


Sexuality and relationship experiences of women with spinal cord injury: reflections from an Indian context

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Abstract: *Spinal cord injury (SCI) is one of the most devastating physical disabilities. It leads to varying degrees of loss in sensations and mobility below the level of injury and causes loss in autonomic functions, such as bladder/bowel control, and sexual impairments. Research, mostly conducted in the developed western nations, reveals that coming to terms with one's sexuality after SCI is most crucial for early reintegration in the society and quality of life for persons with SCI. Thus, experts advocate that the sexual rehabilitation of persons with SCI is an integral component of comprehensive rehabilitation. In the Indian context, however, the sexuality of persons with SCI, particularly women, has been largely overlooked by the disability rights movement, and discourses on gender, sexuality and rehabilitation. This article is based on an in-depth study of the experiences of sexuality and intimate relationships of 24 women with SCI in India. It demonstrates that sexuality and intimate relationships are integral aspects of health and well-being for women. But there are wide gaps in the sexual rehabilitation and support needs for women with SCI in India, making their sexual adjustment extremely challenging. By analysing women's journeys of sexual adjustment and rediscovery of sexual pleasure that echo their voices as sexual beings, this article argues for the development of evidence-based and gender-sensitive sexual rehabilitation services for women with SCI in India. DOI: 10.1080/26410397.2022.2057652*

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Background

Every year, around 250,000–500,000 people acquire a Spinal Cord Injury (SCI) worldwide.¹ SCI can be traumatic (following road accidents, falls, sports injuries, violence) or non-traumatic (involving an underlying pathology, such as infectious diseases, tumours or congenital problems). Road traffic injuries, falls and violence are the most common causes of SCI. Around 80% of these injuries are sustained by men.¹ From a medical point of view, SCI is a complex condition involving complete or incomplete damage of one or more levels of spinal cord and/or the nerve roots in the spinal canal that affect the connection between the brain and other parts of the body. Depending on the level of injury, the SCI can cause varying degrees of loss of motor (the ability to control body movements), sensory (the ability to sense

touch, temperature, pain) and autonomic functions (including breathing, heart rate, blood pressure, temperature control, bowel and bladder control, lubrication, orgasms, etc.) in an individual.¹

Unlike various other physical disabilities, SCI leads to varying degrees of impairment of sexual function in men and women. Men experience problems related to erection, ejaculation and fertility, while women's ability to lubricate and reach orgasm or experience pleasure through genital stimulation is affected.² The psychological and social impacts of altered body image, lowered self-esteem and sexual confidence, and internalisation of negative societal stereotypes about sexuality and disability further complicate sexuality after SCI.³ Recognising the impact of altered sexual function and resulting perceptions of sexual inadequacy on psychological well-being, interpersonal relationships, and hence quality of life, sexuality counselling has

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been advocated as integral to making a healthy adjustment to injury, and reintegration of persons with SCI in society.⁴ Cole⁵ argues that “of great importance to the paraplegic and quadriplegic is the awareness that the satisfaction and the sense of adequacy derived from one’s sexuality may be quite independent of the presence or absence of bodily sensations”. Hence, sexual rehabilitation, which focuses on an individual’s physical, psychological, and interpersonal circumstances (which were possibly altered with the SCI) has been progressively acknowledged and advocated globally as an integral component of a holistic rehabilitation for persons with SCI.^{3,6}

A review of sexuality, disability, and rehabilitation literature on persons with SCI reveals a severe gender bias: a historical neglect and narrow conceptualisations of women’s sexuality.^{7–9} This has been explained by the lower incidence of SCI among women and the marked gender differences in the impact of SCI on sexual function in men and women. Since SCI does not affect a woman’s ability to menstruate, to become pregnant, to carry and deliver a child *vis-a-vis* a man experiencing erectile dysfunction and infertility after SCI, their sexuality is “assumed” to be less compromised and hence has historically merited less attention in the literature.^{7,9} Ingrained in such views were traditional notions of women’s sexuality as passive, expressed solely within heterosexual marital contexts where a wife’s role within marriage is to satisfy the sexual needs of her husband.

This perspective also reflected phallogocentric views of women as passive partners in sexual activity, predominantly perceived as restricted to penile-vaginal intercourse in “prescribed standard” positions with the man being on top of the woman.¹⁰ Since the role of a woman in sexual activity was reduced to solely “lying on her back” for the pleasure of her “husband” and an individual’s capacity to participate in sexual activity was measured by their ability to perform, rather than to feel, changes in sexual function experienced by women were not seen as problematic or necessitating any further exploration. Several popular works† of the 1970s rather explicitly articulated these beliefs to justify the relevance

of focusing on the sexual health of men as compared with women. In the absence of contrary citations from women in the literature, these notions were accepted as truth internationally,¹⁰ contributing to the bulk of existing literature in this area. Predictably, until the 1990s, among the limited works on the sexuality of women with SCI, the overriding focus remained on female reproductive functioning, i.e. the return of menstruation, conception, pregnancy, and delivery.^{10,13}

The 1990s saw a departure from an explicit focus on the pathophysiological impact of SCI on sexual function towards a more holistic study of female sexuality and sexual and reproductive health (SRH). Over the years, the discourse on sexuality after SCI has evolved and delved into issues of women’s subjective experiences of sexuality and sexual rediscovery after SCI,^{7,9} including sexual intimacy and pursuits of pleasure;^{14,15} reconstruction of sexual identity;⁸ sexual esteem and body image;¹⁶ partner relationships;¹⁷ sexual functioning, experience, and adjustments;⁶ sexual rehabilitation;¹⁸ and fertility, reproductive desires and service needs.¹⁹ These studies suggest that SCI does lead to sexual impairments that might alter a woman’s ability to experience pleasure in conventional ways (such as penile-vaginal intercourse) due to loss of genital sensations or difficulties in achieving orgasm. Women’s ability to participate in sexual activity like their own able-bodied prior self, or counterparts, due to various physical (ability to position self, leakages, pain, etc.) and psychological (such as altered sexual identity and sense of self) challenges could further affect sexual satisfaction after SCI. Despite these challenges, however, sexuality – sexual desires, intimacy, intimate relationships, and awareness of being able to lead fulfilling sexual and reproductive lives – remains important. Identifying gaps in existing rehabilitation services across global settings, which are either silent on sexual aspects after SCI or mostly geared towards men’s concerns, these studies unanimously advocate for gender-sensitive sexual rehabilitation for persons with SCI.

While the review highlights significant strides in the existing research in the area of the sexuality of persons with SCI, including women, it also underscores marked geographical disparities. Most knowledge in the area of female sexuality and sexual and reproductive lives after SCI comes from developed western nations, while there is a critical

†See Sandowski¹¹ and Cole.¹²

neglect in the Asian countries, particularly the South Asian and Indian context. This could be explained by the narrow conceptions of women's sexuality as passive and veiled in concerns over marriage and reproduction in non-western societies. Limited views of women with disabilities as unmarriageable and asexual further add to silence in this area. Another plausible reason relates to the limited capacities of health systems in lower- and middle-income countries to meet the comprehensive health care needs of persons with SCI. Research from the Asian Spinal Cord Network (ASCoN) region[‡] underscores that the number of SCI centres and services, including those for comprehensive rehabilitation offered through a multidisciplinary approach, are often insufficient to meet the needs of the population or unavailable.

