



Unmet Need for Sexual Rehabilitation after Acquired Brain Injury (ABI): A Cross-Sectional Study Concerning Sexual Activity, Sexual Relationships, and Sexual Rehabilitation after ABI

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Abstract

In relation to brain injury rehabilitation, research has stressed the importance of including sexuality issues due to increased risk for sexual dysfunctions after Acquired Brain Injury (ABI). This study aims to explore experiences after non-stroke ABI concerning individual and relational aspects of sexuality, received information about sexuality at rehabilitation, and gender differences. A postal nationwide survey was conducted in Sweden, 2018–2019. The sample included individuals who had participated in brain injury rehabilitation 2014–2016, response rate 40% (250/624). Among all participants 78% had resumed sexual activity, and there was a significant difference between males (84%, 118/140) and females (69%, 76/110, $p=0.004$). Among all participants, 95% reported physical intimacy as important, 80% considered sex as important on an individual level, and 91% stated sexuality as important for the relationship (no gender differences). Significantly more females (52%) than males (22%) reported that they had tried sexual aids ($p=0.000$), and more males (29%) than females (16%) reported that professionals addressed sexuality issues during brain injury rehabilitation ($p=0.024$). However, only a few participants were offered specific sexual counseling during brain injury rehabilitation, such as individual counseling (3%), couples counseling (2%), and group counseling (3%). To conclude, the vast majority valued both individual and relational aspects of sex and sexuality highly, and more males than females had resumed sexual activity. Few had received information about sexuality after ABI, and even fewer females compared to males reported that the issue was raised during rehabilitation. Clinical implications are discussed in relation to sexual rehabilitation.

Keywords Acquired brain injury · Sexuality · Rehabilitation · Counseling · Relationship · Gender · Sweden

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Introduction

Acquired Brain Injury (ABI) is an umbrella term [1] including injuries that occurred after birth such as Stroke (incidence, 220/100,000) [2]; Traumatic Brain Injury (TBI) (900–1,300/100,000) [3]; and Subarachnoid Hemorrhage (SAH) (6/100,000) [4]. Previous studies on sexuality after ABI include a variety of methods, samples, and research questions, complicating comparisons. Research does implicate, however, that sexuality can be affected after ABI [5–8], and acknowledges that sexuality issues should be raised and assessed during brain injury rehabilitation [8–10].

Consequences of ABI can include both physical and cognitive impairments [11]. Dulhanty et al. [11] explored self-reported needs after SAH, and individuals three to five years afterwards still reported some needs concerning mobility (31%) but, to an even greater extent, needs concerning fatigue (72%), mood (58%), and cognitive aspects such as concentration (62%) and memory deficits (59%). Since these functions are important when it comes to sexual interactions and sensational experiences, these impairments are likely to affect sexuality to some extent.

Previous research reports that individuals with ABI to a large extent resume sexual life, but that sexual dysfunctions are common [10, 12–15]. Sander et al. [13] found that more than eighty percent of individuals post-TBI had resumed sexual life, but sexual activity occurred less frequently for more than half (55%), while a decrease in sexual desire (34%) and sexual function (29%) were also reported. Two review articles, Moreno et al. [12] studying sexuality after TBI and Grenier-Genest et al. [14] focusing on a post-stroke population, reported a variation of erectile dysfunction (ED) ranging from 28 to 75%. In the post-stroke population decreased lubrication was reported by 50 to 77% [14]. These studies highlight changed sexual function after TBI or stroke and the need for raising sexuality issues within health care.

Sexuality after ABI concerns both solo sex and partnered sex activities. The knowledge about solo sex experiences among the general population clarifies the importance to include individual experiences of sexual activity and use of sexual aids when assessing sexual issues, also when it comes to rehabilitation of individuals with an ABI. Research in general populations have shown gender differences with more females than males having tried sex-toys and sexual aids [16–19]. This could be a result of differing societal norms regarding attitudes towards male versus female use of sexual aids [16–19]. These different attitudes might also affect sexual rehabilitation after ABI, both from health care professionals' and patients' perspectives.

Biopsychosocial Perspectives

A holistic approach including a biopsychosocial perspective is suggested for health care in general [20], but also for sexual rehabilitation after ABI [7, 21]. According to a biopsychosocial perspective, medical and physical issues, neuropsychological and psychological effects, and relationship aspects all contribute to sexuality [12]. Bivona et al. [7] included a biopsychosocial approach on sexuality among males and their partners post-TBI and found that all participants rated their sexual desire and frequency of sexual intercourse as reduced compared to pre-injury. The researchers [7] emphasize, however, that even though sexual dysfunctions among the participants could occur due to brain injury location, dysfunctions could also occur due to psychosocial aspects, such as changes in relationships related to

TBI. In a recently published Norwegian study, Vikan et al. [22] investigated how several biopsychosocial factors were associated with lowered satisfaction with sexual life after stroke, and reported that two thirds were unsatisfied with their sexual life and that more females than males were experiencing sexual difficulties.

Some researchers have emphasized that relationships [23], and especially sexual relationships [6, 7, 24] can be affected by ABI. Bannon et al. [23] stress that interpersonal relationships are of great importance for the general outcome in mild TBI. In another study, Sander et al. [10] found in the U.S. that partners of individuals with TBI experienced more sexual problems if the individual had sexual dysfunctions or was older, and indicated that sexuality issues concerning both patients and partners should be considered in rehabilitation. In a Norwegian qualitative study, Kitzmüller & Ervik [25] investigated female spouses' perspectives of sexual life after partner's stroke and identified four themes, including changes in partner's personality, becoming patient/caregiver, lack of communication regarding sexuality, and "a void to live with." In a U.S. qualitative study, Kneipman & Kerr [26] also identified four themes regarding sexual life among partners of stroke individuals, which covered: experiences of maintaining closeness, redefining sexuality, coping with lack of resources, and a wish for professionals to raise the issue of sexuality. Both studies discussed that sexuality issues should be included in stroke rehabilitation and involve partners [25, 26]. Another study [8] including sixty-two patients in the Netherlands who had received sexual counseling in stroke rehabilitation showed that five years later the patients still experienced sexual dysfunctions, but their relational satisfaction was still high. In a Swedish study concerning sexuality six years after stroke, Nilsson et al. [27] reported that few of the patients had spoken to professionals about sexuality, though such need was identified. While the above studies have focused on stroke, there is a shortage of studies covering other brain injury diagnoses.

Rehabilitation Settings

Brain injury rehabilitation settings can differ depending on regional or local structure and organization. Some rehabilitation clinics are accredited by independent non-profit organizations such as CARF (Commission on Accreditation for Rehabilitation Facilities) [28], and these accreditations include standards also for sexual rehabilitation after ABI. In the sub-acute phase, brain injury rehabilitation can occur in a hospital as inpatient rehabilitation, but brain injury rehabilitation can also take place in outpatient clinics.

