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ORIGINAL ARTICLE

Sexual well-being in adolescent and young adults born with arm: the perspective of the patients

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Abstract

Purpose Sexual well-being and sexual functioning are understudied in patients born with ARM. The aim of this exploratory study was to investigate sexual history, main fears, and problems encountered during sexual relationships.

Methods Before participating in a sexual education intervention, 21 adolescents or young adults (12 males; mean 28.8; SD 10.6) born with ARM, answered a ten-item questionnaire specifically developed to evaluate sexual well-being. Percentages and Chi-square were calculated.

Results 52.4% were married/had a partner. The majority (71%) declared that had sexual relationships. Mean age of the first sexual relationship was 18.8 (2.7) and 22.7 (3.8) for males and females, respectively. Females reported both more fear and experience of pain during sexual intercourse, compared to males. Main experienced problems and fears for male patients were loss of feces and premature ejaculation, followed by the fear of lack of erection and managing contraception. Main experienced problems and fears in females were loss of feces, pain, lack of desire, and lack of lubrication. In only few cases, patients asked for advices to a pediatric surgeon or to an adult surgeon specialized in ARM.

Conclusions Adult and adolescent patients may benefit of andrological/gynecological evaluation, psychological support, and sexual counseling to improve their sexual well-being.

Keywords Sexual functioning · Anorectal Malformations (ARM) · Patient perspective · Pediatric surgeons · Sexual well-being · Quality of life (QoL) · Fecal continence

Introduction

Many children born with anorectal malformations are now usually followed into adolescence. The Consensus by the ARM-net consortium regarding transition recommends that every hospital treating ARM patients pay attention, among other issues, also to sexual and reproductive function [1].

Previous studies indicated different forms of impaired sexual functioning (e.g., erectile dysfunction, vaginal stenosis, or dyspareunia) in these patients [2–5]. In a systematic review on active long-term problems in patients born with ARM, the prevalence of erectile dysfunction ranged from 5.6 to 11.8% and the prevalence for ejaculatory dysfunction was between 15.6 and 41.2%; in this review, no data were available for females [6].

Sexual dysfunctions can occur even with an excellent anatomic repair, being caused by associated problems, like poorly developed sacrum, deficient nerve supply, and spinal cord anomalies [5]. Patients may face sexual problems and embarrassment also due to associated urogenetical anomalies and to scars of the previous surgical interventions in the abdominal wall or in the genitalia [5, 7, 8]. Finally, fear of fecal and urinary incontinence may negatively influence sexual intercourse and occasions of intimacy [8]. Sexual functioning and sexual satisfaction should not be neglected, as they greatly contribute to a better quality of life [9]. Indeed, difficulties in close and sexual relationships have

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been associated with depressive feelings in adult patients born with ARM [10].

Based on these premises, we think that it is important to investigate which specific sexual difficulties the patients born with ARM face and what they would like to address with the pediatric surgeon. The aim of this explorative study was, therefore, to investigate patients' sexual history, which issues the adult patients may like to address within the medical consultation and the main fears and problems encountered during sexual and intimate relationships. These aspects will be investigated separately for males and females to consider the different problems and necessities of the patients. Knowing the perspective of the adult patients on this matter may help surgeons to better address patients' needs.

Methods

In January 2018 and in September 2018, the Italian Parents' and Patients' Association for Anorectal Malformation (AIMAR) organized two group encounters on sexual issues for adolescents and young adults born with ARMs. A total of 21 adolescents and young adults participated to the group encounters. The encounters were held by a sexologist and announced through the Association's magazine. At the beginning of each encounter, participants were invited to answer a ten-item questionnaire, developed by the AIMAR association, to assess sexual concerns and well-being. Participants (12 males; mean age 28.8; SD 10.6) were asked for informed consent and answered the questionnaire. Example items were "Did you have sexual relationships with someone else?", to which patients could answer on a dichotomous scale yes/no, and "What issues related to intimate relationships would you like to address?", where patients could choose one or more alternative from a given list.

