Original Report

Sexual Experience before Treatment for Vaginal Agenesis: A Retrospective Review of 137 Women

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A B S T R A C T

Study Objective: To summarize the self-reported sexual experiences of women with vaginal agenesis before treatment and discuss the clinical implications.
Design: A retrospective review of pretreatment baseline sexuality data and medical records of women with vaginal agenesis seeking vaginal construction.
Setting: A specialist multidisciplinary center for women with genital differences associated with diverse sex development.
Participants: One hundred thirty-seven women with untreated vaginal agenesis associated with Mayer-Rokitansky-Küster-Hauser Syndrome and complete androgen insensitivity syndrome aged 15 to 41 years (mean age, 20 years).
Interventions: Gynecological examination and completion of questionnaires.
Main Outcome Measures: (1) Sexual Experiences Questionnaire; (2) Multidimensional Sexuality Questionnaire; (3) Vaginal Self-Perceptions; and (4) vaginal length.
Results: A sizable proportion of women reported having had sexually intimate experiences before any medical intervention on the vagina. Vaginal length, which ranged from dimple to 7 cm and averaged 2.7 cm for the cohort, was unrelated to the range of sexual experiences. Most women perceived their vagina as being too small, but less than half believed that a sexual partner would notice this. Two-thirds of the cohort subsequently completed the dilation program, which was not predicted by pretreatment vaginal length or sexual experience.
Conclusion: Contrary to the assumption that a vagina of certain dimensions is a prerequisite for women to "have sex," many women with Mayer-Rokitansky-Küster-Hauser syndrome and complete androgen insensitivity syndrome reported having experienced genital and nongenital sexual activities with no medical interventions. It is recommended that treatment providers affirm women's capacity for sexual intimacy, relationships, and enjoyment before they introduce the topic of vaginal construction as a non-urgent choice.
Key Words: Vaginal agenesis, DSD, MRKHS, CAIS, Intersex, Vaginal dilation, Sexual health, Sexual Experience Questionnaire, Multidimensional Sexuality Questionnaire, Clinical psychology

Introduction

Mayer-Rokitansky-Küster-Hauser syndrome (MRKHS)[1] and complete androgen insensitivity syndrome (CAIS)[2] are associated with vaginal agenesis and female-typical external genitalia. Medical management is focused on normalization of the vagina.[3] Psychosocial studies suggest that whatever the method, vaginal construction is psychologically complex,[4–6] not least because it is a cognitive, emotional, and physical process that is likely to bring women closer to, rather than bypasses, the reality of their anatomical difference.[6]

Reconstructive surgery used to be the main treatment option that involved dissecting and lining a neovaginal space with a skin graft (taken from thigh or buttock) or a segment of the intestine.[7,8] Postoperative complications of these major procedures include contracture, persistent bloody and/or offensive discharge and scarring,[9,10] and risk of malignant changes in the neovagina.[11] Furthermore, postoperative dilation is usually required to prevent stenosis. Newer techniques involving laparoscopic surgery are less invasive with quicker recovery but they too require a postoperative self-managed dilation regimen.[12] The long-term psychological and sexual outcomes of these interventions have not been quantified.[3] Interviews with women suggest that despite what is deemed a successful anatomical outcome by treatment providers, they might remain sexually inhibited for years after surgery.[5]

Vaginal size can also be increased without surgery, by gradual dilatation over several months.[13–15] It is the first-line approach in the United Kingdom, and some European countries as well as in the United States. Ongoing dilatation of the vagina is psychologically demanding especially for women who have not processed their emotional reactions to the diagnosis or who are sexually inhibited. There are other barriers to sustaining a dilation regimen, such as not feeling knowledgeable and confident enough[16] perhaps because of inadequate psychological preparation and support.

The capacity of women with vaginal agenesis for sexual intimacy and pleasure could be unduly undermined by culturally shared assumptions that sex must means coitus.[5] It has been suggested that the routine presentation of normalizing treatment, on the basis of the norm-based

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assumptions, could reinforce the negative meaning. A recent qualitative study suggests that the assumptions are widely held by health professionals working in the field.[6] Being culturally mandated to have a vagina of certain dimensions[5,6] could backfire. For example, the pressure to "normalize" might result in hasty treatment decisions, unrealistic expectations, and inadequate preparation, resulting in despondency and disengagement.[6]

Prompted by these discussions and the wider critique of normalizing treatment on medically benign genital differences,[17] we reviewed the pretreatment psychosexual data of our MRKHS and CAIS cohorts over a 10-year period. The purpose of our study was to assess the level of sexual experience before vaginal construction.

