

Sexual Functioning in Men Living with a Spinal Cord Injury—A Narrative Literature Review

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ABSTRACT

Background: Sexual dysfunction is a major concern for Indian men living with a spinal cord injury

Objectives: To examine the literature related to sexuality traumatic cord injury and its impact on sexual functioning.

Materials and Methods: Databases using Cumulative Index to Nursing and Allied Health Literature (CINAHL) 2000–2012, Medline 1989–2012, Applied Social Sciences Index and Abstracts (ASSIA) 1989–2012 and Google Scholar were the search engines used used for literature review.

Results: The search yielded a total of 457 articles and only 75 of them were found relevant. The minimum number of articles required to meet the inclusion criteria for this review was 25–30 articles. Out of the 75 articles, 33 were considered relevant or related to the topic of sexual functioning, spinal cord injury, and paraplegia. Six areas were identified: Sexual stigmatization, physiological barriers to sexual satisfaction, clinical aspects of sexual functioning, biomedical approaches to sexual dysfunction, partner satisfaction, and lack of accessibility to sexual education.

Conclusion: Spinal cord injury and sexual functioning affects a large segment of the male Indian population, yet most current research focuses on quantitative measurement with the emphasis on ejaculatory dysfunction, orgasm impairment, incontinence, and other physiological dysfunction. Further research is needed to address the subjective accounts of patients themselves with respect to the emotional and social impact of sexual disability. This would help to identify the best possible outcomes for both treatment and rehabilitation.

Key words: Indian men, Qualitative research, Sexuality, Sexual dysfunction, Sexual stigmatization, Spinal cord injury

INTRODUCTION

Annual incidence of paraplegia in India is around 20,000.

^[1] Men who are actively involved in their respective communities find that they not only have to adjust to physical changes resulting from the spinal cord trauma, but also have^[2] to cope with neuropathic pain, sexual dysfunction, incontinence of the bowel and bladder. And lack of self-confidence.^[3] Medical system has viewed

spinal cord trauma mostly in terms of its physical aspects. The neurological dysfunction has major adverse effects on the psychological and social domains of the person, as well as overall quality of life. Common causes of spinal cord trauma are fall from construction sites and trees and road traffic accidents, majority of people affected are young men. And resultant sexual dysfunction could have a major impact on the psychosocial domain.

OBJECTIVES

To examine traumatic literature related to sexuality and spinal cord injury and its impact on sexual functioning. This paper seeks to examine the extent of adequate research on sexual functioning post spinal cord trauma in Indian male population.

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LITERATURE REVIEW

A narrative search of relevant literature in English language was undertaken using these databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL) 2000–2012, Medline 1989–2012, and Applied Social Sciences Index and Abstracts (ASSIA) 1989–2012; and search engine of Google Scholar. The search was undertaken by the two first authors MMS and PHB and reviewed by Dr MRR for any identified discrepancies in the findings. The minimum number of articles required to meet the inclusion criteria for this review were 25–30 articles in order to ensure adequate content for discussion. In the inclusion criteria, articles were limited to English language, Indian male population with sexuality issues, all age groups history of a spinal cord injury with resultant paraplegia. The following key words and phrases were used: Spinal cord injury and sexuality, paraplegia and sexuality, paraplegia and sexual functioning, Indian males and spinal cord injury, Indian males and paraplegia and sexual attitudes, Indian males and sexual functioning and sexual perspectives, male attitudes and spinal cord injury and sexual attitudes, and males and spinal cord injury and sexual functioning. Given the paucity of research exclusively focused on Indian men and sexual functioning the search was widened to include men from countries outside India in addition to the above search terms. The search yielded a total of 457 articles and 311 were excluded after reviewing the title. Seventy-one articles were excluded from the remaining 146, based on the inclusion criteria. In the remaining 75 articles, 68% of which were peer-reviewed; 18% were case studies and 14% were reviews or clinical practice guidelines, for example, systematically developed statements to help patients or practitioners to make decisions. Out of the 75, 33 articles were considered relevant or related to the topic of sexual functioning and spinal cord injury with paraplegia. Of these 33 articles, only 19 were specifically related to male views on sexuality [Figure 1]. Six of these were qualitative studies. No qualitative studies were found specifically addressing sexual views and/or attitudes in Indian men based on first-hand narrative reports.