Statistical analyses

Percentages and Chi-square statistics were calculated. All analyses were performed with the Statistical Package for Social Sciences (SPSS, version 25).

Results

Sociodemographic characteristics of the sample are reported in Table 1. Nine of the participants were single, 12 were married or live with a partner, and 3 had a not cohabitant partner. One indicated another type of relationship. One person declared to be bisexual, and all the others declared to be heterosexual.

The majority of the patients (eight males and seven females) declared that they had sexual relationships. Mean age of the first sexual relationship was 18.8 (2.7) and 22.7 (3.8) for males and females, respectively. In a reference population, the mean of the first relationship was 17.1 for both females and males [11]. No one of the women were in menopause.

Table 1 Sociodemographic characteristics

	Patients, *N* (%)
Gender	
Female	9 (42.9)
Male	12 (57.1)
Sexual orientation	
Heterosexual	20 (95.2)
Homosexual	1 (4.8)
Relationship status	
Single	9 (42.9)
Married or live with a partner	8 (38.1)
Have a partner not cohabitant	3 (14.3)
Other type of relationship	1 (4.7)
Mean age (SD)	
Males	29.7 (10.9)
Females	29.3 (10.9)

Table 2 reports the information about the past sexual experiences and sexual practices.

Considering the sexual practices experienced during the first sexual relationship, most males reported to have practiced mutual masturbation ($N=5$) or coitus ($N=4$). Most females reported petting ($N=6$) or coitus ($N=5$). Considering the sexual practices experienced during their life, most males reported to have practiced mutual masturbation ($N=7$) and coitus ($N=6$). Most females reported to have practiced coitus ($N=7$) and petting ($N=6$).

In Table 3, the issues related to intimate relationships that patients would like to address are shown. Considering these issues, males were mainly interested in knowing if they can have children ($N=7$) and how to tell a sexual partner of being born with an ARM ($N=6$). Females were mainly interested in receiving information on how to tell a sexual partner of being born with an ARM ($N=6$) and in how to manage loss of feces ($N=5$).

In Table 4, problems and fears connected to sexual health are shown. Considering the problems encountered, in three cases, male patients experienced loss of feces accidents and, in two cases, premature ejaculation. These were also the most reported fears in males: loss of feces ($N=4$), premature ejaculation ($N=4$), followed by lack of erection ($N=3$), and managing contraception ($N=3$). Main problems encountered by female patients were loss of feces ($N=5$), pain ($N=4$), lack of desire ($N=3$), and lack of lubrication ($N=3$). Accordingly, main reported fears were loss of feces ($N=7$), pain ($N=5$), lack of desire ($N=4$), and lack

Table 2 Past sexual experiences and sexual practices

	Males, ($N=12$) N (%)	Females, ($N=9$) N (%)
Did you have sexual relationships with someone else?		
Yes	8 (66.7)	7 (77.8)
No	4 (33.3)	2 (22.2)
If yes, which sexual practices did you experience the first time?[a]		
Mutual masturbation	5 (41.7)	2 (22.2)
Petting	3 (25)	6 (66.7)
Oral sex	2 (16.7)	1 (11.1)
Anal sex	0 (0)	0 (0)
Coitus	4 (33.3)	5 (55.6)
If yes, which sexual practices did you experience during your life?[a]		
Mutual masturbation	7 (58.3)	5 (55.6)
Petting	5 (41.7)	6 (66.7)
Oral sex	5 (41.7)	5 (55.6)
Anal sex	3 (25)	1 (11.1)
Coitus	6 (50)	7 (77.8)
Age first sexual relationship Mean (SD)	18.8 (2.7)	22.7 (3.8)
Number of partners Mean (SD)	5.6 (5.4)	3.6 (2.6)

[a]Patients were given the possibility to indicate more than one option

Table 3 Issues related to intimate relationships that patients would like to address