In India, persons with SCI have been accorded limited space in national priorities/discourses. Thus, they remain invisible in the national data repositories. To date, India has no national database/registry or a comprehensive epidemiological study on SCI.²⁰ The existing 2011 national census further fails to capture diversity within locomotor disability by providing data under a single head of "locomotor" disability. Conservative estimates report the incidence of SCI in India at around 20 per million people, or about 20,000 fresh cases each year.²¹ Most studies report a higher incidence of SCI in men, due to the gendered divisions of work; more men are engaged in outdoor activities, exposing themselves to a higher risk of injury.²⁰ There are a few studies which suggest that – contrary to the accepted view – women's more active/outgoing role in the face of changing social norms in India means that they are just as likely as men to incur SCI.²² In addition, inequitable gender norms might limit the access of women with SCI to comprehensive health care, particularly rehabilitation, in India.

In the context of the sexuality of persons with SCI, the handful of works that emanate from India are mainly quantitative enquiries addressing sexuality concerns in men.^{23,24} Such research studies mostly echo the voices of men because the recruitment of women participants generally remains less than their male counterparts.²⁵ These studies rely on standardised questionnaires

for data collection. Thus, they fail to capture the lived experiences of participants – how people with SCI navigate through various physical, psychological and societal challenges of an altered sexuality and sexual function that are unique to the Indian context.

Despite many advances in sexual rehabilitation, development of training curriculums, client and provider needs assessment research designs and tools in western countries,^{26,27} sexuality as a rehabilitation concept is yet to be fully acknowledged in India. Often health care professionals tend to neglect sexuality due to their insensitivity to the sexual needs of the disabled or a lack of understanding and expertise in this area.²⁸ H.S. Chhabra,²⁹ the chief of spine service and medical director, Indian Spinal Injuries Centre (ISIC), which is a nodal Specialised Spinal Centre (SSC) in the country, ascribes the neglect to ignorance, misconceptions, cultural taboos and negative attitudes towards sex. Sexual relationships between husband and wife are mainly thought to be for having children. Cultural beliefs, such as that having sex with an ill female is immoral or that it can transmit disease/illness to the male, continue to exist. The double standard of sexual behaviour for men and women in Indian society further implies that women are mostly in a disadvantaged position as compared to men.

Women with SCI are the most marginalised among women with disabilities (WwDs) in India. Given the limited research on women's sexuality after SCI, a general silence in the relative disciplines, and glaring gaps in gender-sensitive sexual rehabilitation, the issue of women with SCI is a human rights issue. This article provides an in-depth understanding of the lived sexuality and relationship experiences of women in India following SCI, initiating a discourse on gender-sensitive sexual rehabilitation services for women with SCI.

Methods

This article presents the sexuality and relationship experiences of 24 women with SCI. It derives from my doctoral work that documented and analysed the SRH situation of women with SCI in India. The data was collected in two phases, using qualitative research methods. In the first phase, 17 experts (academics, representatives from NGOs and national disability institutes, specialists, and peer educators) working on issues of persons

[‡]Bangladesh, China, India, Malaysia, Nepal, Pakistan, Sri Lanka, Thailand, and Vietnam.

with disability in India were interviewed. Some of them had a lived experience of disability. The experts were asked to share their perspectives on the pressing SRH concerns of WwDs in India. These interviews exposed me to a much-needed practical understanding of a multitude of issues that WwDs face in their everyday lives (especially in the context of SRH), and also helped me to refine and sharpen the focus of my research. The scope of the research was narrowed to focus specifically on women with SCI within locomotor disability. I then spent some time in a rehabilitation setting to gain a deeper understanding about SCI and the lives of people living with this condition. Observation, interviews, and informal interactions with the rehabilitation experts, men, and women with SCI in the centre helped me shape my ideas for the interview guide with women with SCI.

The paper focuses on the second phase of the study with women with SCI which took place between September 2018 and February 2019. Twenty-four in-depth interviews (IDI) were conducted with women with SCI in Delhi, Chandigarh and Mumbai, India. Each of these cities has spinal rehabilitation facilities, including one of India's most advanced SSCs. Participants were identified through snowball sampling with a few initial contacts shared by the Spinal Foundation, a pan-India SCI self-help group working towards improving the quality of life of persons with SCI. The Foundation facilitated data collection with women with SCI. The interviews were conducted in English or Hindi languages and in the homes or any location convenient to the participants. Interviews lasted between 40 minutes and 4 hours and were audio-recorded, transcribed verbatim, and translated in simple English to retain the essence of women's voices. Prior to the interviews, informed consent was sought from all after briefing them about the purpose of the study and how the information collected from them would be used for research and publication purposes. Participants were informed that the data would be treated in a confidential manner and a verbal/written consent was obtained. Informed consent to audiotape the interviews with the help of a digital voice recorder was also sought. All potential participants were free to abort the interview or skip questions if they so desired.

This manuscript draws on the data from the second phase of the study. While the perspectives of the experts shaped the overall

conceptualisation of this study, these did not directly inform the data that emerged from this round of the study. An outline of the IDI guide for the larger study is provided in Appendix I (see supplementary materials). Women with SCI in the study included both married and unmarried women between the ages of 18 and 45, at least one year after SCI, irrespective of the severity, levels and cause of SCI.

Profile of participants

The average age of participants was 29 years (range: 18–44) and the average time since injury was 10 years (range: 1–30). Women hailed from diverse geographical locations: Himachal Pradesh (HP), Uttar Pradesh (UP), Haryana, Delhi and Chandigarh in North India, Bihar in Eastern and Mumbai in Western India. The majority (63%) lived in urban areas and were at least graduates, and slightly more than half (56%) were employed. All women who were employed or continued work after injury either belonged or could migrate to urban areas due to prior employment and/or family support. At the time of the interview, more than half (54%) were unmarried and the remaining women either ever married or divorced/separated. The majority (92%) had paraplegia,[§] and the remainder tetraplegia[¶]. Most women (88%) sustained SCI due to traumatic causes (falls from a height, road traffic accidents, etc.), and the remainder due to non-traumatic causes (spinal tumour, myelomeningocele disease). The majority (79%) were rehabilitated; of these, a few immediately after injury (32%), and the remainder (68%) with a lag of about 5 years (range 6 months to 14 years) between sustaining SCI and receiving rehabilitation. [Table 1](#) presents the overview of participant characteristics.

Analysis

Overall, the larger study followed the modified Van-kaam method of analysis as propounded by Moustakas.³⁰ The researcher first familiarised herself with the data by reading and re-reading the transcripts. Data relevant to people's lived experiences of sexuality and SRH were then identified through the process of reduction and elimination,

[§]Paralysis of the lower limbs and trunk without the involvement of the upper limbs.

[¶]Formerly called quadriplegia and entails a paralysis of all the four limbs and trunk.