Materials and Methods

Ethics approval was obtained for the study, which took place at a tertiary center for adolescent and adult women born with genital differences including vaginal agenesis. The study was approved by the United Kingdom National Health Service National Research Ethics Service (reference 16/LO/0682, April 29, 2015).

Participants

Baseline questionnaire data and medical records were available for inspection for 137 women with a diagnosis of MRKHS and CAIS who sought treatment for vaginal agenesis between 2003 and 2015. All 137 women with complete records were included in the study.

Treatment Protocol

Every woman who seeks vaginal treatment at our multidisciplinary clinic has a gynecological examination. Non-surgical dilation is the first-line approach for women deemed suitable, which means most women. The gynecologist ascertains that the woman has the physical dexterity and confidence to insert a dilator and records the baseline vaginal length in centimeters in the medical file as well as the diagnosis and age.

When accepted into the dilation program, the nurse specialist meets with the woman to further explain about the process and the materials involved and to discuss follow-up contact, which usually comprises a mixture of face-to-face and telephone appointments depending on the woman's preferences. Vaginal construction using any method is a deeply emotional journey for women.[6] Psychological input is offered at any time during the program at the request of the woman or recommendation of the gynecologist or nurse specialist. The women complete the baseline questionnaires listed in the Measures section.

The dilation program is deemed to be completed when vaginal length reaches 7 cm or the woman reports that she is able to engage in coitus comfortably. Women who are unable to continue with dilation and seek further treatment are offered a laparoscopic Vecchietti procedure.[12] The Vecchietti procedure is preferred because it has fewer complications and is more reversible compared with the more invasive and complex vaginal surgeries. Although dilation is required to maintain vaginal patency post-Vecchietti, the process is less intensive than non-surgical dilation.

Measures

Sexual Experience Questionnaire

The Sexual Experience Questionnaire (SEQ)[18] is a checklist of sexual acts (eg, "you caress your partner's nonsexual areas"; "your partner caresses your nonsexual areas with you naked"). Participants are asked to tick the sexual act if they have ever experienced it. Each act is scored 1 if ticked, and 0 if not ticked. Developed in the United Kingdom in relation to HIV prevention in the 1990s, the SEQ assesses sexual experiences of young people. After the pilot phase,[18] the assessment tool was never finished as a psychometrically robust measure. It was adapted for this study to provide qualitative information rather than as a clinical measure to detect treatment changes. In the current study, the adapted SEQ listed 25 sexual acts, and the women ticked the ones that they had ever experienced (frequency of each sexual act and quality of experience was not assessed). The total SEQ score is simply the sum of all of the sexual acts ticked by each participant—that is—the minimum score is 0 and maximum 25. The higher the score the more sexual acts experienced.

Multidimensional Sexuality Questionnaire

Unlike the popular sexual function scales that typically require the participant to be in a current sexual relationship, the Multidimensional Sexuality Questionnaire (MSQ)[19] is a self-reported assessment of psychosexual wellness, responses to which can be on the basis of a current, past, or imagined relationship. Because the full MSQ is long and comprises 12 subscales each with 5 items (60 items), to avoid overburdening our patients, only 6 of the 12 subscales (30 items) were incorporated into the current evaluation, as per our previous studies.[13,20] The subscales were: sexual esteem, sexual anxiety, sexual assertiveness, sexual depression, fear of sexual relationships, and sexual satisfaction. Individuals rate their level of agreement with each item on a 5-point Likert scale (0 to 4).

Vaginal Self-Perceptions

The Vaginal Self-Perceptions had been developed at our unit for a previous study[13] to test the association between actual vaginal size and self-perceptions.

Statistical Analysis

Independent t tests and Pearson correlational analysis were used to test for significance of relationships between the continuous variables that were normally distributed. For non-parametric data, Mann-Whitney U test and Spearman correlational analysis were used. χ^2 Statistics were used to compare categorical data.