THEMATIC FINDINGS

- Sexual stigmatization
- Barriers to sexual satisfaction following a spinal cord injury
- Clinical aspects of male sexuality following a spinal cord injury
- Biomedical approaches to sexual dysfunction following a spinal cord injury

- Partner or spousal satisfaction
- Lack of access to education and/or counseling regarding sexuality after spinal cord injury.

Sexual stigmatization

Existing literature often focusses on the social stigma and lack of public education regarding sexual needs of people with a spinal cord injury. Many doctors and caregivers do not respond to patients’ sexual anxieties or concerns and frequently meet them with disregard or even dismissal.^[4]

Traditionally, the sexuality of people with spinal cord injury has not received social acknowledgment and has been stigmatized.^[5] This is due to a lack of public awareness, lack of exposure to the sexual needs of people with paraplegia, and a lack of recognition that the sexual lives of paraplegic patients are important aspects of their overall health. In a recent Canadian study, Esmail *et al.*, (2010)^[6] qualitatively explored attitudes and perceptions towards sexuality with participant groups including service providers, people with visible disabilities, and people with invisible disabilities. The study revealed that “individuals with disabilities are commonly viewed as asexual due to a heteronormative idea of sex and what is considered natural”. This study concluded that societal stigma may influence the person’s self-confidence negatively, reduce the motivation to find a partner and also create a distortion of the person’s sexual self-concept.^[6,7]

An early study conducted in Hong Kong drawing on in-depth interviews with 10 men who had become paraplegic following trauma, focused on sexual adjustment and whether or not these participants had received help

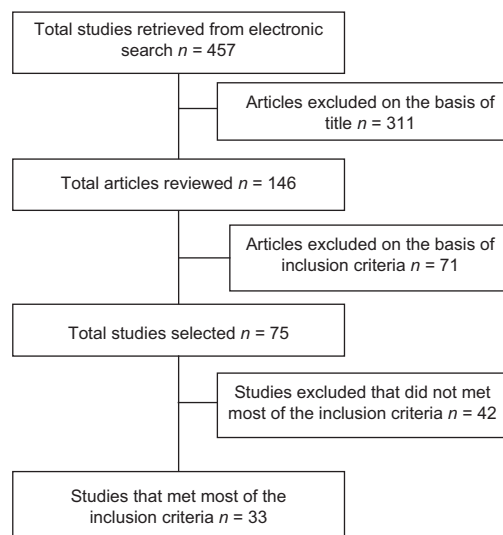


Figure 1: Literature search on sexual functioning and spinal cord injury

from their healthcare providers.^[7] This study concluded that the problems faced by people with paraplegia were similar to those faced by paraplegic populations elsewhere, but were of greater proportion in this study group due to the lack of experienced counseling following the traumatic event. Most of the respondents were seen to be “hampered by an environment which does not accept the sexuality of persons with a physical handicap as a normal and natural occurrence”.

Similarly, in a review of the literature examining the subjective experiences of sexual intimacy for men and women as they pursue preinjury relationships, Ostrander (2009)^[8] identified people to remain sexually active following a spinal cord injury, and the barriers identified were “society’s neutering perspectives, internal oppression, and the loss of physical sensation”. Moreover, “partners who become involved with individuals with a spinal cord injury may also experience social criticism from friends and family”. It has also been reported that men in particular experience significant changes in their sexual functioning following a spinal cord injury. Burns *et al.*, (2008a)^[9] reported that of the 250,000 people in the United States with a spinal cord injury, men constitute roughly 82% of this population. While changes in sexual functioning following a spinal cord injury pose a serious threat to men’s sense of masculinity, little is known about the factors that promote or impede adjustment to these changes.^[10]

In one qualitative study conducted in Greece using unstructured in-depth interviews with six paraplegic men, Sakellariou (2006)^[5] noted that human sexuality has been largely medicalized and reduced to a biomedical component. Participants identified several barriers to a satisfying sexual life, which included social disapproval, lack of employment, inappropriate personal assistance, and a lack of accessibility to others. Overall, these men reported an unsatisfying life with limited chances to express their sexuality. This study identified the need to challenge current societal attitudes including misinformation by the public and prejudice towards the sexuality of people with a spinal cord injury.