Table 1. Participant characteristics

Name*	Age	Age at injury	Education**	Employment status	Marital status	Location	Rehabilitation status (lag years)	Self-reported injury classification
Rima	24	13	Graduate	Customer Service Executive	Unmarried (UM)	Urban Delhi	Yes (9 mths)	Tetraplegia
Nikki	35	19	Graduate	Unemployed	UM	Urban Delhi	Immediate	Paraplegia
Pari	24	16	Class XII	Unemployed	UM	Rural UP	Yes (8)	Paraplegia
Arundhati	22	13	Graduate	Unemployed	UM	Urban Delhi	No	Tetraplegia
Lata	24	17	Illiterate	Unemployed	UM	Rural HP	Yes (7)	Paraplegia
Shabnam	18	17	Illiterate	Unemployed	UM	Rural UP	No	Paraplegia
Vaidehi	29	18	Graduate	Unemployed	UM	Rural Bihar	Yes (10)	Paraplegia
Neha	27	22	Graduate	Unemployed	UM	Rural HP	Yes (5)	Paraplegia
Shonali	29	16	Graduate	Unemployed	UM	Urban Delhi	Yes (1.5)	Paraplegia
Bhavya	24	23	Graduate	Nurse	UM	Rural Punjab	Yes (6 mths)	Paraplegia
Karina	27	25	Graduate	Marketing Executive	UM	Urban Delhi	Yes (Immediate)	Paraplegia
Jyotsana	27	10	Post Graduate	Data Analyst	UM	Rural UP	Yes (14)	Paraplegia
Geeta	28	27	Graduate	Homemaker	Divorced after SCI	Urban HP	Yes (1)	Paraplegia
Urvashi	30	17	Class XII	Homemaker	Married after SCI	Urban Delhi	Yes (Immediate)	Paraplegia
Katherine	36	25	Post Graduate	Professional Athlete	Married after SCI	Urban Mumbai	No	Paraplegia
Dimple	28	23	Class XII	Homemaker	Separated after SCI	Urban Delhi	Yes (5)	Paraplegia
Kusum	34	21	Class X	Supervisor-Housekeeping	Separated after SCI	Rural HP	Yes (10)	Paraplegia

(Continued)

Table 1. Continued								
Name*	Age	Age at injury	Education**	Employment status	Marital status	Location	Rehabilitation status (lag years)	Self-reported injury classification
Prabha	26	21	Primary	Homemaker	Married	Urban Delhi	Yes (Immediate)	Paraplegia
Natasha	31	17	Class XII	Professional Athlete	Married after SCI	Urban Mumbai	Yes (Immediate)	Paraplegia
Manjula	31	26	Post Graduate	Police Constable	Married	Rural, Haryana	Yes (1.3)	Paraplegia
Gurnoor	44	42	Graduate	Entrepreneur	Married	Urban Chandigarh	Yes (1.5)	Paraplegia
Anna	30	8	Post Graduate	Tax Assistant	Married after SCI	Urban Delhi	No	Paraplegia
Naina	36	21	Graduate	Fitness Trainer	Married and divorced after SCI	Urban Delhi	Yes (Immediate)	Paraplegia
Komal	30	At birth	Graduate	Unemployed	UM	Urban Delhi	No	Paraplegia

*All names are pseudonyms.
 **Class XII/ Senior school certificate examination.
 **Class X/Matriculation/ Secondary school examination.

followed by manual coding and thematic analysis to ensure representation of participants' experience. The resulting themes were discussed with one participant to ensure clarity and precision in data analysis. Thereafter composite tables of textual (verbatim) and structural (researcher's interpretations of context) descriptions for each participant were created to identify common themes to be synthesised into a comprehensive understanding of women's lived experiences of sexuality. For the purposes of this manuscript, these themes were revisited through a human rights-based lens.³¹ The central theme of non-discrimination in women's access to the highest standard of health care, and including rehabilitation encompassing sexuality information and services, emerged as the guiding framework. The analysis process entailed iteratively engaging with the following questions to assess the voices of women: What rights are being violated? How are these rights being violated? How do contextual diversities exacerbate vulnerability to sexual and reproductive health and rights (SRHR) violations? Are the results reflective of intersectionality? Who are the duty bearers? Is there a potential for recommendations on policy change in relation to non-discrimination? Does the research throw light on the discrimination faced by women with SCI in India?

Ethical statement

The research complies with all institutional guidelines to ensure scientific knowledge creation and ethical rigour, as mandated by the requirements of the University Grants Commission of India for award of the degree of Doctor of Philosophy. The interview guide and the protocol of the larger study along with the Doctoral Internal Advisory Committee and external experts at the Tata Institute of Social Sciences, India (a mandate for all doctoral works), were also reviewed and approved by three experts of the Spinal Foundation (July 2018). These experts constituted a clinical psychologist (spinal rehabilitation expert); an academician, peer SCI counsellor and an analytics expert who verified the protocol and interview guide for its sensitivity towards women with SCI.

Results

The major themes that emerged with data analysis were: (a) decreased sexual interest, (b) innate desires and early relationship experiences, (c)

sexual activity, (d) sexual reproduction, and (e) sexual rehabilitation.

Decreased sexual interest

Sexual interest is the desire a woman feels and the importance she places on sexuality.⁸ Soon after the injury, the women with SCI experienced a lack of interest in sexual activities for various reasons that they associated with many different factors, affecting their altered lives.

Survival and prolonged recovery

The initial period after SCI was characterised by a general decline in sexual interest, as basic survival needs were prioritised. Women's energies were largely focused on understanding the new condition, their altered bodies, managing activities of daily living, especially bladder and bowel regimes, along with the emotional and psychological trauma of the life-altering impact of the injury. A participant who was married with an adolescent child at the time of the injury describes the initial period as emotionally and physically devastating for her and her husband. Describing how then sexuality was the least priority she says:

"My husband was mentally and emotionally broken – depressed, could not sleep, and lost appetite. I was physically weak while he was constantly anxious about my health. For around one and a half years, sexual aspects never crossed our minds. Our daughter was our priority as she was also going through a lot because of my injury. Gradually, we started thinking and talking about our past sex life, wondering if we would ever be able to have it [intercourse] again." (Gurnoor, age 44, two years post-SCI, paraplegic, Urban, Chandigarh)