Results

Of the sample, 115/137 (84%) had a diagnosis of MRKHS and 22/137 (16%) had a diagnosis of CAIS. The mean age at

the point of completing the pretreatment baseline assessment was 20 years, with a range of 15 to 41 years. The mean age of the CAIS group was 23.8 years (SD, 8.4) and the MRKHS group 19.3 years (SD, 3.7) The former group was significantly older than the latter ($P < .001$).

The average vaginal length for the entire cohort was 2.71 cm ranging from a small dimple to 7 cm. The average vaginal lengths for the CAIS and MRKHS groups were 4.1 cm (SD, 1.5) and 2.6 cm (SD, 1.6), respectively. The difference was significant ($P < .001$).

Vaginal Self-Perceptions Data

One hundred thirty-six of 137 women completed the Vaginal Self-Perceptions questionnaire. Most perceived their vagina as too small or needing to increase in size (112/136; 82%). However, less than half of the sample believed that a sexual partner would notice that they were different to other women (54/136; 39%).

SEQ Data

The percentages of the MRKHS and CAIS groups and the total sample that had participated in the 25 types of sexual acts are presented in Table 1. A larger proportion of the MRKHS group than the CAIS group had participated in each of the sexual acts in the listing, but the differences were not statistically significant.

On average, the cohort had participated in 10.1 (SD, 7.7) sexual acts of a maximum of 25. The MRKHS group had participated in an average of 10.5 sexual acts (SD, 7.6) compared with an average of 7.7 (SD, 8.1) acts for the CAIS group, but the difference was not significant ($P = .12$). Twenty-three percent of the sample reported having experienced coitus (item 17). A quarter had experienced orgasm (item 18).

MSQ Data

The scores on the 6 MSQ subscales were not normally distributed. The median values and ranges are presented in Table 2. There were no significant differences between the CAIS and MRKHS groups on any of the subscales. The scores of this cohort are broadly similar to previous reports of women with the same diagnosis.[13,20]

The SEQ and MSQ scores were significantly but weakly correlated. The strongest correlation was between the number of types of sexual activities experienced and sexual self-esteem ($r = 0.43$; $P < .001$).

Treatment Engagement

On reviewing the medical files, 93/137 women (68%) were recorded as having subsequently completed the dilation program and 9/137 (7%) went on to have surgical construction. There was no significant difference between the MRKHS and CAIS groups in terms of completion rate. The remaining 35/137 women (25%) did not attend clinic after the start of the dilation program and did not seek further treatment. From the medical notes, the reasons for disengagement included school or college examinations, leaving home because of entry into higher education or overseas travels, and loss of motivation.

Table 1
Percentages of Women Having Experienced Listed Sexual Acts (SEQ)

Item Number	Item Description	Percentage of Whole Sample (N = 137)	Percentage of CAIS Group (N = 22)	Percentage of MRKHS Group (N = 115)
1	… caressing with hands partner's face, arms… or other non-sexual areas with your clothes on	68.6	50	72.2
2	…hugging each other with your clothes on	78.1	68.2	80.0
3	…kissing partner's face, arms, leg, neck or other nonsexual areas with clothes on	70.1	59.1	72.2
4	…kissing mouth closed	73.7	63.6	75.7
5	…deep kissing with tongues touching	72.3	63.6	73.9
6	…caressing with hands partner's genitals with clothes on	54.0	45.5	55.7
7	…partner caressing your breasts with your clothes on	58.4	36.4	62.6
8	…hugging each other naked	44.5	40.9	45.2
9	…caressing with your hands partner's genitals when naked	46.0	36.4	47.8
10	…partner caressing your genitals (clitoris, vagina, pussy) with your clothes on	49.6	31.8	53.0
11	…partner caressing your genitals with you naked	45.3	31.8	47.8
12	…partner caressing your face, arms, legs, back or other nonsexual areas with your clothes on	57.7	31.8	62.6
13	…partner caressing your face, arms, legs, back or other nonsexual areas with you naked	46.0	31.8	48.7
14	…partner putting finger in your vagina	38.0	27.3	40.0
15	…orally stimulating partner's genitals	39.4	36.4	40.0
16	…partner orally stimulating your genitals	32.1	31.8	32.2
17	…partner puts his penis inside your vagina	23.4	13.6	25.2
18	…you had an orgasm (came)	24.8	13.6	27.0
19	…partner ejaculated (came) inside your vagina	12.4	9.1	13.0
20	…partner ejaculated (came) outside your vagina	33.6	18.2	36.5
21	…partner putting his penis inside your anus (back passage)	10.2	9.1	10.4
22	…partner ejaculated (came) inside your mouth	22.6	22.7	22.6
23	…using sex toys	5.1	0	6.1
24	…partner dressed up in a particular way	2.2	4.5	1.7
25	…you dressed up in a particular way	5.1	0	6.1

CAIS, complete androgen insensitivity syndrome; MRKHS, Mayer-Rokitansky-Küster-Hauser Syndrome; SEQ, Sexual Experiences Questionnaire.

