

# If not the Disability, then what? Barriers to Reclaiming Sexuality Following Spinal Cord Injury

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**Abstract** Human sexuality has been medicalized and largely reduced to its physical components. This has led to a focus on the performative part of sexuality, and to a lack of interest in its social component. Men with spinal cord injury often report an unsatisfying sexual life, with limited chances to express their sexuality. This study shows that sociocultural barriers may be as disabling as physical impairment. The participants of this qualitative study felt that several barriers compromised their right to a satisfying sexual life, including certain social beliefs and attitudes (e.g. social disapproval and exclusive notion of sexuality), lack of employment, inappropriate personal assistance and inaccessibility among others. Impairment per se was not viewed as a barrier, since the new situation assumed status of normality. It is suggested that changes in education as well as the removal of physical barriers may positively influence societal attitudes and make sexuality more “accessible” to disabled people.

**Keywords** Sexuality · Masculinity · Physical impairment · Spinal cord injuries · Social attitudes

## Introduction

Sexual expression is a fundamental right of every individual. However, disabled people are far too often refused masculinity or femininity, among many other things that are taken for granted for the non-physically challenged population [1–4]. For many years disability was defined under a medically oriented approach and was thought of as arising solely from biological causes located within the individual [5].

However, in the last decades the concept of disability is seen under a sociological perspective and is defined as a dynamic, interactive relationship between a person with an

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impairment and his/her surroundings [5, 6]. As Davis put it, “disability is not so much the lack of a sense or the presence of a physical or mental impairment as it is the reception and construction of that difference” (cited in [7]). The emphasis is thus moved from the individual to the social environment [5, 8].

Instrumental in this change of emphasis was the disability rights movement which stemmed out of grassroots organizations during the 1970s and which demanded that the needs of disabled people be respected and met [5]. A major accomplishment of the disability rights movement is that it brought about the mostly influential concept of self determination, which prompted disabled people to take control of their lives and claim their right to sexuality [5].

Notwithstanding these changes in societal beliefs and attitudes impairment may still overshadow every other trait that the individual possesses, so that the person is no longer a person with an impairment but rather a disabled person; disability thus becomes the paramount characteristic, the inescapable social label of the person [1]. This may lead to disabled people being unilaterally excluded from the sexual arena, since sex is perceived as “a privilege of the white, heterosexual, young, single, non-disabled” [4] and physically attractive people [1].

Male sexuality in particular is perceived in an exclusive, phallogentric and oppressive way commonly based on physical performance and this may lead disabled men to feelings of castration and emasculation [9–11]. Instead of acknowledging the continuum of sexuality and sexual practices, of which penile penetration is only a part, society views sex under a narrow and exclusive perspective [2, 11] where penis and its performance assume the leading role [4, 12].

Sexuality however is not based only on physical performance as the emphasis on it strongly implies, but is closely connected with emotional closeness and pleasure, which can be achieved through any of a range of practices [13]. Studies have shown that sexual pleasure correlates more with psychosocial rather than physical factors [14] and that disabled people may view disability as a learning opportunity with regard to sexuality [15–18]. It is a mostly unfortunate fact that the majority of the studies regarding sexuality of men with spinal cord injury have focused solely on issues of fertility and physical function considering them the main constituents of male sexuality [13].

The aim of this paper is to discuss barriers that may compromise the sexuality of men with spinal cord injury. The results stem from a broader study that had as its aim to explore sexuality issues from the perspective of men with spinal cord injury [17, 18]. The research procedures followed are detailed in previous work [18, 19]. In brief, the research received ethical clearance from the Institutional Review Board of Sapporo Medical University, Japan. Data collection was conducted in Greece through unstructured, in-depth interviews with six informants (all of them adult Greek males who had sustained spinal cord injury at least three years prior to data collection), who gave informed consent. Data were analyzed thematically based on phenomenological methodology [20, 21].

## Findings

### Dependency

One of the main male traits is considered to be independency. This is a really ambiguous term and it is doubtful whether anyone can claim total independency, something illustrated by one of Cole’s informants:

I am independent. What does that mean? I often ask that of delegates in a seminar. I say stick your hand up if you traveled here independently today. and everyone puts his or her hands up. Then, I ask how many came by train, and half put their hand up, and I ask, ‘OK, how many of you built the train?’ ([15], p. 227)

The meaning of independency in our society is actually closely connected to the notion of self executed (as opposed to self directed) bodily performance and this often puts men with spinal cord injury in conflict. As John said:

It is an issue that bothers me, when I have to ask a girl to help me with taking off my pants, because manhood is directly associated with having sex, doing as you like, hammering the nail and driving the car.