Delays in rehabilitation due to lack of referrals/information from health facilities providing acute care and unequal distribution of SSC in the country further delayed the process of sexual adjustment after injury. Many described how sexuality was their lowest priority when they lacked basic knowledge about their injury and awaited the expected recovery of walking again. After the injury, only six women were rehabilitated before reaching home (see [Table 1](#)). All belonged to urban areas where most of the rehabilitation facilities of the country are located. The rehabilitation experiences of women also varied depending on the facility from which they were rehabilitated – SSC, regional rehabilitation centre, general rehabilitation wards, public or private

facilities and so on. Those who were rehabilitated in an SSC described their rehabilitation as comprehensive as it covered many aspects that were integral to independent and quality living after SCI: patient and family education on SCI and after care, psychological counselling, occupational therapy-self-care, independent living, training in assistive devices, bladder/bowel and pressure sore management, physiotherapy, and sexuality information, amongst others. On the other hand, those who were rehabilitated in a general facility expressed dissatisfaction with their rehabilitation experience as it lacked training on many of these crucial aspects. These women, along with the many who experienced lags in rehabilitation or were never rehabilitated, faced many challenges in their everyday lives which contributed to negative body images and devalued self-concepts. Most experienced hopelessness and doubted their abilities to resume their past roles and responsibilities. In such a prolonged and complex process of recovery after trauma, many expressed that it was difficult to have any positive feelings about their bodies or perceive themselves as sexual beings. A participant who had not been rehabilitated to date and continues to battle recurring pressure sores, describes her initial years with SCI:

“I was all the time lying naked on the bed, mostly covered with a thin cotton sheet and suffering from pressure sores. My elder sister would bathe me. Sometimes, it was my father who had to attend to me. I felt extremely helpless and embarrassed – showing my naked body to them. I was no longer a child but a grown-up girl with well-developed body parts. It was the most depressing experience for me. I can’t put those feelings into words. I had nothing but contempt for my body. This painful phase lasted for about four years.” (Arundhati, age 22, nine years post-SCI, tetraplegia, Urban, New Delhi)

Married and in-relationship women

Women who were married or dating at the time of the injury shared that their sexuality took a backseat in their lives when they were confronted with doubts about their sexual adequacy, abilities to satisfy their partners’ sexual needs and undesirability as a wife/partner. Negative partner attitudes further validated their apprehension, making them feel sexually disenfranchised after the SCI. Often the role reversals within

relationships, arising out of the caregiving and nurturing burdens placed on women’s husbands, created stress and conflicts in marriage. A participant describes feeling sexually disenfranchised due to lost genital sensations, negative attitudes of her spouse and feedback received from him and his family (mostly her mother-in-law) that conveyed her inadequacy to fulfil the expected marital roles:

“After the injury, my husband has lost (sexual) interest in me. Now we hardly have sex, once in two months. He often complains that my lower limbs are numb and my body feels like a dead person’s body. ‘So, how can I enjoy it (sex) with a dead person’. I also feel that when I have no sensation, why bother having sex ... At times, I take the initiative that he often resists. He doesn’t like my body any more. I also don’t force him. Now, his parents (especially mother) are insisting to get him another woman – a ‘proper wife’ – who could take care of him, the family, and probably me also.” (Manjula, age 31, five years post-SCI, paraplegic, Rural, Haryana)

A few women who were dating and planning their marital futures with their boyfriends at the time of the injury reported a drastic change in their relationship status after SCI. The painful dissolution of their relationships, often without a confrontation, devalued their self-esteem and caused them to internalise feelings that they would not be accepted for a future marital relationship. A participant painfully recalled her experience thus:

“My boyfriend passionately reasoned, ‘I have my whole life ahead of me and it’s best that we separated’. It left me speechless. Now I feel that a married life is a distant dream for a person like me. I belong to a world that is completely different from the world of those who can walk. There are so many women who are normal, yet unhappy in their married lives. What chance do you think a person like me stands who is not normal and already unhappy.” (Vaidehi, age 29, 11 years post-SCI, paraplegic, Rural, Bihar)

Another participant shared how she internalised the notion of being incapable for marriage and sexual relationships because of her status as a WwD. It led her to consciously decline the sexual advances of her partner.

“After my injury, I tried to push my partner away. Normally, in a relationship, we expect our partner

to be emotionally and sexually available and look after us if something terrible like this (injury) happens. I felt I could no longer give him those comforts after the injury. So, for his own good, I decided to keep him at bay. I just wanted him to be my friend and nothing more.” (Katherine, age 36, 11 years post-SCI, paraplegic, Urban, Mumbai)

Young and single women

Some women were too young at the time of the injury. They had not yet developed sexual interest or experienced any sexual relationship. Rima (age 24, 11 years post-SCI, tetraplegic, Urban, New Delhi) notes: *“I never thought about it [sexual feelings and activity] as I was just 13, and my priorities were to gain in self-care, complete my schooling and get a good job”*. Some shared how misconceptions about the impact of the injury on their ability to menstruate and procreate made their families believe their daughter had now become an asexual person.

“My parents were informed that because of the catheter I will never menstruate after the injury. Hence, a normal sexual life and pregnancy were not possible for me. So, marriage is off the cards for me. Now, since I menstruate, I know what the doctors said was not true. But I do not feel any sensations there [genitals]. So, why should I bother having sex with my boyfriend, if it is only for his pleasure?” (Jyotsana, age 27, 17 years post-SCI, paraplegic, Rural, UP)

A participant belonging to a rural agrarian household shared how it was difficult for her to even think about marriage when SCI compromised her ability to perform the gendered roles expected from women in her village.

“The thought of getting married scares me. I would love to, but given my condition, I don’t know what will happen after marriage. If a girl is physically fit, she can perform all the roles expected from a married woman. I often wonder if I would ever be able to fulfil their expectations. If not, how will they react? Would they understand my situation? Will they scold and abandon me soon after the marriage? Marital homes are not like natal ones. No one really knows if they will get loving in-laws or hostile strangers. Also, why would a normal man want to marry me when he can find many normal women?” (Lata, age 24, seven years post-SCI, paraplegic, Rural, HP)

Traditional gender roles and expectations thus limited the women’s ability to reintegrate into society. India is a patriarchal society wherein women are expected to manage household chores and care work besides helping their husbands in earning a livelihood. The sexuality of women residing in rural areas was further complicated due to a lack of facilities for even basic health management, restricted mobility in wheelchair-unfriendly terrains within and outside home and the manual nature of domestic work (cattle rearing, grass cutting and so on). Thus, making reintegration into expected female roles for a woman after SCI is particularly challenging in rural areas.

Innate desires and early relationship experiences

The sexuality of most married women was complicated by the internalised beliefs and attitudes of their partners towards their disability and their capacity to resume the marital roles of nurturing caregiver and sexually capable/attractive partner. Most unmarried women expressed that changed parental attitudes and negative societal messages subtly conveyed their asexuality. Shonali (age 29, 13 years post-SCI, Urban, New Delhi) recalls:

“my parents tell people ‘now we don’t want to get her married. She is our son!’ They never think about my marriage and have never asked my views. If someone from outside initiates any discussion, they tell them also, ‘we won’t give our responsibility to anyone else’, people don’t treat ‘good girls’ properly, our daughter is still disabled, no one can care for her more than us!”

For women in rural areas with no opportunities to migrate to urban areas through education or employment, it was a passive submission to “unmarriageable” – hence asexual – identities, given the rigid manual nature of work associated with marital roles and internalised negative views of disability. Amidst the pervasive societal devaluation and negative messages silencing and dispelling their sexualities, however, a few shared their innate desire for love, romance, dating, sex, and marriage, normalising conversations on sexuality and disability.

