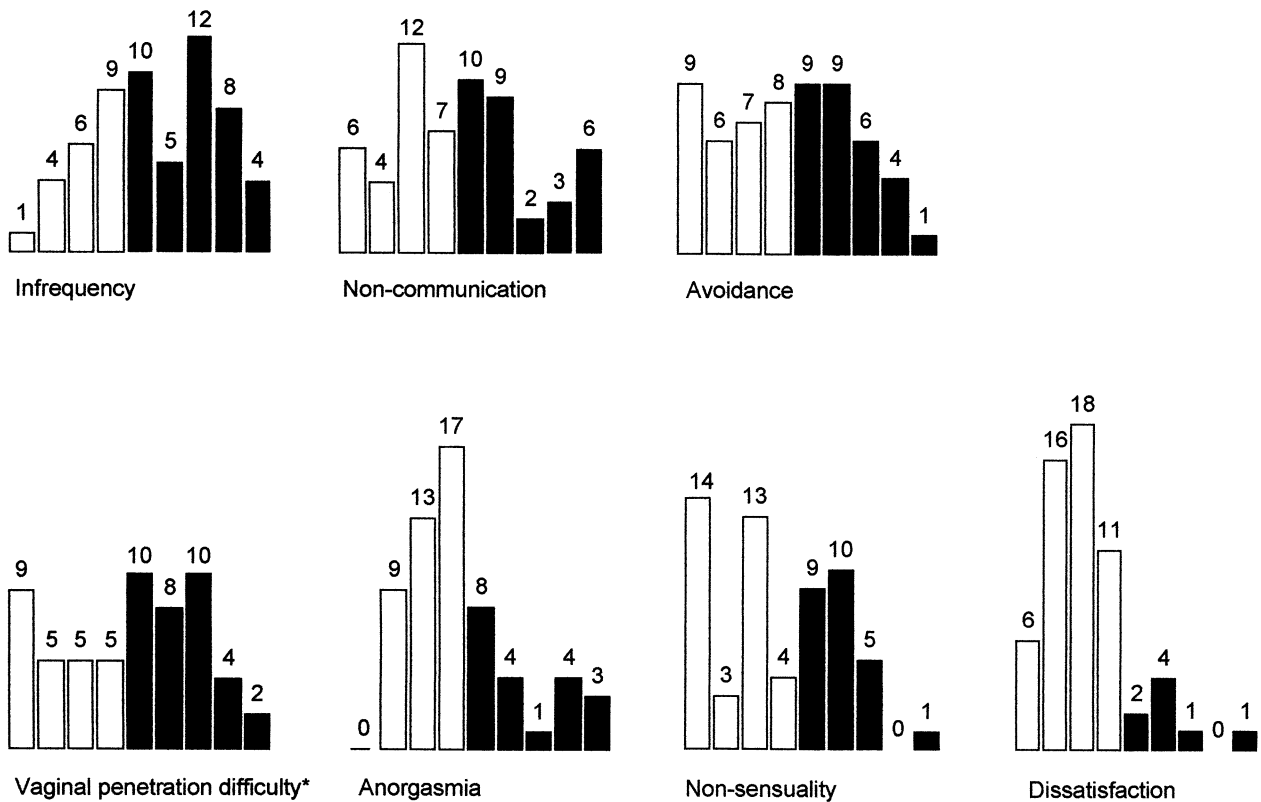
Many areas of sexual function were related; for example, women with sexual dissatisfaction were more likely to also have problems with nonsensuality ( $r = 0.36, P = .005$ ) and orgasm ( $r = 0.45, P < .001$ ). Women with vaginal penetration problems were more likely to have avoidance of sexual activity ( $r = 0.46, P < .001$ ) and communication problems ( $r = 0.35, P = .007$ ). No difference was found in the prevalence of sexual difficulties according to sample source (clinical setting 90%; peer-support setting 89%;  $\chi^2 = 0.1, P = .92$ ). Participants who had undergone treatment(s) for vaginal hypoplasia had similar rates of sexual difficulty (86% vs. 94%, Fisher's exact test,  $P = .41$ ) compared with those who had not had any intervention.