Barriers to sexual satisfaction following a spinal cord injury

While there has been broad research emphasis on barriers to sexual satisfaction following spinal cord injury, there has been consistent emphasis on the lack of psychological resources and inadequate knowledge by health providers about the emotional aspects of sexuality.^[11] This is evident even though most men who sustain a spinal cord injury suffer from ejaculatory dysfunction and are infertile.^[12]

In a study assessing the interacting physical, psychological, and social aspects of men using an 86-item questionnaire; it was reported that “patients with spinal cord injury yearn to continue with sexual functions despite physical disability”^[13] and that these patients are in need of peer support, literature, and counseling. This research emphasizes the issue of needing to sustain male pride in sexual ability post injury, as well as problems of shame and emotional distress of not being able to perform sexual functions. Psychological factors such as need to adhere to traditional masculine norms expectation for a man to maintain emotional control and to rely on himself rather than others contribute to physical issues.^[9] These factors impact on men’s masculinity compounded by issues related to lack of employment secondary to the injury.^[5] Similarly, Burns *et al.*, (2009b)^[14] reported that men’s sexual desire is associated with higher rates of depression when sexual prowess as male adherence to masculine norms is observed. Drawing on an internet-based survey with 116 United States men, Burns *et al.* (2009b)^[14] tested the hypothesis that male norms emphasizing sexual prowess may contribute to men’s emotional adjustment towards sexual functioning. The results showed that while men with a strong sexual desire demonstrated higher rates of depression, those men with less sexual desire were likely to show lower rates of depression. This study concluded that adherence to the norms of masculinity or what is considered the sexual norm for the male gender could be representative of an important aspect of men’s identity with respect to this type of physical disability. Literature emphasizing psychological barriers suggest that all aspects must be considered within a holistic perspective and multiple factors must be considered if barriers are to be mitigated. Ricciardi *et al.*, (2007)^[15] in a review of the literature on sexuality and spinal cord injury noted that sexuality must be considered in context of the degree of the injury and also its location. They noted that all aspects of the person must be considered such as age, gender, comorbid medical conditions, and the degree of satisfaction the person has with his sexual partner. These researchers advocate using a holistic developmental team approach to help with psychological issues such as grief related to the injury, self-concept, and problems associated with body image.

It has been suggested that sexual satisfaction may need to be assessed subjectively in men with spinal cord injury rather than objective measurement alone as sexual satisfaction is closely linked to pre injury sexual function status.^[16] Although a few qualitative studies were identified that assessed subjective responses of participants, Basson *et al.*, (2003)^[17] conducted a phenomenological study to

understand the experience of sexuality for men with a spinal cord injury in its total form. This study posed the specific question: “What is it like to experience sexuality post injury as a male with a spinal cord injury?” Through open-ended phenomenological interviews with four men, these researchers identified following emergent themes: Diminished independence and perceptions of masculinity post injury, the loss of and need for intimate contact, including an inability to display intimate physical contact. This study also revealed that religion and certain forms of coping could either help or hinder sexuality post injury, depending on individual’s perspective.

Clinical aspects of male sexuality following a spinal cord injury

There is a strong body of evidence based review of literature outlining clinical aspects of male sexuality and spinal cord injury with respect to anatomical and diagnostic information. This literature focuses on the current state of medical knowledge about sexual functioning in men and is designed as a resource for clinical information. Plausibly, this literature assumes the position that knowledge of neuroanatomy and physiology enables the understanding of sexual dysfunction after a spinal cord injury.^[18] Much of this literature provides helpful neuroanatomical information for the purposes of medical knowledge. The following literature is typical of these reports: There are two control systems situated in the spinal cord associated with erection, namely, parasympathetic and sympathetic nervous systems.^[19,20] The parasympathetic center is in sacral segments S2–S4 and is responsible for reflexogenic erection, which is stimulated by touch in the primary erotogenic areas of skin and mucous membrane. It helps in vasodilatation and opening of arteriovenous anastomoses in the cavernous body of the penis, thereby achieving erection. The sympathetic center is situated in T11–L2 segments of the spinal cord, which is responsible for psychogenic erection, activated by various stimuli from sense organs like eye, ear, nose, and tongue. Stimulation of sympathetic nervous system can lead to partial erection, but not effective for penetration. Ejaculation is under the control of sympathetic, parasympathetic, and somatic nervous system.^[19,20] The person with spinal cord injury goes through different phases of neurological events like spinal shock, reflex return and readjustment, and also various types of erection.^[20] During spinal shock, the genital reflexes are completely abolished or decreased below the level of lesion. When the spinal cord lesion is below L2, the sympathetic nervous system is intact and on stimulation can lead to penile swelling and lengthening without rigidity; but when lesion is above T11, rigidity can be obtained