Earlier studies have concluded the need for sexual rehabilitation after ABI [6], but there might be obstacles for raising sexual issues in general health care, as well as in brain injury rehabilitation. Dyer & das Nair [9, 29] stated in their studies that health care professionals' barriers to raising the issue of sexuality with patients in general (not only those in ABI-rehabilitation) include structural, health care organizational, and personal factors. They also concluded that barriers seemed to grow in some cases such as when professionals encounter patients of opposite gender, older age, or when patients have intellectual disabilities. All these barriers could also apply for ABI individuals—neither receiving information about sexuality after ABI nor sexual rehabilitation. In a Swedish study concerning information about sexuality after cancer [30], nearly half (48%) had not received such information. However, more males than females received information, while individuals irrespective of gender wanted more information [30]. Moreno et al. [31] found in a Canadian study that TBI survivors had little experience of professionals discussing sexuality issues during rehabilitation; but most participants did not consider such discussions inappropriate.

Assessing Sexuality at Rehabilitation

Some researchers have suggested methods for professionals to address sexuality matters in rehabilitation after ABI. According to Khajeei et al.'s [32] scoping review on sexual re-education after TBI, such rehabilitation programs should involve, for example, knowledge about bodily functions and vocabulary regarding sexuality. In addition, sexual rehabilitation should include themes such as sexuality after disability, sexual identity, relationships, coping, and training in social skills and communication [32]. In a review of articles and programs concerning sexuality and relationships programs after ABI, it was found that ABI survivors and relatives were generally positive to sexual rehabilitation, but there was a lack of LGBTQIA+¹ perspectives [1]. In a study involving 324 rehabilitation professionals from 22 countries, Arango-Lasprilla et al. [33] found that about 97% of the professionals thought that sexuality issues should be included in TBI rehabilitation, but only 36% actually included them, while 69% reported that individuals with TBI had raised the issue themselves. According to another study based on the same population, sexuality was here shown as subordinated, since health care professionals mainly focused on how cognitive changes affected individuals with TBI in general [34]. Accordingly, in a Canadian study conducted in a stroke rehabilitation setting, Auger et al. [35] showed that individuals post-stroke considered sexuality issues as important but still secondary to activities of daily living (ADL) [35]. In a review of articles, books, and essays concerning sexuality issues in TBI rehabilitation, many sources highlighted the importance of written materials, and suggested that sexuality rehabilitation should be initiated early in brain injury rehabilitation [36]. Many of these sources referred to the PLISSIT model [37] to assess sexuality in brain injury rehabilitation. The PLISSIT model [37] includes a pyramid-shaped model with a base of "Permission" to talk about sexuality issues, as well as a basic structure for how to involve "Limited Information," "Specific Suggestion," and in some cases "Intensive Therapy."

To summarize, earlier international research indicates that sexual dysfunction after TBI or stroke is common and that a biopsychosocial perspective is needed, since not only biological conditions affect sexuality but also psychosocial perspectives. International research shows that not only solo sex experiences, but also relational aspects connected to sexuality are affected after TBI or stroke. The gender differences shown in the general population regarding solo sex experiences and attitudes to sexual aids need to be further explored because they could also apply to the ABI population. A vast majority of articles on sexuality after TBI or stroke conclude that sexuality is underrepresented both in rehabilitation facilities and in general health care. Hence, there is a need to explore how these aspects of sexual dysfunctions apply for individuals living with ABI in the Swedish context. More specifically, it is essential to include biopsychosocial perspective, relational aspects, gender differences, and how sexual rehabilitation is experienced among individuals who participated in brain injury rehabilitation in Sweden. Since others have been investigating the stroke population concerning sexuality and rehabilitation in Sweden and other Nordic countries, this study will focus on a non-stroke ABI population. To our knowledge, this is the first Swedish nationwide study focusing on experiences of sexual life and rehabilitation, from the perspective of individuals with ABI. Hence, this study aims to explore experiences after non-stroke ABI regarding individual and relational aspects of

¹ Lesbian, gay, bisexual, transgender, queer/questioning, intersexual, asexual, and other identities.

sexuality, received information about sexuality at rehabilitation, and gender differences of these aspects.

Material and Method

A nationwide postal survey was conducted in 2018–2019, consisting of a study-specific questionnaire, developed based on international research [38–40], interview studies [41, 42], discussions in research groups, and clinical practice. Furthermore, both professionals and patients from an outpatient brain injury rehabilitation setting were involved in the validation process of the questionnaire. This was described in more detail in a previous article [15]. To enable the independent participation of individuals with ABI, specific considerations were made throughout the development of the questionnaire. The questions were short and precise in order to facilitate completing the questionnaire, and participants were mainly asked to mark one option per question.

Potential participants ($n=624$) were recruited from a national quality register for rehabilitation, Web-Rehab Sweden²[43], which also provided background data on demography, diagnoses, and assessment of Functional Independence Measure (FIM) [44] at discharge from rehabilitation. FIM is an instrument which is assessed by interdisciplinary rehabilitation teams and consists of eighteen items, of which thirteen cover physical aspects and five cognitive ones. All items range from 1 (indicating a need for full assistance) to 7 (indicating full independence), with 6 indicating independent with the need for extra time or (technical) aid. Hence, the domain for physical items ranges from 13 to 91, and the domain for cognitive items from 5 to 35. The following inclusion criteria were met by all potential participants: completed inpatient brain injury rehabilitation in Sweden between 2014 and 2016; diagnosed with a Traumatic Brain Injury (TBI), Subarachnoid Hemorrhage (SAH), anoxic brain injury, post infectious- or post inflammatory brain injury according to Web-Rehab Sweden diagnosis groups [45]; being eighteen years or older at the time of rehabilitation; Swedish-speaking without interpreter; being able to answer the questionnaire independently. The ability to answer the questionnaire independently was estimated by FIM item for “comprehension” at discharge from rehabilitation, and only individuals scoring equal to independent, or independent with need for extra time, were selected. In Fig. 1 inclusion and exclusion are displayed in a flow chart. Response rate was 40% (250 participants and 374 non-responders out of the 624 individuals who fulfilled the inclusion criteria). Two reminders were sent to non-responders. The postal survey consisted of the study-specific questionnaire, a pre-paid envelope for responding, and information about the study, including how confidentiality was secured, emphasizing that participation was voluntary, and that consent could be withdrawn at any time without giving a reason. Returning a completed questionnaire was considered giving consent to participate. The letter also provided information about how to get in contact with a non-profit counselor for sexual issues, if needed.

² Web-Rehab Sweden changed name and website after material collection. The new name is “Svenskt register för Rehabiliteringsmedicin.”.