Most perceptions of vaginal abnormality were associated with sexual problems. For example, participants who perceived their vagina as short were more likely to have sexual difficulties ( $r = 0.29, P = .03$ ), especially problems with nonsensuality and avoidance ( $r = 0.50, P < .001$ , and  $r = 0.40, P = .002$ , respectively). Vaginal penetration problems were associated with all items indicating that the vagina was perceived as being abnormal or that the participant had a desire for it to be larger in any way ( $r = 0.54, P < .001$ ). The item "my vagina is normal" was inversely correlated with vaginismus ( $r = -0.39, P = .003$ ) and nonsensuality ( $r = -0.29, P = .03$ ).

Statistical analysis of associations between measured vaginal length and prevalence of sexual difficulty was limited by the small sample size. When analyzing the subscale scores for particular areas of sexual function, the women with a

**FIGURE 2**

Participants' sexual function scores for each GRISS subscale (n = 59). Each graph shows the distribution of scores (from 1 to 9 on the x-axis) for each GRISS subscale, with the number of women (y-axis) above each score. Normal scores are 1 to 4 (clear columns) and abnormal scores are 5 to 9 (shaded columns). (\*One woman did not answer questions on vaginal penetration.)



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measured short vaginal length had a higher incidence of vaginal penetration problems compared with those who had a vaginal length of 8 cm or over (86% vs. 50%, respectively); however, this did not reach statistical significance (Fisher's exact test,  $P=.60$ ). No correlation was found between small clitoral size and orgasmic difficulty.

### Genital Examination Results

Twenty women participated in the examination (65% clinic patients and 35% support group members). All of these women had either been sexually active (19 out of 20) or had undergone treatment for vaginal hypoplasia (10 out of 20). No difference was found between women who participated in the genital examination and those who did not for prevalence of sexual difficulties (chi-square = 0.4,  $P=.85$ ), treatment for vaginal hypoplasia (chi-square = 0.60,  $P=.44$ ), and abnormal vaginal perceptions (Fisher's exact test,  $P=.38$ ).

At genital examination, vaginal length ranged from 6 to 11 cm (mean 8.4, SD 1.4). A shortened vaginal length of less

than 8.0 cm, more than 2 standard deviations below the published mean value (15), was found in 35% (7 out of 20) of the women. Fifty-five percent (11 out of 20) had a small clitoris, a transverse or longitudinal diameter of the clitoral glans, or clitoral body length greater than 2 standard deviations below the published mean value (14). Small clitoral size was not associated with shortened vaginal length (Fisher's exact test,  $P=.67$ ). The quality, density, and distribution of pubic hair was variable but markedly reduced in comparison with the general population (see Fig. 1). In all women the majority of pubic hairs were fine vellus hairs, with either none or very occasional thickened sexual-type pubic hairs.

### Discussion

Female sexual function may be affected by many variables. These include physical factors, emotional health, relationship quality, the environment, cultural beliefs, and hormonal factors. Androgens are thought to influence sexual function in females by their affects on sexual motivation and

desire; low testosterone levels have been correlated with sexual infrequency and reduced libido (18). However, few studies have examined the effects of androgen deficiency on sexual function, especially in a young age group. Our study found that the majority of CAIS women have sexual problems. The finding that 66% of women in this study had difficulties with sexual infrequency in combination with complete androgen deficiency supports the belief that androgens are involved in sexual motivation and libido. However, vaginal hypoplasia and various psychological factors undoubtedly also impact sexual functioning in women with CAIS. Thirty-five percent of the women in this study reported orgasmic difficulty. As two-thirds of the sample yielded orgasm scores within normal limits, these results do not suggest that androgens are essential for female orgasm.

These study findings contradict previous reports of unimpaired sexual function in women with CAIS (6–9). Those previous studies were based on small numbers of cases, and employed nonstandardized and nonobjective methods of sexual function assessment. Another explanation for the contradiction in results between our study and previous ones is the nature of the patient-doctor relationship; it might be more difficult for patients to express negative outcomes to the clinicians who have provided their care. To minimize this effect in our study, some patients were recruited from a nonclinical source, and all participants were aware that the questionnaire could be completed anonymously.