“Earlier, I used to think that we (disabled women) can suppress our urges and stay like this forever. But now I feel that everyone needs a partner. After a point, everyone gets busy with their lives. When I see my brothers with their wives, I feel

that I should also be with someone with whom I can share my inner feelings. Often, when my mother tells others that I don't want to get married, I feel like shouting – 'No, mother, I really want to!' Yes, we also crave a married life." (Shonali, age 29, 13 years post-SCI, paraplegic, Urban, New Delhi)

"I want to have sex. And I want my partner not to wear a condom so that I can experience that intense pleasure that my friends often talk about. Even if my marriage does not seem materialising, I will certainly like to have a boyfriend for my sexual needs. Women get married when they are 18 or younger. I am 30 and unmarried. I should at least have a sexual relationship now. I don't know if it's normal to have such feelings despite being in this (SCI) condition, or if there is something wrong with me. We are not supposed to feel and express such urges. That's how society feels." (Komal, age 30, since birth, paraplegic, Urban, New Delhi)

As women made their debut in the arena of dating and intimate relationships after SCI, many realised that an acquired disability does not alter one's sexual feelings and desires, contrary to how they had perceived their sexualities after SCI. A participant recalls thus:

"I used to feel normal with him. I don't think many changes come in sexual feelings after this injury (SCI). I don't know whether it's my low level of injury or if it's normal for the disabled to have those kinds of feelings. We (the persons with SCI) might not feel hunger, but we do feel strong sexual urges, like any other normal woman." (Shonali, age 29, 13 years post-SCI, Urban, New Delhi)

The "first date" held significant importance in the lives of many women. It assured them of their acceptance in intimate relationships, which was contrary to how their sexualities were perceived and interpreted by the society including their family and their own selves. Neha (age 27, 5 years post-SCI, Rural, HP) recalls that *"the first time, I entered a relationship after the injury, I experienced a very different feeling. This made me realise that, these things (love and intimate relationships) are also possible in our lives"*.

Positive attitudes of partners towards the women's disability and sexuality boosted their self-image and contributed to stable relationships after the SCI. Among those who were married at the time of the injury only one reported a stable relationship after the injury. The several factors that mitigated relationship distress in this

woman's case included positive partner attitudes, open communication, many years of a cherished marital relationship, and ability to afford assistance for household chores and self-care. Recalling an initial conversation with her husband on resuming their sex life after injury, she said:

"Even after a significant recovery from the injury, my sexual life was not coming on track. My husband would often ask: 'how will life go on like this?' I once said to him: 'I also have the same sexual urges. But if I am not able to resume a normal sex life, you are free to have a relationship with another woman.' But he said to me, 'I want to be with you. I can't think of a second marriage or having a sexual relationship with anyone else'." (Gurnoor, age 44, two years post-SCI, paraplegic, Urban, Chandigarh)

Sexual activity

Women in intimate relationships were asked about their sex lives and in what ways acquiring a physical disability had affected their sexual relationship with partners. The women shared both psychological and practical challenges they experienced in resuming their sexual lives after SCI. Most psychological concerns were related to their perceived inability to sexually satisfy their partners, of sex being unpleasurable due to lack of genital sensations, fears of further damage to the spine during sexual activity, bladder/bowel leakages during sexual activity, negative body images and fears of rejection as a sexual partner. Often many of these concerns resolved when women experienced a sexual relationship with a partner who was sensitive and accepted the woman's disability.

Practical challenges reported by women included the need for prior preparations such as emptying the bladder or clipping the catheter before initiating sexual activity. This resulted in lack of spontaneity in sexual activity which was at times perceived as psychologically disengaging for the couples. For some, bladder/bowel accidents during intimate moments reinforced feelings of sexual inadequacy and guilt, especially when received negatively by their partners. Women with prior sexual experiences also reported inability to position their bodies during intercourse like before or not being able to experiment with different positions due to lack of mobility, muscle weakness, spasticity, fears of damage and lack of practical knowledge of other safe

positions. During initial experiences some even reported not experiencing any pleasure, but faking it to develop partner confidence and intimacy. A woman married after SCI narrates thus:

“We faced many issues. I often had urine and bowel leakages during the intercourse. This would make me feel very embarrassed. But my husband understood my situation and made me feel comfortable, arguing that such things would not undermine our bonding. He is comfortable with my body which boosted my self-esteem. I feel it depends a lot on the attitude of your partner towards your disability. Despite my disability, he happily married me. During an intercourse, I don’t feel any sensations there [in the genitals]. Initially, I didn’t tell him this clearly. I faked orgasms. It felt good to make him believe that I was getting the same pleasure from sex as he was.” (Urvashi, age 30, 13 years post-SCI, paraplegic, Urban, New Delhi)

Most women did not receive any sexual information and counselling from health care providers after SCI. Gurnoor (age 44, two years post-SCI, paraplegic, Urban, Chandigarh) recalls, *“In the initial period we were having doubts about resuming sexual activity and wanted to seek an expert opinion. But we did not know whom to approach and how our doubts would be perceived because of my disability?”* Some women described devising their own strategies to overcome the challenges they were facing. These include the use of sexual aids, watching pornographic content, cracking adult jokes to tackle the lack of spontaneity, engaging in longer or shorter foreplays, and emptying bladder/bowel before intimate moments. A woman mentioned restricting sexual activity initially to oral sex, when she and her partner feared that intercourse or rigorous sexual activity could hurt her body. Naina (age 36, 15 years post-SCI, paraplegic, Urban, New Delhi), who became sexually active after the injury, describes how even without any sensations in her genitals she experienced sexual pleasure and orgasm during sexual activity. She notes

“I had no prior experiences of sexual pleasure to compare my feelings with. Our foreplay was so strong that I enjoyed the physical and psychological connect with my husband. During our intimate moments I often did not realise that there was no sensations in my lower body because what I experienced was pure enjoyment. I even get orgasm like any able-bodied women.”

For another woman, it was a mix of strategies:

“I started exploring options to mitigate the challenges we were experiencing, like working around my surroundings, increasing the temperature of the air conditioner – low temperature increases the chances of urine leakage during intercourse. I started emptying my bladder before and after sexual activity and avoided long foreplays. We would watch pornography together, crack dirty jokes, and send tempting messages to each other on WhatsApp.” (Gurnoor, age 44, two years post-SCI, paraplegic, Urban, Chandigarh)

Women also emphasised consciously not involving their spouses in managing their daily rituals, particularly intimate care tasks. Many felt that when their spouse performed the dual role of being both lover and caregiver, it created stress in the relationship, affecting the sexual intimacy between the couples. A participant who lives in an urban slum, in a one room hovel with her husband, narrated that she remained mostly restricted to her bed. In the absence of a private bathroom facility at home, she was forced to rely on her husband for disposing of her excreta and managing all intimate care works. This, she explained, added to complexities in her marital relationship:

“We rarely had sex after my injury. My husband is also my primary caregiver. He helps me bathe, disposes my excreta, and cleans me afterwards. It’s like a routine job for him. So, he does not feel that attraction towards me anymore. When a man cleans your shit, it is understandable that he won’t find you sexually appealing. That’s what is happening between us. We don’t talk much ... he is always exhausted. It seems care work and his job are taking a toll on him.” (Prabha, age 26, five years post-SCI, paraplegic, Urban, Delhi)