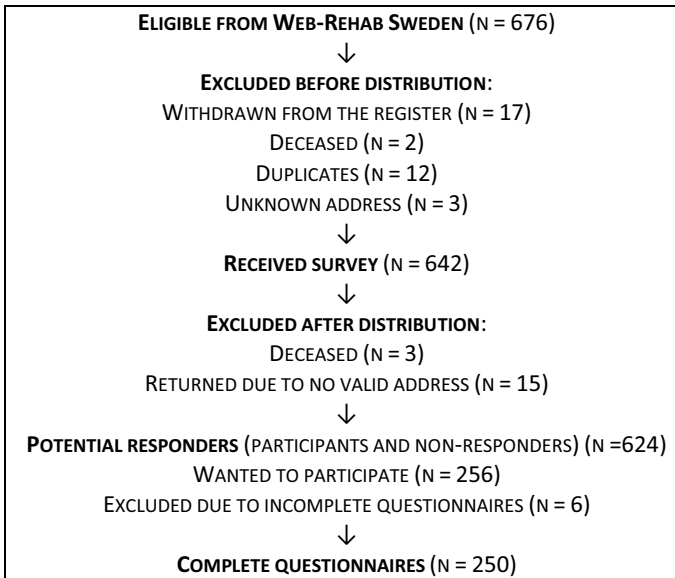


Fig. 1 Flow chart of inclusion and exclusion in the study

The Questionnaire and Coding

This study takes an explorative approach in which several aspects are investigated foremost on a descriptive level. The questionnaire was developed based on earlier research [38–40], interview studies including individuals with ABI [41], and partners [42], and was validated by research groups, professionals from a brain injury rehabilitation setting, as well as outpatients from the same setting. The questionnaire covered four themes: Background information, Functional ability, Sexuality after ABI, and Rehabilitation. This study focuses mainly on Sexuality and Rehabilitation, with the following questions: “Did you receive written information about sexuality after ABI? Did someone during rehabilitation ask you whether your sexuality was affected by ABI? When did someone within rehabilitation ask you if your sexuality was affected by ABI? Did you receive group information or attend a talk regarding sexuality after ABI? Were you offered individual counseling concerning sexuality after ABI? Were you and your partner offered couple-counseling concerning sexuality after ABI? Did you ask someone about sexuality after ABI? When? Did you want to ask someone about sexuality after ABI? Do you feel that you are missing information about sexuality after ABI? What would you have wanted information about, concerning sexuality after ABI? Have you adjusted your sexual life due to ABI? What did you try out that worked well? What did you try that did not work well? Other?” In addition, questions from the other themes were included, such as: “Are you currently in a relationship? Were you in a relationship at the time of the injury? How do you experience that the following are affected after ABI: My role among family and/or friend has changed after ABI; Sometimes others do not notice that I have an ABI; It is harder to have contact with others after ABI.” But also questions such as: “Do you consider sexuality important in a relationship? Is sex important to you? Is physical intimacy important to you? When was the first time you had sex after ABI? How was sex after ABI resumed? How did you experience sex the first time after ABI? When was the last time you had sex with a partner? What do you think

about sexual aids (for example dildos, vibrators, penis-rings, vacuum-pumps)?” This study also included the two opposite statements: “Sometimes I want to have sex, but I do not because...” and “In the past, I sometimes have had sex with a partner even though I did not want to.” We also included questions relevant to participants in a present relationship such as: “In the context of sexual activity, to what degree do you feel accepted by your partner?” and “To what degree do you experience that you can communicate with your partner regarding sex and your situation?” followed by “Do you experience appreciation from your partner regarding your situation in general?”.

Most questions had fixed response alternatives, while some questions were multiple-choice (with multiple responses allowed), two questions concerning degree of acceptance and communication with partner were Likert-scales ranging from 1 (not at all) to 6 (very high degree), yet a few questions were open-ended and provided the possibility of free-text answers.

Analysis

Descriptive data for background characteristics are presented as frequencies, percentage (%), means, standard deviation (SD), and range. Student’s *t*-test was calculated for quantitative data, while Chi-squared tests were calculated for nominal data. A two-sided *p*-value < 0.05 was considered to indicate statistical significance. Dichotomizing was generally performed when there was a clear positive and negative weighting in the response options, receiving the answers 1 = yes and 0 = no, while options “do not know” and “do not recall” were coded as missing. Likert-scales were also dichotomized: 1 to 3 = 0, and 4 to 6 = 1. For statistical analysis the variables were also re-coded into 1 = the statement and 0 = not the statement.

Cronbach’s Alpha index was calculated to measure the internal consistency of the following constructs: “Cognitive functions” (0.859), “Sexual functions” (0.818 males, 0.855 females), “Importance of sexuality and intimacy” (0.779), “Partner’s acceptance and communication” (0.830), and “Orgasm and satisfaction in sexual activity” (0.870).

All statistical analyses were performed using SPSS statistics, version 25. Free-text answers are presented thematically, based on the existing themes in the questionnaire. Quantitative and nominal data are presented in parallel with the free-text answers.

Study Ethics

Specific ethical considerations have been taken in all phases of this project, since individuals with ABI are considered a vulnerable group and the topic of personal sexuality is sensitive. This study was performed in line with the principles of the Declaration of Helsinki [46], and ethical approval was obtained from the Ethical Review Board in Lund, Sweden (EPN: 2017 799).

Results

Quantitative data, and qualitative data from free text answers will be presented intertwined in the result section.

Table 1 Background characteristics of participants and non-responders ($n = 624$)

	Participants ¹		Non-responders ²		<i>p</i> -value
	$n = 250$		$n = 374$		
	<i>n</i>	%	<i>n</i>	%	
Age, years					
Mean (SD) ³ ,	53.66	(14.24)	53.95	(15.98)	.815
Range	20–90		20–94		
Gender					
Female	110	44	146	39	.217
Male	140	56	228	61	
Diagnosis					
Traumatic Brain Injury (TBI)	116	46.4	199	53.2	.232
Subarachnoid Hemorrhage (SAH)	86	34.4	101	27.0	
Anoxic Brain Injury	27	10.8	39	10.4	
Post-infectious/-inflammatory	21	8.4	35	9.4	
FIM Item for Comprehension: Fully independent	166	66.4	230	61.5	.213
Independent with aid or extra time	84	33.6	144	38.5	
FIM ⁴ Cognitive Items Total Score, mean (SD),	32.16	(3.01)	31.58	(3.41)	.032
Range	17–35		14–35		
FIM ⁴ Physical Items Total Score, mean (SD),	85.77	(9.58)	83.56	(13.58)	.018
Range	27–91		13–91		
LOS, days					
Mean (SD),	35.15	(27.79)	36.56	(31.48)	.568
Range	5–183		2–262		
Discharged to independent living without dependence	173	69.2	220	58.8	.022
Educational level					
Elementary school	21	8.4	67	17.9	.003
Senior high school	115	46.0	154	41.2	
University	72	28.8	80	21.4	
Other	42	16.8	73	19.5	
Ethnicity					
Born in Sweden	228	91.2	330	88.2	.591
Residence ($n = 246$): In a City or smaller town	184	74.8			
Vocational situation ($n = 247$): Working	96	38.9			
Retired	64	25.9			
Sick leave or disability pension	70	28.3			
Unemployed, Studying, Other	17	6.8			
Sexual orientation ($n = 245$): Heterosexual	232	94.7			
Homo-/bisexual	4	1.6			
Other or do not want to answer	9	3.7			
Perceived Good health (very/fairly) in the last 12 months ($n = 245$)	178	72.7			
Medication ^{5,6} ($n = 249$)	203	81.5			
Other disease ^{5,7} in the last 12 months ($n = 246$)	124	50.4			
Walking without aid ($n = 249$)	191	76.7			