Another major difference between this and previous studies related to the participants' knowledge about CAIS. In one previous study (6), the investigators admitted that 57% of their patients "exhibited no understanding of CAIS," whereas 96% of the participants in our study understood that they had an intersex condition called complete androgen insensitivity syndrome in which a female has internal testes. The impact on sexual function and other outcomes from physician policies of either withholding the diagnosis from patients or full disclosure about the condition is unknown. In our clinic we practice full disclosure in a supported environment, and believe this has a better long-term outcome for the patient.

There are two weaknesses of this study: the potential bias of the samples and the inability to control for other factors that may affect sexual function. There are potential biases in this study from both the populations used and from the samples drawn from those populations. The participants in this study were recruited from both a clinical and a nonclinical setting to sample a more diverse population and to maximize sample size. Response rates differed between clinic patients (83%) and support group members (38%). Not sampled by this study are patients who have had their intersex diagnosis withheld from them, and those who choose not to participate in either clinical or peer support. Additionally, due to the option of anonymity and the recruitment from the peer support group, we have no data on nonresponders.

Clinic patients may have a higher incidence of problems, including sexual difficulties, that prompt them to seek medical help; participants recruited from the peer-support organization may also have experienced a relatively high incidence of problems that have prompted them to seek support. Some clinicians have suggested that peer support organizations have a high proportion of individuals with poorer outcomes who are those least happy with their encounters with the medical profession (19). Alternatively, participation in peer support could be viewed as a reflection of personal resourcefulness, indicating a higher chance of better outcomes. In this study, subgroup analysis showed no statistically significant difference in outcome measures between women from the clinical setting and those from the peer support setting. We feel that, although these data are vulnerable to selection bias, any selection prejudice in our study acts positively to balance the opposing biases in earlier studies.

The factors other than androgen deficiency that might affect sexual function in CAIS evaluated in this study included vaginal hypoplasia, clitoral hypoplasia, hormone therapy use, interventions for vaginal hypoplasia, and perceptions of genital normality. There are also other factors that might have important effects on sexual function that we did not explore in this study, including the social stigma attached to having an intersex condition, diagnostic secrecy practiced by some clinicians, and other unresolved psychological issues and anxieties related to living with an intersex condition.

Vaginal hypoplasia has always been assumed to be a feature of CAIS, but the prevalence of this characteristic within a CAIS population has not previously been studied. Due to the action of fetal testicular antimüllerian hormone (AMH) on the developing müllerian ducts we hypothesized that CAIS might be associated with 25% to 33% loss of vaginal length. The normal range for adult vaginal length is  $11.1 \pm 1.0$  cm in women who have not undergone vaginal surgery (15), although variation in length may occur with state of sexual arousal and regularity of sexual activity. Our study finding of a mean adult vaginal length of 8.4 cm in CAIS women lends some support to this hypothesis. However, all the women examined in this study had previously undergone treatment for vaginal hypoplasia or were sexually active; a more reliable measure of vaginal length in CAIS in the context of a clinical trial could be obtained from untreated adolescents before the onset of sexual activity.

Treatments for vaginal hypoplasia are employed by clinicians to increase vaginal size, with the aim of improving sexual function. The first line of treatment is usually vaginal dilation techniques, and this was the method used by the majority of women in this sample, with only a minority having undergone surgery. It is interesting that most (90%) of the women who had undergone treatment still perceived their vagina as abnormal; this study has shown that self-

perceptions of the vagina being short are associated with sexual difficulties. Additionally, those women who had undergone treatments for vaginal hypoplasia had similar sexual function scores and perceptions of vaginal normality to women who had not undergone any treatment. It is likely that those offered treatment for vaginal hypoplasia were a group with more severe vaginal hypoplasia, so no conclusions can be made on the impact of vaginal hypoplasia treatment on the incidence of sexual difficulty. These results do suggest, however, that any treatment for vaginal hypoplasia may be of limited usefulness without concomitant psychological expertise to address other aspects of self-perception. Further studies are needed to prospectively assess changes in body perception, anatomical genital dimensions, and sexual function after interventions for vaginal hypoplasia, and the impact of clinical psychological input on these outcomes.