Women also emphasised experiencing sexual pleasure through a repertoire of sexual expressions such as kissing, hugging or caressing, rather than solely the act of penile-vaginal intercourse. A participant who was married after SCI shares thus:

“Sexual pleasure is about your bonding with your partner. If that is good both accommodate each other’s desires and can enjoy a sexually satisfying relationship. Then even small gestures of hugging your partner sleeping together can give a great feeling. Intimacy is not just about intercourse, and even

a tight hug at times can be sexually satisfying.” (Natasha, age 31, 14 years post-SCI, paraplegic, Urban, Mumbai)

An emphasis on genitals for a pleasurable sexual experience also became irrelevant when women discovered that sensations in their body that were not affected by the paralysis could be as sensuous as caressing of genitals. A woman explains:

“As our relationship matured, we freely began to express our sexual likes and dislikes. We explored our bodies together. This made me realise that my upper body (above the level of injury) feels extreme pleasure during our intimate moments. I feel my breasts are very sensitive. I enjoy when he fondles them. We experience a lot of pleasure together. I no longer believe that a lack of sensation in genitals means that a person cannot enjoy sexual intimacy. Such notions are just mental blockages that one can easily overcome.” (Urvashi, age 30, 13 years post-SCI, paraplegic, Urban, New Delhi)

Sexual reproduction

Urvashi is the only woman in the study who experienced a pregnancy after SCI. Her narrative provides insights into some of the considerations for women wanting to conceive after SCI. She was disowned by her family after marriage as her parents could not understand how a normal man could love and want to marry her. They feared that she would be sexually exploited and sent back home with children, increasing the family’s burden. However, Urvashi and her lover decided to marry anyway. Her spouse hid their marriage from his parents, fearing that they would also bitterly oppose his choice of a life partner. He later lied to them saying “she became disabled after marriage”.

In the first year of marriage, Urvashi conceived naturally and gave birth to a male child. Since the boy was epileptic, Urvashi’s in-laws, particularly her mother-in-law, considered him “a waste child”. In her desire for a “normal grandson”, she coerced Urvashi to conceive a second child. To assure her mother-in-law that she was adequate in all aspects, like any able-bodied daughter-in-law would have been, she agreed to honour her demand. Urvashi’s husband initially detested her decision as he feared that it could harm her body. But later, seeing her determination, he supported the decision. She gave birth to a girl child. Yet, Urvashi’s mother-in-

law, who wanted a male child, was not happy. She began to pester Urvashi to give her a grandson. This unreasonable demand came from her sense of entitlement. She thought that as a mother-in-law, it was her right and duty to demand a *Kuldeepak* (light of family) from her daughter-in-law. Patriarchy, which is deeply entrenched in Indian society, impinges on every aspect of life. In India, sons are viewed as assets, while daughters are seen as liabilities. Hindu scriptures (Urvashi and her in-laws follow Hinduism) accord special roles and status to male over female. For instance, only a male member of the family is allowed to light the fire of a pyre; and if a male (son) does not perform the funeral rights, the soul of the deceased never attains salvation. Blinded by a patriarchal mindset, the mother-in-law kept demanding a son from Urvashi, entirely disregarding Urvashi’s health condition. Given her medical condition, the gynaecologist recommended an instant hysterectomy to Urvashi that she readily accepted.

Any person with an SCI faces challenges. But Urvashi’s journey was particularly difficult because she was a woman. When Urvashi first learnt that she was pregnant, her initial feeling was “*when the tests confirmed it, for a moment I forgot I was paralysed. I did not worry how I would manage everything that was about to happen after this development. I said to myself, I want this child, come what may!*” Since Urvashi was one of the three women who reached an SSC after sustaining an SCI, she was aware and consulted a gynaecologist from the SSC. Urvashi’s entire body below the navel is paralysed (T12 level of injury). But when she consulted a gynaecologist from an SSC, it boosted her confidence in her body. “*Since my gynaecologist was from – (SSC), I trusted her even more. It was important for me then to have one who is fully aware of and could handle any SCI-related complications during the pregnancy and delivery.*”

Urvashi describes her pregnancy as no different from what other able-bodied women experience. While the pregnancy exacerbated some SCI-related health conditions, she believes that these conditions should not limit one’s desire for having children. Timely and accurate information, a supportive and encouraging gynaecologist, and a loving partner can help one overcome most challenges and avoid complications.

“Managing the household chores single-handedly and taking care of self becomes tough during the pregnancy. Some women (depending on the level

*of the injury) can't even feel their baby's movements that make them anxious. I perpetually worried that my sitting posture in the wheelchair could compress my stomach and hurt the baby. Women with higher levels of injury have to be extra careful as they might not experience any discomfort if they get injured. During my pregnancy, I experienced nausea and other common problems like the normal women face. But an increase in urine and bowel leakages was most distressing. Often, I would get loose motions and there would be no control. The excreta would leak out any time. My husband helped me with the intimate care work. I also had to manage the bowel movement with D-stimulation**. In the later months, my husband did it for me. He supported me throughout and never complained even once.” (Urvashi age 30, 13 years post-SCI, paraplegic, Urban, New Delhi)*

However, Urvashi felt disappointed with her gynaecologist's attitude which she felt did not pay much attention to her specific needs, psychological fears and treated her like she would any other able-bodied pregnant woman. Urvashi believed that more information on risks and procedures before and at the time of delivery could have been helpful, but were ignored in her case. For her second pregnancy, Urvashi faced many challenges in finding a health provider agreeable to accept her and not discourage her from going ahead with her pregnancy – without examination, solely on the basis of her disability. She was finally taken in by a gynaecologist in a public health facility. She notes that despite the excessive patient load, lack of provider experience in assisting disabled women for pregnancy and accessibility issues within the facility, she had a hassle-free and memorable childbirth experience. This, she considers, was solely made possible by the compassion and positivity she received not only from her gynaecologist but the entire hospital staff.

“I had difficulties in accessing washrooms and beds because the hospital's infrastructure was not disability friendly. I was the first woman (with SCI) who had been admitted to this hospital for delivery. The hospital staff was extremely caring and supportive of my decision to go ahead with the pregnancy.

**A method of bowel management where the injured person/assistant gently inserts a gloved lubricated forefinger beyond the anal sphincter and gently moves it in stimulating circulating motions to facilitate bowel movements.

But I was very apprehensive about their ability to manage my case as the hospital lacked an SSC. However, I continued consulting them as my earlier experience at the SSC was not good and the hospital staff here was extremely sensitive and accommodative.”