Table 1 (continued)

	Participants ¹		Non-responders ²		<i>p</i> -value
	<i>n</i> = 250		<i>n</i> = 374		
	<i>n</i>	%	<i>n</i>	%	
Independent in Activities of Daily Living (ADL) (<i>n</i> = 247)	221	89.5			
Bladder and/or bowel symptoms (<i>n</i> = 249)	102	41.0			

For participants and non-responders Chi-2 test was calculated for nominal variables, while students T-test was calculated for variables: age, Length of Stay (LOS), and Functional Independence Measure (FIM). ¹Data for participants was collected from WebRehab register, and from questionnaire. ²Data for non-responders was collected from WebRehab register only. ³Standard deviation, ⁴Possible results FIM cognitive total score 5–35, FIM physical total score 13–91, ⁵More than one option possible, ⁶Analgesics (*n* = 49), Neurostimulants (*n* = 5), Sleeping medication (*n* = 37), Epilepsy medication (*n* = 22), Medicine for blood pressure (*n* = 121), Antidepressants (*n* = 62), Contraceptives (*n* = 9), Estragon (*n* = 5), Testosterone (*n* = 8), Other (*n* = 94). ⁷Depression (*n* = 37), Diabetes (*n* = 28), Epilepsy (*n* = 12), Cancer (*n* = 5), COPD, Chronic Obstructive Pulmonary Disease (*n* = 5), Rheumatic disease (*n* = 5), Heart disease (*n* = 21), other (*n* = 54)

Participants' Characteristics

Table 1 presents characteristics of both participants (*n* = 250) and non-responders (*n* = 374). The Web-Rehab register provided background data for both groups. In addition, the participants (*n* = 250) also answered some background questions. All participants reported to be cisgender, which means that the legal gender received from the Web-Rehab Sweden register was the same as the subjectively reported gender in the survey, 140 males, 110 females, and none of the participants self-reporting as transgender or Other. Hence, the group of participants included a higher proportion of males (56%) than females (44%). There were no significant differences, however, compared to non-responders concerning age, gender, diagnosis, length of stay (LOS), or ethnicity. There was a wide range for LOS in both groups, participants vs non-responders. The median was 27 days in both groups, and 75% had a LOS of < 46 days. Inclusion criteria required a high FIM score (6 or 7 out of 7) at the item for comprehension. The highest possible total score for the cognitive domain was 35, while for the physical domain it was 91. Both participants and non-responders presented generally high scores and overall there were only smaller significant differences between participants and non-responders concerning the FIM Cognitive items total score (32.16 vs 31.58, *p* = 0.032) and FIM Physical items total score (85.77 vs 83.56, *p* = 0.018). On the other hand, participants were discharged to independent living without dependence to a significantly higher level than non-responders (69 vs 59%, *p* = 0.022), and the educational level was significantly higher among participants than among non-responders (university 29 vs 21%, *p* = 0.003). The additional background data from the questionnaire received only from the participants revealed that 75% of participants were living in an urban area, 39% were back to work, while 26% were retired (due to age). Almost three quarters (73%) perceived themselves as being in good health, while 82% used some medication, and 50% had some comorbidity. Ninety percent (90%) were independent in activities of daily living (ADL), and 77% stated that they walked without any aid (Table 1). An independent t-test was conducted to compare age and LOS for males versus females participating in the study. There were no significant differences concerning age for males (*M* = 53.34, *SD* = 14.7) and females (*M* = 54.05, *SD* = 13.6; *p* = 0.696, two-tailed), nor concerning LOS for males

($M=37.49$, $SD=30.58$) and females ($M=32.17$, $SD=23.57$; $p=0.133$, two-tailed) (not presented in table).

Individual and Relational Experiences of Sexuality after ABI

Results from the questionnaire provided descriptive data on experiences related to sexuality after ABI, individually or with a partner. In addition, some participants gave free-text answers. Almost eighty percentage of all participants (194/250, 78%) had resumed sexual life, alone or with a partner (Table 2) and, of them, half (97/194, 50%) had also been sexually active with a partner the last month (not shown in table).

Importance of Sexuality–Gender (in-)Differences

Table 2 presents the results of chi-squared tests regarding differences between males' and females' expressed importance of sexuality and adjustments to sexual life. Significantly more males than females had resumed sexual life (84 vs 69%, $p=0.004$), while significantly more females than males had tried sexual aids (52 vs 22%, $p=0.000$). Notably, there were no significant differences between males and females when it came to importance of sexuality and intimacy (Table 2). Moreover, there were no significant gender difference regarding adjustments to sexual life due to ABI.

Experience of Sexual Changes due to ABI

Many participants experienced sexual changes due to ABI, but some considered the changes to be part of other circumstances. About 40% reported that their first sexual activity after ABI was not as good as before (not shown in table). In a free-text answer one participant explained: "... At first intercourse after the stroke (SAH) (I) found out that I did not have the same sensitivity in my genitals. Like, numb. Thank goodness, only the first time, after that it was back to normal." Others stated that they did not know if changes occurred due to life circumstances or ABI: "My changed sex habits have more to do with age and energy. I experience no bigger changes aside from not having the same energy as before" and: "My wife's situation in menopause has affected sexual life more than my head injury, even if my desire/need to have sex has decreased." However, one participant with a negative experience wrote: "The brain injury has destroyed my life..." revealing that it was not a temporary change to sexuality, and not only sexuality, but also relationships and social life were affected.

Adjustments and Strategies with Different Outcomes

Examples of adjustments to sexual life with different outcomes were expressed in free-text answers. While some had positive experiences, others expressed a negative outcome. One participant exemplified what had worked well regarding adjustments in sexual life due to ABI, in the following quote: "(Using a) vibrator, and being open about what I like," and another participant wrote: "sex both with partner, and by myself with vibrator and dildo." Yet another example included visual stimulation: "I can get horny by watching soft porn, but (I am) not driven as when desire comes from within me." Some participants stated that solo sex had worked well, while others described adjustments in partnered sex that also had positive outcomes: "Masturbation, partner helping,

