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ORIGINAL REPORT

SPINA BIFIDA AND SEXUALITY

Michael v. Linstow, MD, PhD[1], Ida Biering-Sørensen, BMD[1], Annette Liebach, MD[2], Marianne Lind, PT[3], Aase Seitzberg, PT[3], Rikke Bølling Hansen, MD, PhD[4] and Fin Biering-Sørensen, MD, DMSc[1,5]

From the [1]Department for Spinal Cord Injuries, Glostrup Hospital/Rigshospitalet, [2]Department for Traumatic Brain Injuries, Glostrup Hospital/Hvidovre Hospital, [3]Clinic for Physio- and Occupational Therapy, Rigshospitalet, Hornbaek, [4]Department of Urology, Frederiksberg Hospital, Frederiksberg and [5]Faculty of Health Sciences, University of Copenhagen, Copenhagen, Denmark

Objective: **To evaluate sexual function amongst adult individuals with spina bifida and to register their subjective satisfaction with their sexual life and relationships.**
Setting: **Department for Spinal Cord Injuries, East Denmark.**
Study design and methods: **Cohort study. Medical record information, neurological examination, personal interview, Functional Independence Measure (FIM^{TM}), Medical Outcome Study Short Form 36 (SF-36) on quality of life, and questions on sexual function and related topics.**
Study cohort: **Fifty-three participants (27 women, 26 men) with spina bifida (mean age 27.1, range 18–35) years. Response rate 74%.**
Results: **Fifty-one percent of subjects regarded their sexual life as a failure or dysfunctional. However, 45% reported being satisfied with their sexual life. Participants with partners were more satisfied with their sexual life than those without partners. Faecal, but not urinary, incontinence was associated with poorer sexual function and less satisfaction. Forty-nine percent of subjects indicated that the sexual education they received at puberty was useful; however, 32% lacked knowledge about their sexual functioning with regard to their disability.**
Conclusion: **There is a need for further sexual education and counselling for adults with spina bifida in order to improve their sexuality and quality of life.**

Key words: spina bifida; myelomeningocele; sexuality; sexual function; sexual counselling; urinary and faecal incontinence; hydrocephalus; quality of life.

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Correspondence address: Michael E. von Linstow, Department for Spinal Cord Injuries, Glostrup Hospital, University of Copenhagen, Havnevej 25, DK-3100 Hornbæk, Denmark. E-mail: michael.ernst.von.linstow@regionh.dk

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INTRODUCTION

The annual incidence of spina bifida (SB) or myelomeningocele in Denmark has been estimated as 3.1 per million inhabitants (1) and has decreased markedly over the last decades, presumably due to prophylactic folic acid supplementation, prenatal alpha-foetoprotein testing, ultrasound screening and subsequent abortions.

In SB, malformations of the vertebrae are usually accompanied by malformations of the spinal cord (SC), the meninges and the lower parts of the brain (Chiari malformation) (2, 3), which may lead to hydrocephalus. The neurological consequences of SC malformations are reduced or absent motor and sensory functioning. Symptoms depend on the level of the developmental defect of the spine, the degree of completeness of the SC lesion, and the extent to which the individual with SB exhibits symptomatic hydrocephalus (2, 3). Hydrocephalus is associated with cognitive impairments, such as dysfunctions in memory, attention and executive functions (4). Another consequence of the neurological injury is impaired bladder and bowel control, including incontinence of urine and faeces.

There is risk of pressure ulcers and often a need for tendon and bone surgery to correct various congenital or early-onset deformities in the lower extremities and spine. In childhood, individuals with SB are more dependent on parents, walking aids (5) and environment in everyday life compared with other children, with regard to mobility, bladder and bowel emptying. Sexual function, including the ability to have sexual intercourse and achieve orgasm, may be affected negatively by reduced or absent motor and sensory function. Men with SB may experience diminished or absent erectile ability, and retrograde or absent ejaculation. Women may experience problems with vaginal lubrication and a flaccid pelvic floor.

Furthermore, the sexuality of individuals with SB may be adversely affected by paralysis of the lower body/extremities, the need for personal assistance, technical aids and/or adapted environment, together with possible cognitive impairment. The above factors substantially complicate the process of individuals developing independence from their parents, and the testing of the individual's own sexuality and personal relationships.