for penetration. Mixed erection occurs in people with a lesion between L2 and S2. Sometimes a spontaneous erection occurs in men with an upper motor neuron lesion. Elliott (2002)^[21] states that even though ejaculation and orgasm occurs mostly at the same time in men, both are different and orgasm can occur without erection and ejaculation. Anderson *et al.*, (2007a)^[22] indicates that when a genital sensation is present in men with a spinal cord injury, the sexual experience may be more enjoyable. He also describes the formation of new areas of sexual arousal above the level of lesion when genital or anal sensation is absent. This may be due to multiple factors including neuroplasticity and psychological adaptation. In patients with a lesion above or at T6 level, autonomic dysreflexia can occur characterized by sudden severe headache, which may be accompanied by flushing, sweating, and cardiac arrhythmias during sexual arousal.^[20] Bowel and bladder incontinence during sexual activity is also a concern for people with a spinal cord injury even though majority of them may not have these problems.^[23]

Biomedical approaches to sexual dysfunction following a spinal cord injury

While it has been previously argued that psychological aspects such as body image, self-esteem, social aspects, culture, self-image, and a person’s aspirations are all part of the sexual identity of a person;^[24] much of the literature reviewed for this study suggests that human sexuality has been largely medicalized placing a focus on sexual issues as a biomedical disorder requiring clinical intervention. The research focus is frequently placed on quantification of the biological performance aspect of sexual functioning for both men and women. This has led to a lack of interest on the social aspects of this disability.^[5] In one review of the literature on spinal cord injury and sexuality in men, Basson *et al.*, (2003)^[17] found a strong emphasis on research in the physical and medical domains with a significant neglect of the psychological aspect of sexuality in men with spinal cord injury.

Two of the most researched areas of study places a strong emphasis on the clinical management of erectile dysfunction and ejaculatory dysfunction.^[22] These researchers conducted a web survey in order to elicit specific information about sexual function from men with spinal cord injuries. The findings revealed that approximately 80% of the men studied had tried to achieve ejaculation post injury; however, only 47.7% of these men reported ever having achieved it. This study places emphasis on the medical methods used by these subjects in order to achieve erectile functioning. These methods included sildenafil,

penile injections, tadalafil, vardenafil, penile prosthesis, and vacuum device. The findings of this study were that spinal cord injury not only impairs male erectile dysfunction but also changes sexual arousal indicative of neuroplasticity. The researchers call for “more basic science and clinical research” encompassing all aspects of sexual function. In the same vein as in other studies on erectile dysfunction, this study calls for more clinical research rather than any emphasis on the psychological aspects or concerns of the men who had not successfully achieved erectile ability.

In a systematic review of the literature conducted on the physical aspects related to penile erection, ejaculatory dysfunction, semen characteristics, and techniques for enhancement of fertility in spinal cord injured men, Biering-Sorensen and Sonksen (2001),^[20] noted “that impaired semen profiles with low motility are seen in the majority of spinal cord lesioned men. It is suggested that some factors in the seminal plasma and/or disordered the storage of spermatozoa in the seminal vesicles are mainly responsible for impaired semen profiles in men.” This study concluded the need for clinical management of ejaculatory dysfunction in spinal cord lesioned men through penile vibratory stimulation with the recommendation for electroejaculation if the latter method fails. Although, this review plausibly considers the physical aspects of ejaculatory dysfunction there is no indication based on this review that other factors were considered. Similarly, DeForge *et al.*, (2006)^[25] conducted a systematic literature review of sexuality for persons with spinal cord injuries with the objective of reporting on the effectiveness of erectile interventions. These researchers evaluated 2,127 unique reports. Only one area of an alternate approach intervention was revealed in the findings and this focused mostly on behavioral interventions such as biofeedback. The overall results showed that male sexual dysfunction was predominantly addressed through clinical interventions such as topical agents, intraurethral alprostadil, intracavernous injections, vacuum tumescence devices, penile implants, sacral stimulators, and oral medication. These researchers conclude that while these medical interventions could positively affect sexuality as a short-term measure, there is a need for more rigorous study of long-term sexual adjustment and for a more holistic approach in order to understand sexuality for men with a spinal cord injury. The study further concludes that existing research literature is limited and recommends the use of qualitative research in order to provide further clarity on this issue.