The sample of women in this study who underwent genital examination was small, so the statistical analysis was limited. A clinically relevant association of short vaginal length with sexual difficulties did not reach statistical significance. Pubic hair varied from Tanner grading 1 to 3, with a surprisingly high proportion (10%) of the examined sample having Tanner grade 3 quantity of vellus-type pubic hair. The majority of our sample have not undergone androgen binding or androgen receptor gene studies, as this is only available as a research tool in the United Kingdom; however, their clinical histories strongly suggest CAIS as the diagnosis. This degree of pubic hair could either represent a minor degree of androgen receptor function or somatic mosaicism. As the pubic hairs of those with Tanner grade 3 were mainly vellus-type, with only the occasional occurrence of sexual-type hairs, this quantity of pubic hair growth is most likely independent of androgen action. Just over half of the examined group (11 out of 20) had a small clitoris, possibly reflecting a lack of androgen action in clitoral development. This finding had no statistically significant association with sexual difficulty, but the examined sample was small.

Psychological factors are undoubtedly important in their effect on sexual function. A high proportion of the women in this study (79%) perceived themselves as having an abnormal vagina. This self-perception can negatively affect a person's sexual esteem and behavior, and we have shown that it is associated with sexual difficulties. Furthermore, 50% of the current sample reported communication problems with their partner, so it is unlikely that these complex psychological issues are fully addressed within the relationship. In this study we have found that the majority of women simultaneously reported sexual satisfaction and high levels of sexual difficulties. One possible explanation for this contradiction is that living with CAIS has contributed to low expectations of sexual functioning—that is, the women might have felt that sexual difficulties were to be expected

and that they should not be dissatisfied. Additionally, the past practice of secrecy over intersex diagnosis that the majority of these women experienced would have meant inadequate information and lack of opportunity for discussion, especially relating to sexual issues. Alternatively, the reported satisfaction in this study, especially in association with sexual infrequency, could indicate a withdrawal from sexual intercourse and a relief from facing the problems of sexual difficulties. Further research is needed in this area; it is clear that simple questioning on sexual satisfaction is not a useful measure for this diagnostic group.

After initial investigation and diagnosis, the medical management of CAIS usually centers on gonadectomy for malignancy risk and treatments for vaginal hypoplasia. The reasons for long-term follow-up include supervision of hormone therapy and, more recently, monitoring of bone mineral density. Long-term psychological and sexual outcomes have been poorly studied, and largely ignored in clinical management. They may be, however, of overwhelming importance in their impact on quality of life and adaptation to living with CAIS. The findings in this study have implications for clinical management. Intersex conditions such as CAIS should be managed within an expert multidisciplinary team that integrates endocrinology, gynecology, and clinical psychology expertise. Equal priority should be given to quality of life outcomes, including psychological and sexual treatments, as is currently given to the traditional clinical concerns. Treatments offered to lengthen the vagina should be undertaken with both gynecologic and psychological approaches. Adolescents with CAIS should, at a time deemed suitable by them, be offered an appropriate genital examination to provide information on genital normality and determine their vaginal potential. This also provides a chance to discuss any aspects of their intersex condition that they may wish to explore, to consider treatment options for vaginal hypoplasia to help avoid the trauma of unsuccessful penetration or hemorrhage due to vaginal vault tears, and to minimize potential negative psychological reactions. Expert psychological care should also be made available as an option for all CAIS patients with the aim of reducing the impact of social and psychological problems in sexual function, and to potentially improve quality of life outcomes.

The current study has also highlighted the need for further investigations in a number of areas. First, more research is needed to improve our understanding of the psychosocial and psychosexual aspects of living with intersex conditions. Second, the relative contribution of hormonal factors in sexual dysfunction in CAIS has yet to be elucidated. Third, a rigorous approach to treatment evaluation relating to vaginal hypoplasia is needed. Finally, longitudinal studies in-

corporating prospective evaluation of interventions should be undertaken.

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