At puberty the physical development of women with SB is often a couple of years in advance of (6) their mental maturity, which makes the handling of sexuality even more difficult.

Sexual life is a considerable challenge for people with SB, as reflected by the fact that a large proportion of this group of people are unhappy with their sexuality (7, 8).

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The manner in which people with SB experience their sexuality, how this affects their quality of life (QoL), and how they perceive the information they receive about sexuality has not previously been systematically described in Denmark. The aim of this study is therefore to elucidate the situation related to the sexual functioning of persons with SB and their own perception of QoL, factors influencing it, and their experience of counselling.

MATERIAL AND METHODS

The study is based on a cohort of people with SB, born in 1965–84 and living in Eastern Denmark. It is part of a larger study focusing on QoL, neurological status, sexual function and social status.

All participants signed an informed consent, approved by the local ethics committee, prior to the survey.

In Eastern Denmark, which has 2.5 million inhabitants, the follow-up of individuals with SB has been centralized for the past 20 years; from birth they are monitored at the Clinic for Rare Disabilities, Rigshospitalet. From the age of 16 years medical follow-ups take place at the Department for Spinal Cord Injuries, Glostrup Hospital/Rigshospitalet.

Patient archives were reviewed, and 125 potential participants identified. Patients with traumatic SC injury, encephalocele, sacral agenesis, meningocele and spinal lipoma were excluded ($n=53$). Of the remaining 72 individuals, 12 declined to participate and 7 did not respond.

In total, 53 individuals with SB (27 females and 26 males) participated, i.e. a response rate of 74%. The participants' mean age was 27 years (range 18–35 years; females 27.1 years (standard deviation (SD) 4.7), males 27.1 years (SD 5.2)). There were no significant differences in gender, age or completeness of injuries between the participating ($n=53$) and non-participating ($n=19$) individuals. Among the participants with SB 38 (72%) had hydrocephalus, whilst this was unknown for 3 participants. Concerning the level of the SC lesion, 7 participants had a cervical, 16 a thoracic, and 30 a lumbosacral lesion (4 sacral). Only 5 individuals had complete lesions (2 lumbar, 2 thoracic and 1 cervical).

Where possible the study was performed in conjunction with planned annual follow-up visits, including questions concerning bladder, bowel and sexual function, as well as civil status and pension (Table I).

In order for participants to describe their subjective perception of whether their sexual life was satisfactory, supplementary not-validated questions about partner relationship, sexual life and social contacts (Table II) were included using an interview scheme.

The Functional Independence Measure (FIM^{TM}) was used in accordance with the recommendations of the American Spinal Injury Association (ASIA) (9).

The FIM^{TM} includes 18 items, scored from 1 to 7 based on level of independence, where 1 represents total dependence and 7 indicates complete independence in relation to activities of daily living. Thirteen items are physical domains, divided into self-care (6 items), sphincter control (2 items), transfers (3 items) and locomotion (2 items), and 5 are cognitive items, divided into communication (2 items) and social cognition (3 items). The total score ranges from 18 to 126, with higher scores indicating greater independence.

Finally, the Medical Outcome Study Short Form 36 (SF-36) Health Survey was applied (10). This is a validated health-related QoL questionnaire with 36 items, which measures health in 8 different domains: physical functioning (10 items), role limitation due to physical problems (4 items), bodily pain (2 items), general perception of health (5 items), vitality (4 items), social function (2 items), role limitation due to emotional problems (3 items) and mental health (5 items), with scores from 0 (worst possible health state) to 100 (best possible health state for the particular question), i.e. the higher the score, the better the QoL. All but 1 of the 36 items (self-reported health transition) are used to score the 8 SF-36 scales. Overall, the evaluation measures physical health (first 4 domains: 21 items), and mental health components (final 4 domains: 14 items). The Danish version of the SF-36 is validated against a Danish norm group of 4,080 persons (48% males, age > 16 years), thereby enabling a comparison between the results of this study and normative data (11).