Consistently, in other studies there is little emphasis on the psychosocial aspects of erectile dysfunction and what this might mean for men with sustained paraplegia following a

spinal cord injury. For example, Barbonetti *et al.*, (2012)^[26] evaluated psychological distress features in men with a spinal cord injury with or without erectile dysfunction using the Barthel Index and Sexual Health Inventory for men noting that 84% of those men studied exhibited erectile dysfunction. However, even though this study examined psychological distress, the study concluded the need for clinical management of erectile dysfunction rather than recommending any emphasis on a need for sexual counseling, psychological support, or psychosocial sexual rehabilitation post injury.

Dahlberg *et al.*, (2007)^[27] conducted a study which aimed to estimate sexual activity and sexual satisfaction in men in Helsinki with traumatic spinal cord lesion using a structured questionnaire sent to 92 subjects who came for a clinical visit. In the results of this study, 86% of the men experienced sexual desire and 68% had been sexually active in the last 12 months. This study confirmed the researchers’ earlier findings that the ability to reach orgasm is deficient in spinal cord injured men and that the more severe locomotory disability might adversely affect the sex life of persons with tetraplegia compared to those with paraplegia. However, these authors also note that “although (clinical) treatments for ejaculatory dysfunction are effective, the psychological and emotional consequences of spinal cord injury on sexuality require more attention”. The conclusion of this study was that these problems could be minimized by better sexual counseling and collaboration of the patient with their sexual partners. This is one of the few studies that emphasize the psychological factors in sexual functioning in men with a spinal cord injury.

Partner or spousal satisfaction

Few studies dealt with the issue of partner or spousal satisfaction. Phelps *et al.*, (2001)^[28] in a quantitative survey of 482 male veterans with a spinal cord injury aimed to clarify the significance of partner status of these men and to further investigate the importance of relationship factors on sexuality. Within this survey, a sample of 50 men with spinal cord injury who responded were from a large Californian regional spinal cord injury rehabilitation center. The results showed that in men who were married or who had sexual partners, positive factors that influenced sexual satisfaction were presence of partner, ability to please a partner, and knowledge of non-intercourse expressions. This study concluded that married men or those with partners who reported low relationship satisfaction or who had a low sexual desire should be referred for sexual counseling and evaluation for marital dysfunction. These researchers also concluded that “sexual satisfaction behaviour and

enjoyment is not only related to physiological parameters but also strongly associated with quality of the relationship and the partner's sexual satisfaction".

In a review of literature on the effects of spinal cord injury on marital relationships and effects of family on people with spinal cord injury, Young (2003)^[29] found that while spinal cord injury impairs sexual functioning, sexual satisfaction is more dependent on sexual desire, perceived partner satisfaction, and relationship quality rather than the physical factors such as erectile dysfunction, genital sensation, or orgasmic capacity.^[28] In this review it was noted that "while sex is important but is not always necessary for sexual satisfaction or sexual activity.

However, in a recent qualitative study by Angel and Buus (2011),^[30] it was concluded that when the spinal cord injured person's partner is affected, the event causes a major psychosocial and existential crisis for the patient, their partners, and their families.