It is argued that it is not the lack of total physical independency that causes frustration and feelings of unworthiness, but rather the social imperative for bodily performance. As John put it: ‘‘Disability is not so much about being able or not to move your legs as it is about the social reality around you’’.

### *The Spread Phenomenon*

Disabled people in general and men with spinal cord injury in particular may find that their identity as persons is submerged by their identity as disabled. All their personal traits and characteristics, their distinctive features and attitudes are of secondary importance; disability is infinitely magnified and overshadows the person [22]. What matters is the impairment per se and there are accounts of wheelchair users, who say they feel that people usually first see the wheelchair and then the person who sits in it.

This phenomenon is called the spread phenomenon and, as Murphy [10] asserted, it colors most of the interactions between disabled and non-disabled persons. The main reason for this phenomenon is the ambiguous social status of disabled persons. There are no known guidelines and both parties feel like walking on dangerous ground and they are not sure of what should and what should not be said. Impairment represents an anomaly, a distortion of known physical and social rules and therefore disabled persons are aliens to normative society. Even what before the injury was seen as normal, the same thing acquires special significance after the injury and may be connected with the physical impairment. This may lead to feelings of frustration as John recounted:

I still can’t figure it ... what has changed after the accident? The thing is, no girl is hitting on me anymore, so I can’t help thinking that I’m changed, I’m not the same person I used to be; I am though, I am the same, I am still John .... the only thing is, my wings are now trimmed.

It may also be seen as a challenge, according to Alexandros:

I won’t flirt the same way I used to. Now, imagine we go out together and go in a bar ... who do you think everybody is going to stare at? Me, right? And not because I’m super gorgeous or anything but just because I’m sitting in a wheelchair. However, that gets me in a process that I want to challenge other people and draw attention on me and I really do make a point of getting everybody talking with me.

Indeed, the only way to make someone see beyond this aura of disability is to normalize the situation and this can be accomplished by putting the disability out in the front instead of acting as if it was not there. In Pavlos’ words:

Let's not assume that everybody know about our sexuality. To those who I feel they don't know, I explain what it means to me, how I experience it. I do that with every potential sexual partner.

Hahn [1], a psychologist, suggested that "breaking through" may be a necessary process for the formation of meaningful personal relationships.

### *The Body Beautiful*

Although not yet an imperative for men, the notion of the Body Beautiful is steadily gaining ground and men increasingly find themselves surrounded by images of tall, lean and muscular male bodies. The body needn't only be clean, it should have a certain shape as well and conform to the ideals of beauty, unattainable however they are for most people. This may make disabled people resentful of their bodies, as illustrated by one of Morris' informants:

I have my tube-shaped muscle-less legs and swollen ankles; my fat abdomen and my tendency to hunch up in the wheelchair ... YES!! The body beautiful image makes me feel bitter and resentful (cited in [15], p. 150).

Moreover, it may lead to a kind of aesthetic anxiety towards disabled people. By not conforming to ideals of physical appearance men with spinal cord injury represent a violation of the rules, a threat to the popular notion of attractiveness and sexuality. The Body Beautiful is a fairly dangerous concept that may lead to starving diets, unnecessary shopping sprees and feelings of self-pity and can be potentially detrimental to anybody not conforming to it.

### *Social Disapproval*

Disabled people are viewed under a paternalistic prism and considered as child-like and in need of protection, totally void or unworthy of sexual drives and as a result their sexuality is a taboo issue. Therefore, relationships between disabled and non-disabled partners may encounter considerable social resistance [1].

Even if a man with spinal cord injury enters in a sexual relationship, he and his partner are likely to face social disapproval, since it is considered inappropriate for disabled people to be sexual and even more to enter into relationships with non-disabled people [1, 2]. John said:

A girl I was badly in love with, once told me: come on now John, people are staring at us even when we only go out for a cup of coffee ...that was to the effect of: how could you ever fit in my world, how could I present you to my family?