Table 2 Importance of sex, and adjustments

	Males n = 140			Females n = 110			Total n = 250			Chi-Square	p-value			
	Yes	No	%	Yes	No	%	Yes	No	%					
	n	n	%	n	n	%	n	n	%					
Physical intimacy is important to me (n = 249)	132	95.0	7	5.0	104	94.5	6	5.5	236	94.8	13	5.2	0.022	0.883
Sex is important to me (n = 248)	115	83.3	23	16.7	83	75.5	27	24.5	198	79.8	50	20.2	2.361	0.124
Sex is important in a relationship (n = 245)	128	93.4	9	6.6	95	88.0	13	12.0	223	91.0	22	9.0	2.209	0.137
Have resumed sexual activity (n = 250)	118	84.3	22	15.7	76	69.1	34	30.9	194	77.6	56	22.4	8.182	0.004
Have not resumed sexual activity, but wants to ^a (n = 56)	9	40.9	13	59.1	8	23.5	26	76.5	17	30.4	39	69.6	1.908	0.167
<i>Initiated the first sexual activity after ABI</i>														
(by myself, or with a partner) ^b (n = 194)	67	56.8	51	43.2	35	46.1	41	53.9	102	52.6	92	47.4	2.133	0.144
Have adjusted my sexual life due to ABI (n = 235)	47	35.9	84	64.1	26	25.0	78	75.0	73	31.1	162	68.9	3.203	0.073
Have tried sexual aids ^b (n = 180)	24	22.0	85	78.0	37	52.1	34	47.9	61	33.9	119	66.1	17.380	0.000
Provided examples of adjustments in free text (n = 250)	46	32.9	94	67.1	39	35.5	71	64.5	85	34.0	165	66.0	0.185	0.667

^aIncludes only participants who had not resumed sexual activity; ^bIncludes only participants who had resumed sexual activity

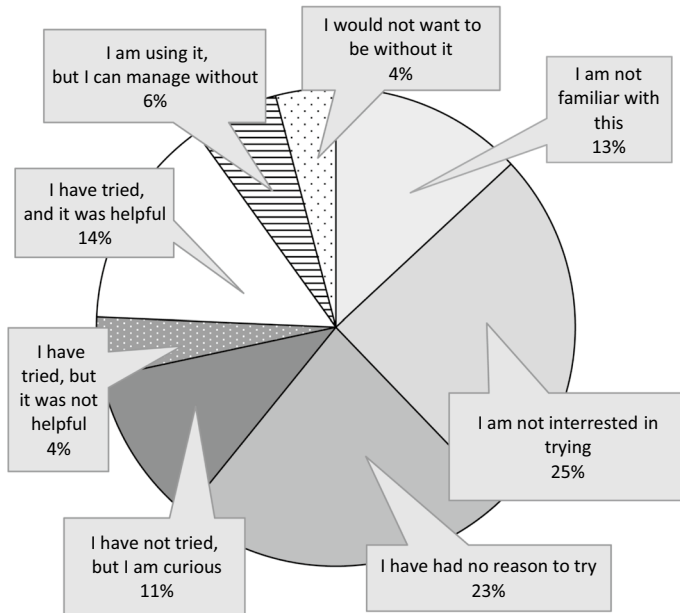


Fig. 2 What do you think about sexual aids? For example dildos, vibrations, penis-rings, vacuum-pumps ($n=222$)

oral sex. Partner on top since I am half paralyzed.” Positive experiences of medication were also expressed, exemplified by a man: “Blood samples revealed that I had low testosterone levels, and the last year I have received Nebido and this has helped me, and also I got a prescription for Viagra with good results.” One participant explained how cognitive aspects could improve if sexuality was affected: “By utilizing thoughts and feelings since I lack the sense of smell, and therefore a decreased sense of attraction.” However, there were also examples of what they had tried out that did not work so well, exemplified by a woman: “Vibrator worked well before, but I can’t get there anymore. The sensation is diminished and (my) genitals are going numb ‘fall asleep,’” and a man: “Penis-ring with vibration to get an ejaculation; but has not succeeded. (It) was my own initiative with this!” The importance of timing was explained by a man who could not find the right timing to be alert in sexual activity: “Intercourse isn’t always functioning due to problems maintaining erection, sometimes. As sexual activity mostly occurs evening time, since we have small children, it’s also the time when I am most tired, which decreases the performance.” Some participants emphasized the importance of adjusting sexual life since the conditions had changed and one participant formulated that it had not worked well: “To (try to) be like before physically. (I) am much weaker throughout the body.” Another participant wrote that “taking it slowly” resulted in a positive outcome while “quick jerks” did not. Yet other participants wrote that they did not have sex anymore (as a response to how they adjusted sexual life). Hence, different aspects of adjustments to sexual life were exemplified in the free-text answers.

Participants’ opinions about sexual aids, including both those who had resumed sexual life and those who had not, are presented in Fig. 2 ($n=222$). Almost a quarter (24%) had a positive experience with some sexual aid, while 11% stated that they had not tried but are curious (Fig. 2). In the free-text answers regarding adjustments, participants showed

examples of positive attitudes to sexual aids by stating that they had tried vibrators, dildos, lubricants, penis-rings, and erotic movies.

To get a perspective of what might have caused less sexual activity than desired, participants who had resumed sexual life were presented with the statement “sometimes I want to have sex but I don’t because...:” which was followed by multiple-choice response options. Half of the responders (66/131, 50%) answered “I am too tired” and a quarter (32/131, 24%) “I want to have sex with someone, but have no partner.” Another quarter (32/131, 24%) responded “I want to have sex, but my partner(s) does not want to,” yet one fifth (26/131, 20%) had no erection or lubrication (data not shown in table). Participants who had resumed sexual life were also presented with the opposite statement “sometimes I have had sex even though I did not want to, because...:” followed by multiple-choice response options. The most common answer was “I want to be someone who has sex” (30/67, 45%), followed by “I don’t want to disappoint my partner” (26/67, 39%). However, almost as frequently selected were the alternatives “my partner wants to, and I don’t want to say no” (24/67, 36%) and “I don’t want to spoil it for my partner by not having sex” (18/67, 27%). The alternatives Feeling pressured (3/67, 4%) or Partner nagging (6/67, 9%) were less common. (Data not shown in table.)

Individual and relational experiences of sexuality after ABI had been influenced by both physical and cognitive changes, such as hormonal changes and fatigue. While some had positive experiences regarding how they handled the sexual changes e.g., by using sexual aids, others expressed negative experiences such as a non-existent sexual life. Hence, both males and females reported about adjustments and strategies in free-text answers and reasons for having sex or not; and gender differences occurred in their report of using sexual aids.

Changed Role, and Sexual Relationships after ABI

Many participants experienced role changes, but occasionally the ABI was unnoticed by others, and while some of the relationships had ended, new relationships were also established. A majority (74%) of the participants reported being in a relationship at the time of injury, and 16% reported that the relationship had ended, which means that 58% were in the same relationship as before injury. However, 67% reported a current relationship, which indicates that new relationships were established (Table 3). Chi-squared analyses concerning gender differences in role changes and experiences of relationships are presented in Table 3. There were no significant differences between genders regarding roles and relationship status. While many participants (79%) reported that others sometimes did not notice their ABI, about 60% stated that their role among family/friends had changed due to ABI (Table 3).