Sexual rehabilitation

Irrespective of the lags in rehabilitation, some women, who received sexuality information during rehabilitation, experienced their interaction with a psychologist/physician as a one-off unidirectional monologue. In these sessions, the most important advice that women received was: “Your organs are the same, you can still get married or pregnant if you wish to”. A few women, who had made incorrect assumptions about their SRH capacities after SCI, welcomed even this basic information as it reaffirmed their sexuality. Most women, however, found it difficult to relate themselves with concepts such as “marriage” or “reproduction” as they had internalised the notion that they were asexual. Yet, some women wanted to get more practical information about how to engage in sexual activity and experience pleasure after they had lost genital sensation. They wanted to know how they could resume their sexual life without hurting their bodies. They had numerous questions related to sexual positions, contraception, management of bladder and bowel issues, and protection from urinary infections or unwanted pregnancies. They also expressed the need to connect with other women with SCI and learn from their experiences. A participant summarised her single sexuality information talk as:

“Once, the clinical psychologist said to my mother, ‘get Shonali married, if she wants to’. To this, my mother replied, ‘how is it even possible? Who would want to marry her?’ The psychologist reasoned that ‘Shonali's organs have not changed, it's the same body, everything is possible, she can be sexually active and can conceive a child like normal women’. I found the psychologist's arguments comforting and intriguing. I began to wonder how it (sexual activity and pregnancy) is possible given that our pelvic area is weak, and bladder leakages happen frequently. I had several questions that I wanted to pose to the psychologist. But how could I ask those things in my mother's presence?” (Shonali, age 29, 13 years post-SCI, paraplegic, Urban, New Delhi)

Access to even basic information was restricted to only those who managed to reach the urban-based SSC. Natasha (age 31, 14 years post-SCI, paraplegic, Urban, Mumbai) and her partner consulted a gynaecologist before marriage to discuss their sexual apprehensions. The gynaecologist explained to her: *“you won’t be able to fully satisfy yourself because of lack of sensations in your genitals. You can however fully satisfy your husband as he is normal. He will experience it (sexual pleasure/orgasm) with you like with a normal [i.e. able-bodied woman] ... pregnancy is possible after SCI”*. The emphasis on women’s limitations of lost genital sensations and inability to experience pleasure needs to be carefully examined in the light of women’s experiences globally, as echoed in this study. Limited understanding of the nuances of pleasure, sexual activity, and disability by medical/rehabilitation specialists, who women with SCI consult, could reinforce the traditional logics that are often rooted in patriarchal ideologies and that further marginalise women’s position in all aspects of their lives.

Discussion

This research presents a picture of sexuality as experienced by women with SCI in India. The results both demonstrate that sexuality and intimate relationships remain important after SCI and draw attention to the wider gaps in sexual information and support needs, making sexual adjustment challenging for women with SCI. From having lived without a disability, women had to suddenly adapt to the changed circumstances for themselves as well as deal with how their families, partners or significant others relate to them.

A lack of timely comprehensive rehabilitation of women with SCI not only complicates the process of physical recovery, social and psychological adjustments to the altered body, but it also affects their sexual and feminine identities. Numerous factors such as the fear of not being able to please one’s partner or not feeling attractive enough for them, and role reversals within relationships (being on the care-receiving end) contributed to feelings of sexual disenfranchisement and loss of self-esteem for many after injury. Negative partner attitudes with limited understanding about women’s functional capacities particularly cause immense distress to women and even lead to dissolution of existing relationships.

Women with SCI are deemed to be damaged people who are perceived as repulsive by able-bodied standards. Since they become incapable of fulfilling normative feminine roles, most women who were married at the time of injury, face unique forms of sexual violence – threats of abandonment and denial of marital rights as provided by the law. Women’s negative self-image, social stigma, and perceived lack of a role, which is further exacerbated by misinformation about their bodies and functional capacities, contribute to their vulnerabilities.

Positive relationship experiences after SCI assumed added significance because they reinstated in women their lost sexual self-esteem, fostering feelings of completeness despite their altered bodies. As women engaged in sexual activity after SCI, they experienced a range of apprehensions, psychological and physical challenges, including fear of bowel/bladder leakages, positioning issues or fears of getting hurt amongst others, as pointed out in this study. In the absence of any sexual information or support, women rediscovered their sexual abilities to experience pleasure, albeit with an altered body, through trial and error. Their experiences shed light on broad conceptualisations of what it means to be “intimate”, beyond the very act of sexual penetration and functional losses after SCI.

The diverse experiences of sexuality that this study reveals add richness to the existing qualitative evidence on sexual self-image and sexuality experiences of women from across global settings.^{10,15,17–19} They lay the foundations to advocate for a need to prioritise and accommodate women’s sexual apprehensions, needs and priorities as an essential component of comprehensive rehabilitation after SCI in India. The voices of women in this study echo the need to create an enabling environment wherein persons with SCI, including women, have access to information and space to articulate their concerns related to sexuality and reproduction.

The research posits that lack of access to comprehensive health care, including rehabilitation services that take gender-sensitive cognisance of the sexuality needs of persons with SCI, is a human rights issue, a fundamental violation of people’s right to health as enshrined in various^{††}

^{††}Article 25.1, Universal Declaration of Human Rights affirms: “Everyone has the right to a standard of living adequate for

international covenants and policy instruments. As humans, our sexuality is inextricably linked to our overall health, happiness, and sense of well-being. To attain the “highest” standard of health, all individuals must first be empowered to exercise choice in their sexual and reproductive lives. They must feel confident and safe in expressing their own sexualities.

Sexual and reproductive rights have been progressively enshrined under various international human rights covenants and policy instruments to which India is a signatory. Specifically in the context of persons with disabilities, India ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2008 and undertook to protect, promote and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity. This includes the right to equality in receiving health care, including SRH care (Article 25)^{‡‡} and access to comprehensive rehabilitation (Article 26)^{§§} to attain maximum independence, full physical, mental, social, and

the health of himself ... necessary social services”. Further, the International Covenant on Economic, Social and Cultural Rights provides the most comprehensive article (12.1) on the right to health. While article 12.2 enumerates, by way of illustration, a number of “steps to be taken by the States ... to achieve the full realisation of this right”. Additionally, the right to health is recognised, *inter alia*, in article 5 (e) (iv) of the International Convention on the Elimination of All Forms of Racial Discrimination of 1965, in articles 11.1 (f), 12 of the Convention on the Elimination of All Forms of Discrimination against Women of 1979 and in article 24 of the Convention on the Rights of the Child of 1989. Several regional human rights instruments also recognise the right to health.

^{‡‡}Article 25: Right to Health: “... persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties ... to ensure access ... including in the area of SRH ... (b) Provide those health services ... including early identification and intervention ... (c) ... as close as possible to people’s own communities, including in rural areas”.

^{§§}Article 26: Habilitation and rehabilitation: “States Parties shall take effective and appropriate measures ... to attain and maintain maximum independence ... full inclusion and participation in all aspects of life. States Parties ... extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health ... (a) Begin at the earliest possible stage, ... (b) ... including in rural areas”.

vocational ability, and full inclusion and participation in all aspects of life. This accords sexual and reproductive rights recognition within a rights-based framework and obligates the State to ensure their protection, promotion and fulfilment as per international human rights standards that demand services to be available, accessible, acceptable and of good quality (AAAQ)^{¶¶}.