Which issues related to intimate relationships would you like to address?[a]	Males, $N=12$ (%)	Females, $N=9$ (%)
How to tell a sexual partner of being born with an ARM	6 (50)	6 (66.7)
Address my being "diverse"	2 (16.7)	4 (44.4)
Understand if my sexuality can be the same of people with no ARM	2 (16.7)	4 (44.4)
Manage possible feces loss accidents	1 (8.3)	5 (55.6)
Manage possible urine loss accidents	1 (8.3)	2 (22.2)
Know more about contraception to avoid sexually transmitted infections	0 (0)	0 (0)
Know more about contraception to avoid unwanted pregnancy	0 (0)	0 (0)
Know more about sexual problems	3 (25)	1 (11.1)
Know how to use tools which may be of help during my sexual experience	1 (8.3)	3 (33.3)
I would like to know if I can have children	7 (58.3)	2 (22.2)
Other	0 (0)	0 (0)

[a]Patients were given the possibility to indicate more than one option

of lubrication ($N=4$). When comparing females and males about the experience of pain during sexual relationships, females reported more pain [χ^2 (1, $N=21$) = 5.6, $p=.018$]. When considering fears, again, females reported more frequently fear to feel pain during sexual relationships [χ^2 (1, $N=21$) = 7.5, $p=.006$].

Considering the figures to whom patients turned to ask for advices about sexual and intimate relationships, male patients refer mostly to parents ($N=5$), friends ($N=4$), and psychologists ($N=4$). None of them asked for advice to a pediatric surgeon and one asked for advice to a surgeon for adults specialized in the treatment of ARM. Females asked for advices mainly to a gynecologist ($N=6$), a psychologist ($N=3$) and to friends ($N=3$). One female patient had asked advice to a pediatric surgeon.

Discussion

Sexual well-being and sexual functioning are understudied topics in patients born with ARM and only few studies have specifically addressed these issues. The aim of the present study was to investigate through a brief questionnaire sexual history, main problems, and fears encountered during sexual relationships in a sample of Italian patients belonging to

Table 4 Problems and fears connected to sexual health

	Males, ($N=12$) *N* (%)	Females, ($N=9$) *N* (%)
Which of these problems have you had during sexual intercourse?[a]		
Loss of feces	3 (25)	5 (55.6)
Loss of urine	0 (0)	1 (11.1)
Manage contraception	1 (8.3)	0 (0)
Lack of sexual desire	1 (8.3)	3 (33.3)
Lack of erection	1 (8.3)	0 (0)
Lack of vaginal lubrication	0 (0)	3 (33.3)
Lack of orgasm	0 (0)	0 (0)
Lack of ejaculation	1 (8.3)	0 (0)
Premature ejaculation	2 (16.7)	0 (0)
Lack of sexual satisfaction	0 (0)	1 (11.1)
Pain	0 (0)	4 (44.4)
Other	1 (8.3)	0 (0)
Which of these problems are you afraid to have during sexual intercourse?[a]		
Loss of feces	4 (33.3)	7 (77.8)
Loss of urine	1 (8.3)	2 (22.2)
Manage contraception	3 (25)	0 (0)
Lack of sexual desire	0 (0)	4 (44.4)
Lack of erection	3 (25)	1 (11.1)
Lack of vaginal lubrication	0 (0)	4 (44.4)
Lack of orgasm	0 (0)	1 (11.1)
Lack of ejaculation	1 (8.3)	1 (11.1)
Premature ejaculation	4 (33.3)	0 (0)
Lack of sexual satisfaction	1 (8.3)	1 (11.1)
Pain	1 (8.3)	5 (55.6)
Other	2 (16.7)	0 (0)
Have you ever asked anyone for advice about sexuality or intimate relationships?[a]		
No, I did not ask advise to anyone	3 (25)	3 (33.3)
Friends	4 (33.3)	3 (33.3)
Parents	5 (41.7)	2 (22.2)
Relatives	0 (0)	0 (0)
Teachers	0 (0)	0 (0)
Pediatric surgeons	0 (0)	1 (11.1)
Gynecologists/andrologists	1 (8.3)	6 (66.7)
Surgeon specialized in the treatment of ARM for adults	1 (8.3)	0 (0)
Psychologist	4 (33.3)	3 (33.3)
Nurse	0 (0)	0 (0)
Others	0 (0)	0 (0)

[a]Patients were given the possibility to indicate more than one option

the Italian Parents and Patients Association for Anorectal Malformation (AIMAR).