Table I. *Questions from the structured electronic patient record, and the answers given by the participants with spina bifida (*n = 53*)*

	n (%)
All	
Pension	
No	28 (53)
Yes	25 (47)
Marital status	
Unmarried	38 (72)
Married	5 (9)
Cohabitants	9 (17)
Divorced	1 (2)
Urinary incontinence	
No	16 (30)
Yes, only when urinary tract infection	2 (4)
Yes, less than once a week	12 (23)
Yes, less than daily and more than once a week	4 (8)
Yes, daily	19 (36)
Faecal incontinence	
No	12 (23)
Yes, only when diarrhoea	24 (45)
Yes, less than once a month	4 (8)
Yes, less than once a week and more than once a month	4 (8)
Yes, more than once a week and less than daily	2 (4)
Yes, daily	7 (13)
*Women only (*n = 27*)*	
Number of children delivered	
3	1 (4)
2	2 (7)
1	3 (11)
Vaginal lubrication	
No	0
Normal	15 (56)
Sparse	1 (4)
Do not know	10 (37)
Unknown	1 (4)
Menstruation	
No	2 (7)
Regular	22 (81)
Irregular	3 (11)
*Men only (*n = 26*)*	
Erection	
Not tried	0
No	8 (31)
Yes	18 (69)
Quality of erection ($n=18$)	
Hard	5 (28)
Soft	6 (33)
Unknown	7 (39)
Ejaculation	
Not tried	2 (8)
No	8 (31)
Yes	16 (62)

Statistical methods

Fisher's exact test and Students *t*-test were used, and $p<0.05$ (2-tailed) was chosen as level of significance. The internet-based statistical program, VasserStats for direct data-entry, was utilized for data testing (http://vassarstats.net/).

In the analyses, tests were performed by grouping the subgroups' answers in order to achieve reasonable sample size in the tests, while preserving meaningfulness, as shown in Appendix I.

Table II. *Supplementary questions on partner relation, sexual life related issues, and social contacts, and answers given by the participants with spina bifida (*n = *53)*

	n (%)
Have you, within the past year, had a girlfriend/boyfriend/spouse?	
Yes	31 (58)
No	22 (42)
How important is it for you to have a girlfriend/boyfriend/spouse?	
Very important	22 (41)
Important	15 (28)
Not very important	13 (24)
Irrelevant	3 (7)
If you must describe your sexual life during the last year, is it?	
Total failure	17 (32)
Dysfunctional	10 (19)
Fairly functional	13 (25)
Well-functioning	13 (25)
What does it mean to you that your sexual life is as you describe it?	
Are you very unhappy and feel it affects your whole life negatively?	4 (8)
Are you unhappy about it and wish it was different?	9 (17)
Do you wish it was different, but accept the situation?	16 (30)
Are you satisfied with the present situation?	24 (45)
Do you think you are missing information about how you function sexually with your disability?	
Yes	17 (32)
Do not know	2 (4)
No	34 (64)
Do you think that you, in connection with puberty, got a useful sexual education?	
Yes	20 (38)
Do not know	7 (13)
No	26 (49)
How old were you when you thought you needed sexual education? Mean: 15.1 years	
10 years	1
12 years	5
13 years	4
14 years	8
15 years	11
16 years	5
17 years	3
18 years	4
19 years	1
20 years	1
22 years	1
Unknown	9
Are you satisfied with the number of friends you have?	
Yes	42 (81)
No	10 (19)
Unknown	1
Are you generally satisfied with your social life?	
Yes	44 (85)
Do not know	1 (2)
No	7 (13)
Unknown	1

RESULTS

Table I shows the responses of the SB participants to questions concerning pension, marital status, frequency of urinary and faecal incontinence, and sexual function.

Among the SB individuals who did not receive invalidity pension (Table I), 17 were in ordinary employment, while 11 were in sheltered employment. Of the 6 women who had given birth to the 10 children, 5 were married or cohabitating, whilst 1 was unmarried (Table I). None of the men had fathered children.

Table II shows the responses to questions on partner relationships, sexual life related issues, and social contacts.