Despite the introduction of several programmes and initiatives by the Government of India, such as the enactment of the Rights of Persons with Disabilities Act (2016), disabled sexuality – particularly with persons having SCI – continues to be overlooked in research and political spaces. Given the general silence, the initiative to discuss the sexual concerns of persons with SCI within rehabilitation settings is laudable and accords health professionals the responsibility to actively address sexuality like other physical, psychological and social impacts of SCI, as also supported in research from other settings. This could equip women and their partners/families with information to help them understand their bodies and functional capacities, circumvent the internalisation of body deficit ideas of “sexual inadequacies”, and reinstate in women positive body images and sexual self-esteem. It is extremely important that women with SCI should be quickly reintegrated into their past life patterns with maximum functional independence.

Persons with SCI should be seen as sexual people. Access to SRH services and information could leave the door open for more detailed consultations when women experience specific concerns and informational needs in their unique journeys of sexual adjustment after SCI. Nevertheless, such efforts need to be expanded to be gender-sensitive, guided by lived experiences of sexuality as echoed in this study.

Given the diversity of women’s rehabilitation experiences across settings, this research further calls for national protocols for management, including the rehabilitation of persons with SCI along with setting up more SSC across the country to ensure timely access to comprehensive health care, even to those residing in rural and remote parts of the country. In the absence of a uniform definition of comprehensive rehabilitation across

^{¶¶}General comment No. 22 (2016) on the right to SRH (article 12 of the International Covenant on Economic, Social and Cultural Rights).

facilities and literature, including for India, this study draws attention to the need to deliberate on a comprehensive package of rehabilitation services for India, with gender-sensitive sexual rehabilitation as an integral and mandatory aspect. The rehabilitation*** legislation of the country, which is completely silent on sexuality as a rehabilitation concept and in which the body deficit discourses adopting the medical lens to define disability appear to be ingrained, needs changes.

There are glaring rural-urban disparities in access to rehabilitation services. Equitable access to basic trauma and rehabilitation infrastructure and appropriate referral services is sorely needed in rural India, where the greatest number of India's poor and disabled population are located. There is also an urgent need to sensitise and train health care providers in general by bringing much-needed changes in medical curricula and trainings. Such measures would ensure timely and ongoing access to SRH information and services to many, closer to their own communities. Unless these systemic shortcomings are addressed, and the need to acknowledge women's sexuality after SCI is recognised, the onus of confronting their sexual needs will continue to fall on women (and their families) who will, in the meantime, continue to be treated as less than fully human, and to face stigma and discrimination.

The present study only includes voices of heterosexual women. Future research should examine the sexual experiences of persons with SCI with alternative genders and sexualities, as their experiences also remain unexplored and understudied in the literature on sexuality and disability in India. Sexual rehabilitation is integral to the right to health of persons with SCI. Future research in India should also assess knowledge, attitudes, comfort levels, barriers and perceived training needs of rehabilitation staff in addressing sexuality after SCI.

Conclusion

This study advocates the development of gender-sensitive sexual rehabilitation which (a) acknowledges the diverse sexual needs of women after SCI, (b) educates women, their partners and families about the impacts of SCI on their sexual

capacities and functions, (c) facilitates a form of sexual expression that is acceptable to individuals/couples, (d) offers a spectrum of continued sexuality counselling even when individuals have been discharged and possibly have had options to better understand their sexualities and sexual concerns, (e) provides necessary psychological counselling/support to help women overcome their sexual fears, apprehensions, negative body images, and rebuild positive sexual self-esteem and communication abilities, (f) offers skills training to foster role adaptations, and (g) facilitates increased self-care skills and decreased partner roles, especially with intimate care works. The sexual experiences of women in this study should also be used to expand the conceptualisations of what it means to be sexually intimate and hence acknowledge a greater repertoire of sexual expressions while counselling women.

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No potential conflict of interest was reported by the author(s).

Data availability statement

The authors confirm that the data supporting the findings of this study are available within the article.

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Résumé

Les lésions de la moëlle épinière (LME) sont l'un des handicaps physiques les plus dévastateurs qui aboutissent à plusieurs degrés de perte de sensations et de mobilité au-dessous du niveau de la lésion et qui provoquent une perte des fonctions autonomes, avec par exemple une incontinence urinaire et fécale, et des troubles sexuels. La recherche, principalement menée dans les pays occidentaux développés, révèle que l'acceptation de la sexualité après une LME est cruciale pour une réinsertion rapide dans la société et la qualité de vie des patients. Par conséquent, les experts avancent que la rééducation sexuelle des personnes atteintes d'une LME fait partie intégrante d'une réadaptation complète. Dans le contexte indien, cependant, la sexualité des personnes avec LME, en particulier des femmes, a été largement ignorée par le mouvement de défense des droits des personnes handicapées, ainsi que par les discours sur le genre, la sexualité et la réadaptation. Cet article est fondé sur une étude approfondie des expériences de la sexualité et des relations intimes de 24 femmes atteintes d'une LME en Inde. Il démontre que la sexualité et les relations intimes sont des éléments de la santé et du bien-être des femmes. Mais il existe de vastes lacunes dans les besoins de rééducation sexuelle et de soutien pour les femmes atteintes de LME en Inde, ce qui rend extrêmement problématique leur ajustement sexuel. En analysant le parcours des femmes vers l'ajustement sexuel et la redécouverte du plaisir sexuel et en se faisant l'écho de leur voix comme êtres sexuels, cet article plaide en faveur du développement de services de rééducation sexuelle à base factuelle et sensibles aux différences de genre pour les femmes avec une LME en Inde.

Resumen

La lesión de la médula espinal (LME) es una de las discapacidades físicas más devastadoras, que causa diversos grados de pérdida de sensaciones y movilidad por debajo del nivel de lesión y causa pérdida de funciones autónomas, tales como control de la vejiga o el intestino y deficiencias sexuales. Las investigaciones, en su mayoría realizadas en naciones occidentales desarrolladas, revelan que adaptarse a su sexualidad después de una LME es imperativo para la reintegración temprana en la sociedad y para la calidad de vida de las personas con LME. Por ello, los expertos argumentan que la rehabilitación sexual de las personas con LME es un componente fundamental de la rehabilitación integral. Sin embargo, en el contexto indio, la sexualidad de las personas con LME, en particular las mujeres, casi no ha recibido la atención del movimiento de derechos de personas con discapacidad ni de los discursos sobre género, sexualidad y rehabilitación. Este artículo se basa en un estudio a fondo de las experiencias de sexualidad y relaciones íntimas de 24 mujeres con LME en India. Demuestra que la sexualidad y las relaciones íntimas son aspectos fundamentales de la salud y el bienestar de las mujeres. Pero existen amplias brechas en las necesidades de rehabilitación sexual y apoyo para mujeres con LME en India, por lo cual su ajuste sexual es sumamente difícil. Al analizar las vivencias de las mujeres con el ajuste sexual y el redescubrimiento del placer sexual que hacen eco de sus voces como seres sexuales, este artículo aboga por crear servicios de rehabilitación sexual basados en evidencia y sensibles al género para las mujeres con LME en India.