Table 2
MSQ Medians and Ranges According to Diagnosis

	CAIS			MRKHS		
	Median	Percentile		Median	Percentile	
		25	75		25	75
Subscale						
Sexual esteem	3	1	6	3	0	7
Sexual anxiety	6	4	11	9	4	13
Sexual assertiveness	6	2	9	6	3	9
Sexual depression	5.5	3	10	6	2	8
Fear of sex	9	4	13	9	5	13
Sexual satisfaction	4	2	7	3	0	7

CAIS, complete androgen insensitivity syndrome; MRKHS, Mayer-Rokitansky-Küster-Hauser Syndrome; MSQ, Multidimensional Sexuality Questionnaire.

The 93 dilation program completers and the 44 non-completers were compared in terms of their age, SEQ total scores, and MSQ subscale and total scores. There was no difference between completers and noncompleters in any of the variables.

Discussion

To our knowledge, this is the first report of the sexual experiences of a large cohort of women with untreated vaginal agenesis. Many of the women in the sample reported having experienced genital and non-genital sexual intimacy, albeit the quality of their experience is unknown. A quarter of the cohort reported having experienced orgasm, although the assessment did not enable us to ascertain the link between orgasmic experience and any specific sexual act. Scores on the MSQ subscales, which measure psychosexual wellness, were similar to previous reports involving women with MRKHS and CAIS.[13,20] There was a consistent but non-significant trend for the former to be more sexually experienced than the latter despite being significantly younger in age and having a significantly smaller untreated vagina. Vaginal size might not be an overriding determinant of sexual experience.

A quarter of the sample reported having experienced coitus. Gynecologists have observed that some adolescent and adult women latently diagnosed with Müllerian agenesis engage in regular coitus without problem.[21,22] Perhaps, unaware of there being a clinical problem and uninhibited by stigma and anxiety, some women and their partners might have persisted with sexual intercourse and overcome the difficulties without medical treatment.

Far from assuming that untreated women cannot "have sex" because they could not physically engage in coitus, our findings suggest that it is important to recognize the women as sexual beings regardless of their genital anatomy. Instead of introducing vaginal construction as something that the women (will) need to "have sex,"[5] health professionals should emphasize to the women that they are already able to access sexual intimacy, relationships, and pleasure. In situating vaginal construction as a choice within a care pathway with a much broader focus, care providers can avoid exacerbating normative pressures on women to take up vaginal construction (too soon).

Gynecological specialists have observed that many patients, under normative pressure, look to the creation of a vagina as a solution to attaining "normality."[23] Although an immediate vaginal treatment plan might bring some relief from the emotional threat of newly diagnosed vaginal agenesis, "normality," according to the specialists, "is not achieved through anatomic surgical correction alone."[23] Emotion-driven decisions might lead to the minimization of the physical and emotional demand of vaginal construction and inadequate psychological preparation. The reality of the challenges might lead to despondency and disengagement. Even when treatment is anatomically successful, unrealistically high pre-treatment expectations might result in disappointment.[5] Research shows that after vaginal construction, some women struggle to transcend the clinical focus on their genitals to derive sexual enjoyment.[5,24]

In a systematic review of psychological implications of vagina agenesis associated with MRKHS, the authors suggested that "adjusting to the diagnosis of MRKHS is a difficult and traumatic process" that could give rise to "the development of negative self-beliefs, with many women seeing themselves as defective, inferior, or unlovable."[25] There is significant pressure on health professionals to provide solutions. However, premature presentation of vaginal construction with false reassurances could hinder the cognitive and emotional processing that facilitates long-term psychological adjustment and self-acceptance. Research shows that emotional and psychosexual wellness is compromised for women with MRKHS[20] and CAIS.[4,5,26] Therefore, rather than presenting vaginal construction as a stand-alone response to vaginal agenesis, care paths could be re-developed to have a wider focus on emotional and sexual wellness.