At the time of the investigation the majority (72%) of the individuals with SB were unmarried (Table I), but 58% reported having had a girlfriend, boyfriend or spouse within the past year (Table II). There was a trend for more women than men (19 out of 27 vs 12 out of 26 ($p = 0.098$)) reporting having had a relationship within the last year. There was no difference in the frequency of partner relationships with regard to the level of the neurological lesion or the presence of hydrocephalus. Neither vaginal lubrication nor erection influenced the reported relationships within the last year. Those who had a girlfriend, boyfriend or spouse within the past year significantly more often found such a relationship of importance compared with those without such a relationship ($p = 0.002$).

Approximately half of the SB participants regarded their sexual life during the last year as a total failure or dysfunctional, while the rest were divided between a fairly functional or well-functioning sexual life (Table II). There was no significant difference between genders, age at the time of the study, neurological level, or presence of hydrocephalus concerning this aspect, but those who were in relationships reported a significantly better functioning sexual life than those without a partner (Table III).

Of the SB participants, 25% reported being unhappy or very unhappy with their present sexual life, whilst 45% reported being satisfied with the present situation (Table II). There were no differences between the genders in this respect. Those in a partner relationship tended to describe their sexual life as more satisfactory than those without a partner ($p = 0.07$). Higher frequency of acceptance/satisfaction with present sexual life was significantly related to a more functional sexual life.

There was no relationship between the functional description of sexual life within the last year and incidence of hydrocephalus or neurological level of the lesion. However, the higher the lesion, significantly more individuals with SB ($p = 0.049$) were unhappy with their sexual life: cervical 57%, thoracic 38% and lumbosacral 10%.

Of all the men with SB, 69% reported being able to achieve an erection, although often of poor quality, while the others reported being unable to achieve an erection (Table I). All men had knowledge of their ability to achieve an erection. This ability to achieve an erection did not significantly affect the likelihood of a relationship, or influence the description of their functional sexual life (Table III). The ability to ejaculate was significantly related to experiencing a more functional sexual life.

In contrast to men, at least 37% of women had no knowledge of their vaginal lubrication (Table I), still there was no correlation between them being in a relationship, or in their description of their sexual life whether or not they had normal vaginal lubrication (Table III).

Table III. *The 53 participants with spina bifida divided according to their own description of their sexual life during the last year, and related to some of the questions included in the study*

	If you must describe your sexual life during the last year, is it:		
	Total failure/dysfunctional ($n=27$)	Fairly functional/well-functioning ($n=26$)	p-value
Questions from the structured electronic patient record, n %			
Married/living with partner	1 (3.7)	13 (50)	0.0001
Vaginal lubrication normal (1 unknown)	6/12 (50)	9/14 (64)	ns
Erection	9/15 (60)	9/11 (82)	ns
Ejaculation	6/15 (40)	10/11 (91)	0.014
Urinary incontinence daily	10 (37)	9 (35)	ns
Faecal incontinence daily or weekly	9 (26)	0	0.037
Supplementary questions, n %			
Girlfriend/boyfriend/spouse within the past year	8 (30)	23 (88)	<0.0001
Very important to have a girlfriend/boyfriend/spouse	9 (33)	13 (50)	ns
Satisfied with or accept sexual life as is	16 (63)	24 (92)	0.009
Yes, missed information on sexual function	12 (44)	5 (19)	ns (0.08)
Satisfied with number of friends	18 (69)	24 (92)	ns (0.08)
Generally satisfied with social life	21 (81)	23 (88)	ns
Functional Independence Measure (FIM™), median (IQR)			
Self-care (6 items)	42 (3)	42 (0)	0.05
Sphincter control (2 items)	7 (6)	11 (6)	0.01
Transfers (3 items)	21 (1)	21 (0)	ns (0.07)
Locomotion (2 items)	11 (6)	13 (2)	0.0006
FIM™ motor (13 items)	80.5 (11)	87 (8)	0.003
Communication (2 items)	14 (2)	14 (1)	ns
Social cognition (3 items)	19 (3)	21 (1)	ns (0.06)
FIM™ cognitive (5 items)	33 (6)	35 (2)	ns (0.08)
FIM™ total (18 items)	112 (18)	120 (10)	0.003
Medical Outcomes SF-36®, median (IQR)			
SF-36® physical health component	39.1 (14.6)	43.4 (10.9)	ns
SF-36® mental health component	49.9 (20)	59.8 (7.6)	ns

SF-36®: Study Short Form 36; FIM™: Functional Independence Measure; ns: non-significant.