Lack of accessibility to sexual education and or counseling post spinal cord injury

In a systematic review of studies on multiple aspects of sexual rehabilitation in women with a spinal cord injury from initial recovery to long-term follow up, Lombardi *et al.*, (2010)^[31] found that there are predictable factors in terms of sexual rehabilitation such as age, sexual orientation, and spinal cord injury ideology. These researchers noted that most information from patients is based primarily on questionnaires. It was noted that no paper was found which provided any detailed analysis on the sexual impact of medical and psychological treatments. Among its conclusions, this study reported the need for "personalized programmable interventions" in order to improve sexual rehabilitation services. These researchers concluded that there is a "dearth" of trained health professionals who have sexual health knowledge and competency; and that although the demand is growing for health professional education in knowledge and skills regarding sexual rehabilitation, this area as a discipline does not exist in many countries.

In a review of literature (Ostrander 2009)^[8] examining the subjective experiences of sexual intimacy for men and women with a spinal cord injury, the thematic findings revealed a loss of physical sensation that was present previously as well as an inability to experience sexual pleasure, which in turn affected the male sense of masculinity. These researchers also found that reproductive functioning in men is affected to a greater extent than

for women, that men experience lower sperm counts and decreased sperm motility following a spinal cord injury. It was also found that men experienced physical changes in their sexual activity and sexual interests 6 months after discharge from the hospital. However, in conclusion of these findings it was emphasized that sex therapy and education sessions need to include medical professionals who possess basic competencies in sexuality issues and education for this population.

In other studies conducted in India, sexuality has been emphasized as an important part of the life of a person with a spinal cord injury. Singh and Sharma (2005)^[32] noted the immediate impact on the quality of life of a person with a spinal cord injury in terms of their emotional, physical, and sexual functioning. They state that "dramatic changes in men after a spinal cord injury particularly erectile dysfunctions and infertility has merited more attention in the literature" (than that of women). Other studies from India focussed on the need for improved treatment of the medical complications of spinal cord injury in relation to sexual functioning. Sharma *et al.* (2006)^[13] assessed the physical, psychological, and social aspects on sexual counseling among 86 men and 14 women with a spinal cord injury and concluded the need for improved treatment, sexual counseling, literature information, and peer support. Singh *et al.*, (2002)^[33] reported that patients with paraplegia have a low self-esteem which affects their attitudes towards sexuality and sexual behavior. They noted that unfortunately, both patients as well as doctors did not like to discuss sexual issues at the first instance.

In this review, no qualitative or quantitative studies were identified that specifically addressed first-hand narrative accounts of Indian males in Kerala with respect to their own views and attitudes on sexual functioning following a spinal cord injury.

In summary, this section has identified six broad areas in the research literature as relevant to sexuality and sexual functioning in males with a spinal cord injury and sustained paraplegia. Themes identified were: Sexuality and stigmatization, barriers to sexual satisfaction, clinical aspects of sexuality following a spinal cord injury, medicalization of sexuality following a spinal cord injury, partner or spousal satisfaction, lack of accessibility to sexual counseling following spinal cord injury, and clinical interventions. Few qualitative studies drawing on first hand subjective accounts were identified in either the broader medical literature or literature specific to populations in India. Most research was focused on quantitative survey studies, longitudinal, descriptive studies, and experimental

design with emphasis on biomedical studies relating to ejaculatory dysfunction, orgasm impairment, infertility, and urinary and bowel incontinence as well as other physical manifestations concerned with sexual satisfaction or dysfunction.

CONCLUSION

Despite evidence that spinal cord injury affects a significant segment of the Indian male population and considerable research on the physiological impact related to sexual functioning, the most prevalent finding in this review is the lack of research on first hand perspectives of the patients themselves. There are significant gaps in knowledge on the emotional and social implications for Indian men, especially from their own perspective with respect to sexual functioning. The majority of current research is focused on quantitative measurement of physiological functioning with emphasis on ejaculatory dysfunction, orgasm impairment, urinary and bowel incontinence, and other physiological dysfunction. Further research on how men themselves perceive and view their sexual disabilities on a subjective and personal level would go a long way towards improved education and training programs as well as the planning of adequate treatment and rehabilitation.

LIMITATIONS

The following limitations of the review are identified.

For the inclusion criteria, articles were limited to English language. The review revealed a very small number of studies from India. In future studies, it may be possible to identify additional existing research relating to Indian men and sexual functioning and resources from languages other than English.

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