Two-thirds of the current sample subsequently completed their dilation program. However, a quarter of the cohort appeared to have disengaged from the service. Women with MRKHS and CAIS generally enjoy good health; some women might prefer to discontinue their hospital visits when they have understood the self-management requirements of the dilation regime, especially for that large proportion of women who live some geographical distance from our tertiary center. Some women might have embarked on relationships and experienced no further concerns. Some might have deferred treatment as they focused upon other key life events such as higher education and travel plans. It is also possible that our particular service did not meet the needs of the women. Future research can help to ascertain the reasons in the interest of improving care quality.

Almost all of the patients diagnosed with MRKHS and CAIS in the study period of the current research had opted for vaginal construction (via nonsurgical dilatation as first-line treatment). An interesting question in the context of this discussion is whether prevalence of vaginal construction and its timing would change if health professionals were to, in principle, engage women and girls in affirming psycho-educational input first (eg, in the form of a group-based workshop), before introducing the topic of vaginal construction. Such a psychologically informed pathway can offer more opportunities for women to be supported to think together about reducing the sense of threat from vaginal agenesis and connecting with affirming ideas about

each other, before contemplating an elective medical intervention.

A further clinical recommendation on the basis of the current findings concerns the privacy of the young women in clinic. Parents, perhaps especially those of teenage girls, are understandably anxious about their daughters. Many might wish to attend clinic with their daughter (often at the daughter's request), to be reassured that there are treatments for a diagnosis that has come to them as a shock. Parental attitudes and support can make a pivotal difference to the young person's overall outlook, so that clinics should offer appropriate support for families. However, the presence of parents and surrogates is very likely to inhibit young people from asking questions about their sex anatomy and using the clinical space to safely explore their sexual preferences with their care providers. It is up to clinical services to construct consultation protocols that protect the patient's privacy and meaningfully engage her supporters.

In terms of future practice, the SEQ could be redeveloped into a bespoke clinical tool whereby women can state whether each of the sexual act referred to is something that they have experienced and/or have any wish to experience. An additional column along the items would enable women to rate the quality of the experience of the activities, if applicable. This could contribute to more information about the women's sexual preferences and enable care providers to tailor their language and clinical focus to individual needs. It can help service providers to avoid the risk of inadvertently shoehorning women into a coital trajectory in the face of pervasive cultural assumptions. On the basis of the findings of the current study, health professionals can confidently acknowledge to girls and women diagnosed with MRKHS and CAIS their existing potential for sexual relations and enjoyment.[27] It makes no sense to begin the patient's journey with a discussion about their perceived incapacity.

Last but not least, in a woman-centered (as opposed to treatment-focused) service, pretreatment assessment should never be limited to a vaginal examination per se, nor should it be extended to include sexuality only. Rather, it should take account of reactions to the diagnosis, treatment perceptions, and overall psychological well-being. Ongoing methodical recording of care user experience and service engagement is further needed to improve care quality.

Conclusion

This study suggests that a sizable proportion of women with vaginal agenesis have engaged in intimate genital and non-genital sexual activities before any medical intervention. If the focus of care were to be transformed to relationship and sexual confidence rather than vaginal size, when counseling women, health professionals might wish to emphasize sensual exploration, emotional intimacy, and sexual pleasure rather than coital performance. Within such a care ethos, vaginal construction is positioned as a non-urgent option along a psychologically informed whole-person care pathway.