Daily urinary incontinence was experienced by 36% of the SB participants while 30% reported that they never had urinary incontinence (Table I). The degree of urinary incontinence had no effect on the probability of being in a relationship. Likewise, the degree of urinary incontinence did not affect the functional description of their sexual life (Table III), or their description of being unhappy or dissatisfied with their current sexual life.

Faecal incontinence was reported to occur daily in 13% of participants, while 23% never experienced faecal incontinence (Table I). The extent of faecal incontinence did not significantly affect the probability of being in a partner relationship. However, faecal incontinence was significantly related to a more dysfunctional sexual life, as was less good sphincter control (Table III). Likewise, faecal incontinence was associated with a less satisfactory current sexual life ($p=0.022$).

Approximately one-third of the participants with SB reported that they lacked knowledge of how they function sexually with their disability (Table II). However, there was no significant difference between groups in their descriptions of their sexual life or how it affects them, either for those with or without a partner.

Correspondingly, nearly half of participants reported that they did not have a useful sexual education in association with puberty (Table II). For those who answered the question "How old were you when you thought you needed sexual education?" (83% of participants), the mean age given was 15.1 (SD 2.3) (range 10–22) years (Table II).

In Table III, the 53 participants with SB are divided by their own description of their functioning sexual life during the last year, and related to variables from Tables I and II, as partly described above, and FIM™ and SF-36 components. FIM™ shows several significant differences between the more dysfunctional and better-functioning participants with SB, always with better scores for the well-functioning group.

When comparing the participants in this study regarding the scores from the QoL evaluation using SF-36 with a healthy group of Danish individuals, the individuals with SB scored significantly lower concerning the physical health component ($p<0.0001$), which is expected due to the physical disability of the participants. However, the mental health component for the participants did not score significantly lower than in the norm group.

DISCUSSION

The literature on SB has mainly dealt with the major somatic problems, such as incontinence, hydrocephalus, movement challenges including joint malpositions, scoliosis, etc.

Studies of SB and sexual function have primarily focused on the effect of neurological damage on sexual function. In particular, problems with erection and ejaculation, orgasm and consistency of sense of touch have been described to some extent (12–16). Our results concerning erection are very similar to those reported in these studies. The response to sildenafil in men with SB who have erectile dysfunction has proven to be good, i.e. 80% (17). Analogously, for women the relationship between the neurological level of the SB, tactile sensation in the vulval area, and ability to have orgasms has been described (13, 18).

Studies that have described how individuals with SB experience sexual life, have shown varying degrees of dissatisfaction (7, 19). This is consistent with our finding that 51% of subjects described their sexual life in the past year as a failure or dysfunctional, with 25% even indicating that their current sexual life made them unhappy. In our study, 45% indicated that they were satisfied with their current sexual life, which is similar to previous findings (8, 20).

People with SB are surprisingly little affected by their self-reported relatively poor sexual life. One possible explanation for this may be that they have a congenital disability, which does not allow for comparison with a normal state. Furthermore, throughout adolescence they have had to adapt to the numerous other problems associated with their SB. Likewise, and in accordance with the experience in the Netherlands (21), we found no difference in the QoL described by the mental health component of SF-36 between the SB participants and the normal Danish population, or between those with dysfunctional vs a more functional sexual life during the last year (Table III). In addition, the majority of the participants with SB (72%) had hydrocephalus, which may have a negative impact on cognition, and which probably also contributed to the fact that 25 of the participants received a social pension and an additional 11 were in sheltered employment.

We found no differences between men and women in terms of functional description or satisfaction with sexual life. This is consistent with the Dutch study (8), whilst others have shown that men are more dissatisfied with their sexual life than women (7, 19), and that women with SB adapt better than men to adult life and sexual life with a partner (13, 22). In accordance with the latter and the findings of Cardenas et al. (19), but in contrast to the findings of Gatti et al. (23), we found a tendency for women with SB to be more likely to have a partner than men with SB. Participants in a relationship described their sexual life as significantly better functioning, and tended to be more satisfied than individuals with SB who were not in a partner relationship.