The majority of the patients declared that they had sexual relationships with others (67% of males and 78% of females). In normative data, the percentage for males and females aged 20–22 years is around 79% [11], and in a large sample of Italian university students, more than half of the participants declared to have had sexual experiences at 17 of age or at an earlier age [12]. Although the present study included also young adults, it seems that male patients with ARM have less sexual experiences when compared with female patients and with normative samples.

Considering the mean age of the first sexual relationship, we noticed that our patients reported a delayed sexual debut. The mean age of the first sexual experience was 22.7 years for females (22.7) and 18.8 years for males. The mean age

of a reference Italian group is slightly lower (17.1 years). Our findings are consistent with another study conducted in Finland, where a delayed sexual debut age was also reported for patients born with ARM [13]. Consistently, it has been observed that adolescents with ARM reach their psychosexual milestones later than healthy peers, maybe due to lack of privacy and overprotection [5]. This delayed sexual activity may be correlated with negative consequences on the patient's quality of life. Indeed, difficulties in close and sexual relationships have been reported to be predictive of depressive feelings in male patients [10].

Considering the sexual practices experienced, we can observe a large variation, with patients reporting different types of practices. During the first relationship, the majority of patients declared that they had experienced reciprocal masturbation and coitus with no substantial differences between males and females. Different sexual practices have been reported also during patients' lifelong sexual life: Reciprocal masturbation and coitus were the most diffused practiced in males. More than three females out of four reported to have practiced coitus, followed by petting (two on three of this sample). Few patients experienced anal sex (three males and one female). We do not know if this last finding is related to the fact that the anal area might be perceived as sick and traumatized in this specific population. To the best of our knowledge, no normative data are available for the Italian general population on this sexual practice. In an American National sample, the percentages of those who had experienced anal sex during their life are higher in both genders, ranging from 4% at 14–15 years of age to more than 40% at 30–39 years of age [14].

Considering the issue of talking about the intimate relationships, many patients express the desire to be able to find ways to tell their sexual partner about their ARM. Compared to the disclosure process in other disabilities, this process may be further complicated in patients born with ARM, as, in most of the patients, the malformation is not a visible defects. The issue of disclosure seems to be important both in males and females and interventions should be tailored to help patients manage this important task. To facilitate this process, a complex set of issues including, honesty, authenticity, timing and how and to whom reveal one's own defect may be taken into account [15].

The possibility to have children is one of the most frequent issues that male patients would like to address. Indeed, reproduction is a delicate topic in this population, since fertility might be compromised in both male and female patients, especially in those with a more severe form of ARM [16]. Moreover, receiving appropriate information about fertility issues is complicated by the fact that each case is very specific and knowledge about fertility in ARM is still limited. Only two women expressed the need to know about their fertility. This may appear as a lack of interest of women on this issue; however, a high percentage of females indicated to have asked advices to gynecologists in the past, and therefore, they might had already clarify their doubts on this issue, not needing, at the moment, additional information. On the contrary, only in few cases, the male population was referred to an andrologist. This difference exists also in the general population, where is common that women refer to gynecologists, while is much less frequent that the men refer to an andrologist [12].

Considering the problems encountered during sexual intercourse and patients' fears, loss of feces emerged as the most frequent problem and as a diffused fear both in males and females. This finding is in line with previous studies in which patients reported that fear of fecal incontinence may negatively influence sexual intercourse and occasions of intimacy [8] and with previous findings, indicating that fecal incontinence is related to sexual anxiety [17]. The fear to incur in fecal incontinence accidents may be probably reduced by giving the patients the opportunity to successfully face the above-mentioned disclosure process.