Being in a Sexual Relationship

Those in a relationship reported to a high degree that their partner was accepting of them, showed them understanding, and that they could communicate about sexuality and their situation with their partner. A total of 73 percent reported that they communicate with their partner about sexuality and their situation (Table 3). One participant emphasized the importance of a supporting partner: “*We know what works for us, sometimes I need to be reminded about what I like. (I) think it’s easier if you have an understanding partner (husband) who can take that sometimes it gets a bit tricky,*” and another wrote “*(It) would have*

Table 3 Role, and sexual relationships after ABI

	Males <i>n</i> = 140		Females <i>n</i> = 250		Total <i>n</i> = 110		Chi-Square	<i>p</i> -value						
	Yes	No	Yes	No	Yes	No								
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%								
Sometimes others do not notice that I have an ABI (<i>n</i> = 247)	107	78.1	30	21.9	88	80.0	22	20.0	195	78.9	52	21.1	0.132	0.716
Harder to have contact with others (<i>n</i> = 250)	45	32.1	95	67.9	47	42.7	63	57.3	92	36.8	158	63.2	2.967	0.085
My role among family/friends has changed after ABI (<i>n</i> = 250)	82	58.6	58	41.4	66	60.0	44	40.0	148	59.2	102	40.8	0.052	0.820
In a relationship at injury (<i>n</i> = 246)	105	76.1	33	23.9	77	71.3	31	28.7	182	74.0	64	26.0	0.722	0.395
In a relationship at injury, but that has now ended (<i>n</i> = 246)	22	15.9	116	84.1	18	16.7	90	83.3	40	16.3	206	83.7	0.023	0.879
In a current relationship (<i>n</i> = 247)	99	71.2	40	28.8	67	62.0	41	38.0	166	67.2	81	32.8	2.327	0.127
In sexual situations, I feel accepted by partner ^{a,b} (<i>n</i> = 142)	68	80.0	17	20.0	51	89.5	6	10.5	119	83.8	23	16.2	2.256	0.133
Partner shows appreciation in general ^b (<i>n</i> = 153)	87	97.8	2	2.2	60	93.8	4	6.2	147	96.1	6	3.9	1.583 ^c	0.208
Can communicate with partner about sex and my situation ^b (<i>n</i> = 163)	71	73.2	26	26.8	48	72.7	18	27.3	119	73.0	44	27.0	0.004	0.947

^aIncludes only participants who had resumed sexual activity, ^bIncludes only participants in a current relationship, ^c 2 cells (50%) have expected count < 5

been good with a counseling session both with and without partner. Important to make the relationship last.” These quotes show that sexual relationships can be challenging, and that partners can facilitate the coping process. However, the lack of, and need for, information about changes in sexuality after ABI and sometimes counseling is also emphasized.

Struggles for New Relationships

In free-text answers participants expressed that finding new relationships could be difficult due to physical and cognitive changes, yet others did not notice any changes after ABI. One participant exemplifies difficulties in establishing new relationships: *“I had no partner before or after, so a bit difficult to answer. With decreased physical and mental health, not always easy to find partners. Contact site for individuals with functional variations perhaps?”* A woman in her mid-seventies wrote: *“After the divorce, it was a time of loneliness. (I) have had some short relationships before I became ill. But lost desire for what sex was. But to have a bosom friend to care for, hug and feel closeness to—I long for that.”* Some did not experience any changes due to ABI, which was expressed thus by one participant: *“I suffered from a brain hemorrhage but have made it without any disability.”* Others gave examples of challenges such as *“Due to the injury the energy to meet new people has not been there → difficult to meet a new partner → in other words, the greatest obstacle to sex is the lack of energy to meet new people, not lack of energy for ‘sex itself’.”* This indicated a wish for sexual activities with a partner, but that the threshold to even find a partner was too high.

Many participants experienced changed roles and changes in their sexual relationships. While some struggled to resume sexual life and longed for intimacy, others expressed that communication and understanding from a partner was helpful.

Information Concerning Sexuality at Rehabilitation

Few participants received sexual counseling at the time of rehabilitation. Table 4 presents experiences of having received information regarding sexuality issues during brain injury rehabilitation, and the need for such information. Chi-squared tests revealed that professionals at rehabilitation facilities had asked significantly more males than females (29 vs 16%, $p=0.024$) if their sexuality was affected by ABI (Table 4). As seen in Table 4, only a few participants received individual counseling (3%), couple counseling (2%), or group information (3%) during rehabilitation, while free-text answers illuminated the need for such information *“Strange that it is not brought up. To me everything was affected, also sexuality. But no information or questions.”* Another concluded: *“Not knowing has been hard. It’s surprising that this issue is not brought to the surface. Not all are 100 years old and maybe uninterested.”* These quotes and the results presented in Table 4 highlight that participants did not have much experience of sexual counseling during brain injury rehabilitation.

Questions on Sexuality at Rehabilitation?

Both participants and professionals in the rehabilitation setting raised issues concerning sexuality after ABI. Table 5 presents distribution of at which specific moments information about sexuality at rehabilitation had been given, and which professionals had been involved in (search for) information. In 58 cases, participants reported that professionals had asked

Table 4 Information concerning sexuality at Rehabilitation

	Males n = 140		Females n = 110		Total n = 250		Chi-Square	p-value						
	Yes	No	Yes	No	Yes	No								
	n	%	n	%	n	%								
Received written information about sexuality after ABI (n = 247)	9	6.5	129	93.5	9	8.3	100	91.7	18	7.3	229	92.7	.271	0.602
Received group information/attended a talk about sexuality after ABI (n = 249)	3	2.1	137	97.9	5	4.6	104	95.4	8	3.2	241	96.8	1.177 ^b	0.278
Someone at rehabilitation asked if my sexuality was affected by ABI (n = 248)	40	28.8	99	71.2	18	16.5	91	83.5	58	23.4	190	76.6	5.128	0.024
Offered individual counseling on sexuality after ABI (n = 249)	6	4.3	134	95.7	2	1.8	107	98.2	8	3.2	241	96.8	1.184 ^b	0.277
Offered couple counseling on sexuality after ABI (n = 174) ^a	3	3.0	98	97.0	0	0.0	73	100.0	3	1.7	171	98.3	2.206 ^b	0.137
Asked someone about sexuality after ABI (n = 249)	24	17.1	116	82.9	14	12.8	95	87.2	38	15.3	211	84.7	.876	0.349
Wanted to ask someone about sexuality after ABI (n = 245)	30	21.7	108	78.3	17	15.9	90	84.1	47	19.2	198	80.8	1.331	0.249
Felt a lack of information about sexuality after ABI (n = 244)	45	32.6	93	67.4	26	24.5	80	75.5	71	29.1	173	70.9	1.897	0.168

^aIncludes only participants who were in a relationship at injury, ^b2 cells (50%) have expected count < 5

Table 5 Distribution of questions from professionals and participants concerning sexuality during rehabilitation. Multiple answers were permitted