The importance of having a partner is emphasized by the observation that 19 out of 22 participants with SB without a partner described their sexual life as a failure or malfunctioning.

The reasons for the sometimes contradictory findings between various studies may partly be attributed to differences in the design, including the wording of questions and interrogation technique, limited group size, variable response rates, excluded subgroups in some, but not other, studies, and national differences in culture and religion.

Even though the neurological level of injury did not affect how participants described their sexual life, those with lumbosacral lesions were more satisfied with their sexual life. The participants with SB who have lumbosacral lesions have less disability, including better mobility, and greater chance of genital sensibility (13), thereby facilitating a more satisfying sexual life. The finding that those with a better-functioning sexual life have better physical functioning in general is reflected in Table III, not least in superior FIM^{TM} scorings. The neurological classification used here may, in this respect, have been too crude.

It has been shown previously that hydrocephalus decreases the probability of establishing a relationship and having sexual contacts (8, 19). In our study there were only 12 participants without hydrocephalus, which may explain why we did not find any differences between groups in this respect. Furthermore, the number and timing of surgery for hydrocephalus can influence the extent of neurological damage and may differ between studies (24). The presence of functional disturbances, in the form of vaginal lubrication difficulties in women and erectile dysfunction in men, has been described previously (8, 13, 25). Amongst women, 41% did not provide information on vaginal lubrication. Thus, there is apparently a difference between the genders in terms of knowledge about how they function sexually. However, we found no gender differences regarding the description of their sexual life, or its importance.

Urinary and faecal incontinence is a problem that many people with SB have to endure. Not being able to trust one's own body is, of course, a burden (26), especially during puberty. It is therefore to be expected that many people with SB will be reluctant to initiate sexual relationships (19). Urinary incontinence has been associated with sexual malfunctioning (19, 27), whereas another study did not find any correlation between urinary or faecal incontinence and satisfaction with sexual life (28).

In our study, faecal incontinence did not affect the likelihood of being in a relationship. However, it impacted adversely on both the description of their sexual life and its implications for the individual. Our study is in agreement with a study by Verhoef et al., which showed that faecal incontinence is regarded as a problem by most individuals with SB (26).

In Denmark sexual education generally takes place in public schools, with 96% of 13–25-year-old Danes having received sexual education (29). Young people with SB also receive this education, which is not adapted to their special needs, as many of them will attend schools with healthy children. Children with SB will, at the age of 16 years, be offered more detailed and specific sexual counselling. During the routine follow-up visits to the Department for Spinal Cord Injuries sexual function is part of the programme. However, in the present study 49% of the SB participants reported that they did not receive useful sexual education in connection with puberty. In this study, 32% of participants were in the age range 18–35 years and stated that they lacked information about how they function sexually with their disabilities, which is similar to the experience of others (8). The reason may be impaired cognition and reduced learning capacity caused by hydrocephalus and by variable quality of the many sources of information. These, include sexual education in schools, information from doctors or hospital staff, information from parents, friends, peers, internet, magazines, etc. Furthermore, health professionals are often subject to time constraints, whereby they have to sacrifice time, allocated to sexuality discussion, to other, more highly prioritized, somatic problems. The propensity for this prioritization is further reinforced by uncertainty in both the SB individuals and the professionals. Lack of knowledge, resources and organisation to handle sexual problems may cause professionals to refrain from discussing the problems (30). A prerequisite for a solution is dedicated time for discussing sexuality, specially trained staff, and an atmosphere in which people with SB feel comfortable to discuss their sexual problems. People with SB are usually interested in discussing their problems, but would prefer that the professional takes the initiative (31).

It is therefore necessary that the health system assumes responsibility in addressing the sexological problems experienced by this group. A prerequisite for implementation of this responsibility is the availability of sufficiently trained health professionals. However, there is no compulsory sexological education in Danish medical education, and there is a lack of continuing education (32). Problems with the dissemination of knowledge to people with SB are further complicated by the fact that some have cognitive impairment (33).