Pain was another frequently encountered problem only in female participants. The finding that sexual pain is more frequent in females compared to males is consistent with a previous study conducted by the German ARM patient association [5] and with findings from the general population [18]. This may be explained by several biological and psychosocial reasons [19].

Few females reported to have had problems concerning lack of sexual desire and vaginal lubrication and none of them reported that managing contraception was a problem or a fear. This was not true for the male patients for whom contraception was one of the most frequent fears. This is quite unexpected and future studies are needed to better understand the reasons of this finding in the male patients.

Only one patient reported lack of erection, which is not more frequent than what revealed in the general population in a multicenter worldwide study [20], and three male patients were afraid to incur in this problem during sexual intercourse. Another patient reported to have problems of delayed ejaculation. In the above German mentioned study, this problem was quite diffused (17%) [5], while the prevalence of delayed ejaculation in the general population is not common and ranges between 1 and 4% [21].

Premature ejaculation problems were quite common in our sample, although still in line with the normative data [22]. Overall, compared to the above-mentioned study with the German patient association [5], we found fewer sexual problems. In addition to the already mentioned differences, none of our patients reported orgasm problems against the 22% of females and the 10% of males in the German sample.

It is possible that the fewer problems reported in our study compared to the German one reflect the advances in surgical techniques and improvements in bowel

management programs. Indeed, recent studies reported that sexual functioning seems quite preserved in ARM patients [7].

Regarding the issue about seeking advices on sexuality and intimate relationships, women refer mainly to the gynecologists, while males refer mainly to the parents. Other important sources of advices for both males and females were psychologists and friends, this last ones, in line with the tendency in the general population [11]. In only few cases, in our sample, patients asked for advices to the pediatric surgeon (one female patient) or to the adult surgeon specialized in ARM (one male patient). This may be due to the embarrassment of the patients in raising these issues within the medical consultation and to the discomfort that doctors may encounter in speaking of sexuality issues with their patients [23]. We think it is important that patients may have the possibility to ask advices to different professionals (gynecologists/andrologists or psychologists); at this regard it is essential the presence of a multidisciplinary team to whom the patient may refer, especially during the transition period, but also during follow-ups. In adolescence, these psychosocial factors and sexuality issues could be addressed during follow-up in the outpatient clinic.

Finally, some limitations of the study need to be acknowledged. First, a selection bias might influenced the generalizability of the results. In fact, patients who answered the questionnaires were involved in an educational section about sexual functioning. Thus, participants could be more motivated toward this topic compared to people who did not decide to participate. Second, differences in sexual functioning and distress may be influenced by the type of anomaly. However, being interested in directly investigating the perspective of the patients, we did not have access to the medical records of the patients. Indeed, we think that this enhanced patients' perception of anonymity, facilitating the revelation of the patients about their sexual issues.

Notwithstanding these limitations, this is one of the few studies which analyses past sexual experiences, problems, and fears related to sexual relationships and sexual practices and the first conducted on Italian patients born with ARM.

In conclusion, we think that the knowledge emerged from the perspective of the patients may be of help for increasing the awareness of pediatric surgeons and of other health providers on the sexual problems that patients born with ARM face and to plan possible interventions.

Patients may benefit of andrological/gynecological evaluation, psychological support, and sexual counseling to improve their sexual well-being. Pediatric surgeons and the other health professionals working with patients born with ARM, may be more proactive in the assessment of these problems, to be perceived as a formal source of information on these aspects.

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Author contribution SE and CG conceived the idea and shape the manuscript. SE and CG wrote the introduction, the methods and the discussion. SE collected the data. All the other authors commented on the questionnaire and on the final version of the manuscript.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Informed consent Informed consent was asked to all participants included in the study.

Ethical approval "All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards".

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