		Professionals asked (<i>n</i> = 58) ¹		Participants asked (<i>n</i> = 37) ²	
		<i>n</i>	%	<i>n</i>	%
A. When was the topic sexuality discussed with professionals at ABI rehabilitation?					
1	I don't remember at which moment	16	27.6	4	10.8
2	At admission to the rehabilitation unit	2	3.4	0	0
3	During rehabilitation	27	46.6	20	54.1
4	At discharge from rehabilitation	5	8.6	4	10.8
5	When revisiting rehabilitation	6	10.3	17	45.9
6	Some other time	5	8.6	2	5.4
		Professionals asked (<i>n</i> = 58) ¹		Participants asked (<i>n</i> = 38) ²	
		<i>n</i>	%	<i>n</i>	%
B. Which professionals asked the participant, or were asked by the participant?					
1	Physician	15	25.9	19	50
2	Registered Nurse	15	25.9	7	18.4
3	Assistant Nurse	3	5.2	4	10.5
4	Social Worker	8	13.8	7	18.4
5	Psychologist	14	24.1	6	15.8
6	Occupational Therapist	3	5.2	2	5.3
7	Physio Therapist	3	5.2	1	2.6
8	Speech Therapist	0	0.0	0	0.0
9	Someone else	1	1.7	–	–
10	Someone, but I can't remember who	19	32.8	10	26.3
				Participants' responses (<i>n</i> = 241)	
				<i>n</i>	%
C. What would you have wanted information about concerning sexuality after ABI?					
1	How sexual functions can be affected			99	41.1
2	How relations to a partner can be affected			68	28.2
3	Reassuring information that there is no increased risk, having sex after ABI			46	19.1
4	Other			6	2.5
5	Nothing			52	21.6
6	Don't know (what kind of information I would have wanted)			63	26.1
7	Provided a free-text answer			35	14.5

¹Only relevant to participants who responded that professionals asked about sexuality, ²Only relevant to participants who responded that they had asked professionals about sexuality

about sexuality, while 37 reported that they had asked a professional themselves. About half of both the professionals and the participants raised the issue of sexuality during rehabilitation. However, when participants revisited the rehabilitation facility, only 10% (6/58) reported that professionals asked about sexuality after ABI, while 46% (17/37) had asked

themselves. Participants who raised the issue of sexuality after ABI had asked the physician in half (50%) of the cases, while registered nurses (18%), social worker (18%), and psychologists (16%) also were asked. This shows that participants were willing to ask different professionals and that there was a discrepancy in when information was given versus when there was a need for information.

Desire for Information about Sexual Functions after ABI

Many participants wanted information about how sexual functions can be affected after ABI. In a multiple-response question regarding which kind of information the participant would have wanted, 41% responded “how sexual functions can be affected” (Table 5). In a free-text answer, one participant expressed that this questionnaire-study provided new knowledge about ABI’s potential impact on sexuality. Others gave examples of needed information such as: “*Tips regarding how to focus more on the present/sexual act, instead of easily ‘losing the treadmill,’*” and “*I experienced decreased sexual desire the first seven months after injury. I tried to masturbate but could not get an erection. I would have wanted the information that one’s ability to get an erection (become lubricated) can be affected.*” Some participants worried whether changes would be permanent and fertility affected by the ABI; “*That the indifference passes, and that you will want (to have sex) again! (Though) I don’t want (to have sex) quite so much as before*” and “*The production/quality of sperm—Is it affected by the injury? Is the ability to have kids affected?*” Yet some participants raised the issue of potential neurological changes or medical side effects such as “*I don’t have all nerve endings in the clitoris, would like to ask someone if I can regain them again*” and “*I would have liked to get information about how medicines affect my body concerning sex/cohabitation etc.*” Hence, some participants were not aware of the risk for changes in sexual functions while others worried about potential and persistent changes.

Desire for Information about Relationships after ABI

A considerable number of participants wanted information about how relationships can be affected by ABI. Of those who answered the multiple-response question regarding desired information, almost one third (28%) wanted to receive information on how the relationship with a partner can be affected (Table 5). Some participants expressed their need for information regarding how to maintain and/or rebuild a relationship, but also when and how to tell a new partner: “*How to act if you meet a new partner? When and how should you tell?*” One participant wrote: “*The relationship is affected, and sexuality is a consequence of a good relationship,*” which underlines the participant’s opinion of how sexuality is intertwined with the relationship.

Desire for Reassuring Information Regarding Having Sex after ABI

A fear of sustaining further injury from sexual activity was bothering some participants. Almost one fifth (19%) wanted to receive reassuring information that there is no increased risk associated with having sex after ABI (Table 5). This was exemplified in free-text answers including the need for information about risk of sexual activity due to an aneurysm and high blood pressure. This kind of worry was also expressed by one participant who had received alarming information: “*When I revisited (rehabilitation), I found out that*

my blood pressure must not get too high. I also was told that having sex could be compared to climbing Mount Everest. This did not make me and my partner want to go home and have sex. Unfortunately, this has stayed in my mind.” The quote exemplifies how the alarming information has affected the sexual life for both the participant and the partner, not just when receiving the information, but also for a prolonged time.

To summarize our results on sexual information at brain injury rehabilitation, we conclude that there has been a limited amount of information. Some participants expressed their appreciation for us investigating the issue, and there seems to be a need for information, which is exemplified in this quote: *“Good initiative. To inform in a group with others, so that you can hear how others experience situations regarding sexuality. Not just sexuality but overall.”* In addition, sexuality issues after ABI concerns both individual aspects regarding bodily changes, and relational aspects regarding social interactions in general as well as in sexual relations. Finally, we want to highlight that there seem to be some gender differences regarding received information about sexuality.

Discussion

The results of this study disclosed that even though a large proportion had resumed sexual life (78%), some had made adjustments, and some experienced an unmet need for sexual rehabilitation after ABI. Significantly more females (84%) than males (71%) experienced that issues concerning sexuality were not raised at rehabilitation. The descriptive statistics reveal that sexuality was highly important for the individual and for the relationship, to both males and females, while free-text answers disclosed additional important aspects.

Among those who responded on the multi-choice question about having had sex even if the individual did not want to, almost half chose that they wanted to be someone who has sex. This is important to reflect upon, as a wish for normality, which Layman et al. [6] discussed in relation to age. In our study, 79% reported that sometimes others do not notice that they have an ABI, which verifies that ABI can be invisible to others. In our sample, a large proportion were able to walk independently and manage their ADL independently. Hence, others might not notice that they have an ABI. Our study revealed that participants to a very low degree (3%) experienced that they had received individual sexual counseling. Without a clear policy within rehabilitation to address sexuality issues for all patients and not only patients with visible disabilities, it can be challenging to meet the need for information. By including a biopsychosocial perspective, which also addresses neuropsychological changes [12], professionals can be better prepared to address sexuality in brain injury rehabilitation. Other obstacles for addressing sexuality issues after ABI can be the striving among individuals with ABI to (perhaps unconsciously) normalize sexual changes. The current study showed examples of such a normalizing process by referring to other diseases, partner’s menopause, living with small children etc. as an explanation for what has changed their sexual life. Even though this might be a reason, sexual rehabilitation after ABI should include how a brain injury might complicate other obstacles regarding sexual life. In a previous study [15], we found that individuals with ABI who experienced sexual dysfunctions also reported more cognitive impairments such as increased tiredness and decreased ability to concentrate [15]. Hence, if the ABI has caused increased fatigue or decreased the ability to concentrate, this will probably make it even more difficult to manage family life and to be able to concentrate on sexual activities. Therefore, a biopsychosocial approach is highly important in rehabilitation.