Thus, it is essential that the clinician is trained to assess the degree of knowledge, imagination, etc. of the patient, and subsequently prescribe the optimal way to provide effective instruction and counselling to the individual. Education and counselling of these individuals is multi-faceted and requires knowledge of psychology, medicine and social conditions. Since few are likely to have access to all the pertinent information about SB, a multidisciplinary team of specialists is a preferred option. The current study shows that there is a need for further efforts in this area in terms of research, teaching and counselling.

Representativeness and limitations

The response rate of 74% is regarded as good, compared with similar studies that have reported participation rates of 24.8–71.6% (8, 19, 13, 23, 28). In addition, there was no significant difference between participants and non-participants in terms of gender and age. The study is therefore judged to be broadly representative of the SB population of Eastern Denmark. However, a major limitation is the relatively small number of participants.

At the time of initiation of the study, we were not able to identify existing and validated questionnaires for assessing sexuality in SB individuals, which is the reason that the present questions were developed. As in other investigations of this patient group, there is a general lack of international standardization that would facilitate comparisons of findings between the studies. In fact, a systematic review has concluded that "there is no clinically agreed SC injury tool for measurement of sexual health outcomes" (34). For this reason FIM^{TM}, and SF-36 were introduced.

For the acquisition of questionnaire data, we selected an interview study because many of the participants have hydrocephalus and/or problems with reading proficiency, both of which limit the number of participants suitable for assessment by a written questionnaire. By use of formal interview techniques we maximized the number of participants and circumvented any misunderstanding on the part of the patient. All participants were interviewed in the absence of their parents, thereby eliminating the risk of potentially problematic parental influence. Interviewers were experienced clinicians with knowledge of SB. We therefore believe that this collection of data, whilst more resource-intensive, is vastly superior to that obtained by postal questionnaires.

Being part of a larger study, questions about sexuality were relatively limited (5, 35). Lack of resources prevented neuropsychological testing. Finally, this study reflects the situation in Eastern Denmark and thus is not necessarily representative of other countries, where the nature of sexual relationships, cultural and religious attitudes, etc. may be different.

Conclusion

In this study 51% of the persons with SB lacked a sexual life or experienced a malfunctioning sexual life. Despite this 45% stated that they were satisfied with the state of their sexual life, probably due to their ability to adapt to challenges resulting from their disability.

Persons in a partner relationship were more satisfied with their sexual life than those who were not in a partner relationship. They also found it more important to be in a relationship than those without a partner.

Participants with lower SC lesions were more satisfied with their sexual life than those with more rostral lesions.

Faecal incontinence, but not urinary incontinence, was negatively correlated with a satisfying sexual life in the total group of participants, and in the group with a partner, but not in the group without a partner.

In this study 49% of subjects reported that they did not receive adequate sexual instruction in school, and 32% (18–35 years of age) lacked information concerning sexuality and SB. There appears to be a gender difference in terms of knowledge of sexual function, as all males could describe their ability to achieve an erection, but 37% of females had no knowledge about vaginal lubrication.

There is a need for more sexual counselling for subjects with SB in order to increase sexual satisfaction and QoL. Considering the high frequency of cognitive impairment, repetitive counselling may be required.

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APPENDIX I. Tests were performed by grouping the answers into the subgroups listed below in order to achieve reasonable numbers in the tests

Subgroup	
Urinary incontinence	(No + Yes, only when urinary tract infection); (Yes, less than once a week + Yes, less than daily and more than once a week); (Yes, daily)
Faecal incontinence	(No + Yes, only when diarrhoea); (Yes, less than once a month + Yes, less than once a week and more than once a month); (Yes, more than once a week and less than daily + Yes, daily)
Ejaculation	(Not tried + No); (Yes)
How important is it for you to have a girlfriend/boyfriend/spouse?	(Very important + Important); (Not very important + Irrelevant)
If you must describe your sexual life during the last year, is it?	(Total failure + Dysfunctional); (Fairly functional + Well-functioning)
What does it mean to you that your sexual life is as you describe it?	(Are you very unhappy and feel it affects your whole life negatively? + Are you unhappy about it and wish it was different?); (Do you wish it was different, but accept the situation?); (Are you satisfied with the present situation?)