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References

1. Pizzo A, Lagana AS, Sturlese E, et al: Mayer-Rokitansky-Küster-Hauser syndrome: embryology, genetics and clinical and surgical treatment. ISRN Obstet Gynecol 2013; 2013:628717
2. Crouch NS, Conway GS: Disorders of sex development. In: Creighton SM, Balen A, Breech L, et al, editors. Pediatric and Adolescent Gynecology: A Problem-Based Approach. Cambridge, United Kingdom, Cambridge University Press, 2018, pp 109–116
3. Nakhal RS, Creighton SM: Management of vaginal agenesis. J Pediatr Adolesc Gynecol 2012; 25:352
4. Alderson J, Madill A, Balen A: Fear of devaluation: understanding the experience of women with androgen insensitivity syndrome. Br J Health Psychol 2005; 9:80
5. Boyle M, Smith S, Liao LM: Adult genital surgery for intersex women: a solution to what problem? J Health Psychol 2005; 10:573
6. Roen K, Creighton SM, Hegarty P, et al: Vaginal construction and treatment providers' experiences: a qualitative analysis. J Pediatr Adolesc Gynecol 2018; 31:247. https://doi.org/10.1016/j.jpag.2018.01.001.
7. McIndoe AH, Banister JB: An operation for the cure of congenital absence of the vagina. J Obstet Gynaecol Br Emp 1938; 45:490
8. Hensle TW, Shabsigh A, Shabsigh R, et al: Sexual function following bowel vaginoplasty. J Urol 2006; 175:2283
9. Creighton S, Minto C, Steele SJ: Feminising childhood surgery in ambiguous genitalia: objective cosmetic and anatomical outcomes in adolescence. Lancet 2001; 358:124
10. Syed HA, Malone PS, Hitchcock RJ: Diversion colitis in children with colovaginoplasty. BJU Int 2001; 87:857
11. Schober J: Cancer of the neovagina. J Pediatr Urol 2006; 3:167
12. Ismail-Pratt IS, Cutner AS, Creighton SM: Laparoscopic vaginoplasty: alternative techniques in vaginal reconstruction. Br J Obstet Gynaecol 2006; 113:340
13. Ismail-Pratt IS, Bikoo M, Liao LM, et al: Normalization of the vagina by dilator treatment alone in complete androgen insensitivity syndrome and Mayer-Rokitansky-Küster-Hauser Syndrome. Hum Reprod 2007; 22:2020
14. Back F, Glanville JM, Balen AH: An observational study of women with Mullerian agenesis and their need for vaginal dilator therapy. Fertil Steril 2011; 96:483
15. Callens N, Weyers S, Monstrey S, et al: Vaginal dilation treatment in women with vaginal hypoplasia: a prospective one-year follow-up study. Am J Obstet Gynecol 2014; 211:228.e1
16. Liao LM, Doyle J, Crouch NS, et al: Dilation as treatment for vaginal agenesis and hypoplasia: a pilot exploration of benefits and barriers as perceived by patients. J Obstet Gynaecol 2006; 26:144
17. Hegarty P, Prandelli M, Lundberg T, et al: How European health professionals draw the line between medically essential and non-essential interventions for intersex. Under review 2019.
18. Breakwell GM, Fife-Schaw C: Sexual activities and preferences in a United Kingdom sample of 16- to 20-year-olds. Arch Sex Behav 1992; 21:271
19. Snell WE, Fisher TD, Walters AS: The multidimensional sexuality questionnaire: an objective self-report measure of psychological tendencies associated with human sexuality. Ann Sex Res 1993; 6:27
20. Liao LM, Conway GS, Ismail-Pratt IS, et al: Emotional and sexual wellness and quality of life in women with Rokitansky syndrome. Am J Obstet Gynecol 2011; 205:117.e1
21. D'Alberton A, Santi F: Formation of a neovagina by coitus. Obstet Gynecol 1972; 40:763
22. Moen MH: Creation of a vagina by repeated coital dilatation in four teenagers with vaginal agenesis. Acta Obstet Gynecol Scand 2000; 79:149
23. Edmonds DK, Rose GL, Lipton MG, et al: Mayer-Rokitansky-Küster-Hauser syndrome: a review of 245 consecutive cases managed by a multidisciplinary approach with vaginal dilators. Fertil Steril 2012; 97:686
24. Guntram L: Creating, maintaining and questioning (hetero)relational normality in narratives about vaginal reconstruction. Feminist Theory 2013; 14:105
25. Heller-Boersma JG, Schmidt UH, Edmonds DK: Psychological distress in women with uterovaginal agenesis. Psychosomatics 2009; 50:277
26. Minto CL, Liao KL, Conway GS, et al: Sexual function in women with complete androgen insensitivity syndrome. Fertil Steril 2003; 80:157
27. Liao -M: Towards a clinical-psychological approach for addressing the hetero sexual concerns of intersexed women. In: Clarke V, Peel E, editors. Out in Psychology: Lesbian Gay Bisexual Transgender and Queer Perspectives. Chichester, UK, John Wiley and Sons, 2007, pp 391–408