In our study, about two thirds of the participants reported a present relationship, while three quarters were in a relationship at the time of injury, which indicates that relationships have ended. However, less than 60% reported being in the same relationship as before ABI, which implies that some are in new relationships. These findings could both suggest that individuals with ABI can struggle with changes in relationships in the same ways as the non-injured, but it could also show that social interactions and relationships might be more difficult to maintain, especially sexual relationships. Therefore, sexual rehabilitation after ABI should also include relational aspects, which was also indicated by Sander et al. [10].

One of the most important findings in this study is that women had not resumed sexual activity to the same extent as men. Men had, however, been asked about their sexuality to a greater extent than had females during brain injury rehabilitation. These findings are consistent with those in Rasmusson et al.'s study [30] about sexuality after cancer, in which men received more information. In our sample there was no significant difference in mean age between males and females, so age does not seem to be the reason. Importantly, we also want to state that there were no significant differences between genders concerning perceived importance of sexuality. Thus, both for clinical implications and for further research it is important to recognize the need for information about sexuality after ABI, irrespective of gender.

Among all participants, many showed a positive attitude towards sexual aids: 28% had tried some and 11% were interested in trying. Women who had resumed sexual life, had tried sexual aids to a greater extent than men (52 vs 22%), which is in line with Ronen [19], Driemeyer [16], Hebernick [17] and Reece [18] et al.'s findings in general populations. It is worth mentioning that participants who wrote free-text answers regarding adjustments that had worked out well emphasized the use of sexual aids, both alone and with partner. Norms regarding sexual aids are emphasizing different attitudes to male and female sexuality, normalizing the use of sexual aids for women but not for men unless it is a part of a relational sexual activity [19]. However Reece et al. [18] found that the use of sexual aids among males was associated with a positive outcome for sexual health, such as erection and orgasm ability. Hence, the norms might impact professionals' attitudes towards giving relevant information about sexuality after ABI. Thus, even though males receive more information about sexuality issues both in this study and in the study with cancer patients [30], they might not be given any information about how to use sexual aids. It is probable that physicians mostly talk about medication such as *sildenafil* for erectile dysfunctions, and less about sexual practices and relationships. Though the study by Driemeyer et al. [16] focuses on young people in general, the high frequency of masturbation (98.9% among males and 85.5% among females) is important to acknowledge and for clinicians to not neglect when it comes to issues concerning sexuality. An important implication for clinicians would therefore be to include sexuality issues irrespective of gender during rehabilitation, and with a holistic perspective of sexuality including both solo sex and partnered sex activities.

Another important issue to consider is the timing for information regarding sexuality after ABI. In this study there was a discrepancy as to when the participants revisited the rehabilitation unit. Namely, among those participants who asked some professional about sexuality after ABI, 46% raised the issue when revisiting rehabilitation, while only 10% reported that professionals raised the issue at that point. Hence, it is plausible that individuals with ABI have had the opportunity to resume sexual activity when revisiting rehabilitation, and therefore it might be an important time to consider sexuality issues.

Study Limitations

The response rate was quite low (40%), but considering the subject and the study population, as well as the tendency of lowered rates in contemporary questionnaire studies, this was expected. There is a minor but significant difference between participants and non-responders concerning FIM Cognitive and Physical total scores, educational level, and being discharged to independent living. This indicates that the group of non-responders is slightly more affected by their ABI and have a lower educational level. This could have some impact on the results, but it is plausible to think that non-responders' sexuality also is affected in similar ways (or even more). In this study the ambition was to include gender diversity, but the only reported genders were cis-males and cis-females. Among participants in this study, about 90% consider intimacy and/or sexuality to be important for themselves, or sexuality to be important for a relationship. This could indicate that individuals who responded are also the ones who think that sexuality is an important part of life after ABI. However, this is often the case in any study, that individuals who participates are the ones interested in the studied topic.

There are limitations in developing a study-specific questionnaire. However, the study has an explorative approach, and there was not any established instrument involving all the aspects which are included in this study. The questionnaire is based on qualitative interviews with both individuals with ABI and partners. Moreover, to validate the questionnaire, both professionals and individuals with ABI were involved in the process to include questions of relevance and to make accurate formulations in both questions and written information.

This study had an inclusion of non-stroke ABI individuals who were estimated to manage and complete a questionnaire independently. Hence, the participants were not selected to be those with the greatest physical and cognitive impairments after ABI, and we might not transfer the results to individuals more cognitively or physically affected. Our study had a narrow inclusion criterion regarding comprehension and thus we cannot be sure about consequences for individuals who are more affected by cognitive or physical impairments.

Concerning brain injury rehabilitation there are structural and cultural differences between countries, and we investigated only Swedish conditions. However, our study is the first that we know of covering sexual rehabilitation in a nationwide context in Sweden, including a patient perspective of sexuality after ABI. That is, the Web-Rehab Sweden register included participants from more than twenty rehabilitation units, and a strength in this study is the inclusion of background information from Web-Rehab Sweden for both participants and non-responders.

Conclusion

In our study, the vast majority of individuals valued both individual and relational aspects of sexuality highly, and more males than females had resumed sexual activity, while significantly fewer females than males reported that sexuality issues were raised during rehabilitation. In contact with rehabilitation medicine, participants experienced lack of information concerning sexuality including bio-psycho-social aspects. A clinical implication for brain injury rehabilitation is the importance of involving questions regarding sexuality, covering both individual and relational aspects. Further research should focus on possible

explanations for why sexuality issues are not addressed, even though research has stated the high prevalence of sexual changes after ABI, and the need for sexual rehabilitation after ABI irrespective of gender.

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Author contribution All authors contributed to the study conception and design. Material preparation and data collection were performed by Ann-Sofie Ek. Analyses were performed mostly by Ann-Sofie Ek, but also with Charlotta Holmström and Eva Elmerstig. The first draft of the manuscript was written by Ann-Sofie Ek and all authors have edited and revised previous versions of the manuscript. All authors read and approved the final manuscript.

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Declarations

Conflict of interest The authors report no conflicts of interest.

Ethical approval Specific ethical considerations have been taken in all phases of this project, since individuals with ABI are considered a vulnerable group and the topic of personal sexuality is sensitive. This study was performed in line with the principles of the Declaration of Helsinki, and ethical approval was obtained from the Ethical Review Board in Lund, Sweden (EPN: 2017 799).

Consent to participate The postal survey consisted of the study-specific questionnaire, a pre-paid envelope for responding, and information about the study, including how confidentiality was secured, emphasizing that participation was voluntary, and that consent could be withdrawn at any time without giving a reason. Returning a completed questionnaire was considered giving consent to participate. The letter also provided information about how to get in contact with a non-profit counselor for sexual issues, if needed.

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