Reasons that are commonly given for the perceived inappropriateness are concerns over parenting, dependency of the disabled partner on the non-disabled and worries regarding the sexual life of the couple. What is quite strange is that while any couple may face these problems, they become an issue when one or both of the partners are disabled and somehow an utterly private issue is transformed into a public one.

Alexandros shared a story, where the brother-in-law of a man with spinal cord injury suggested that his sister should find a lover, since she wouldn't be possibly getting any

sexual satisfaction from her spinal cord injured husband. Social disapproval is rooted in the assumptions and beliefs discussed in the previous paragraphs and is intensified through segregation of disabled people and lack of appropriate sex education.

Lack of socialization stems from societal beliefs about disability and sexuality, and also from physical barriers. John for example, during his studies depended on his parents for transportation, so he could not socialize as much as he wished with his co-students, reducing his chances of meeting a potential partner:

The possibilities for socialization were really limited while at the university. My dad used to drive me to and from classes ... we would hang out (with other students) after class and have a good time and then at a point when they'd say 'lets go have some coffee' I couldn't join them because my dad would come to pick me up.

### *Personal Assistance*

People with tetraplegia often require some kind of personal assistance in order to carry on with their lives. Men with spinal cord injury are increasingly employing paid personal assistants (PA), as in certain cases it may be difficult to ask for assistance from their family. As John said:

Imagine now that I got together with a girl and wanted to sleep with her ... could we possibly manage, unless I have a PA? I have to be put in bed and have my bladder emptied ... I couldn't ask my mother to do that, could I?

While I am with a girl ...

Indeed, asking one's parents for help with positioning in order to engage in sexual activity would not be an option for many people. Personal assistance enables persons to be totally independent and in control of their life. That is, if it is carried out properly. Even if one is receiving what would be considered as respectful and effective personal assistance, finding a PA who can assist with the necessary tasks in order to engage in sexual activity might be challenging.

Requiring personal assistance in order to engage in sexual activity means that at a certain point there will inevitably be more than two persons involved in the process, something highly unusual in Western culture. Sex is something that happens between two people and the presence of a third one at any stage may have an adverse effect [23]. As Shakespeare, Gillespie-Sells and Davies [24] suggested, personal assistance is very useful but should be performed in a very delicate and thoughtful way so as not to embarrass or in any way put in an awkward position the persons involved.

### *Impairment*

Although it is a fact that people with impairments are often disabled by society and not by their physical impairment, renouncing the fact that impairment as such may bear an influence on sexuality would lead to a reverse essentialist approach and to an ultimate negation of impairment. According to Good [25] disease is a "complex and dynamic form of relationship" (p. 167) between the subjective and objective representations of an ailment and a similar analogy also holds truth in the case of disability; sociocultural representations and attitudes interact with the physical impairment to form disability.

Pavlos for example said that although he did not feel that anything had changed, he was restricted as to how many times per week he could have sex, since he was using medication in order to achieve erection:

Apart from things such as standing while making love, my sexuality has remained unaltered. I can make love 3 or 4 times a week and I shouldn't exceed this, since I use drugs to achieve it ... the sensory input is also diminished.

Loss of sensation can also be an issue sometimes. According to Nick:

I surely miss some stuff regarding love and sex ... what I miss more is sensation in my genitalia ... I miss feeling a touch, a kiss, feeling penetration itself ... other than that I don't think I miss anything else.

Moreover, men with spinal cord injury may not be able to enjoy sexual positions or sexual techniques they used to practice before injury. However, the fact that impairment as such does not have all that much to do with sexuality was illustrated by the informants of this study. According to Pavlos: "We can't climb up a ladder but that doesn't mean that we shouldn't have sex ... it's a mind game anyway". Paula, one of Shakespeare, Gillespie-Sells and Davies' informants said:

This waiter that I knew well (...) and he came up to me and said 'You can't, can you ... ?' I said 'Can't what?' ... I knew what he meant, I thought, I'll drag this out a bit, and he said 'well, you can't have sex, can you?' and I said 'You walk while you are having sex? I haven't seen that in the Kama Sutra!' ([24], p. 66).

Concluding, it seems it is not the "how to do it" but the "finding someone to do it with" part that causes the most trouble, as Shakespeare, Gillespie-Sells and Davies suggested [24]. Erectile dysfunction can be resolved with any of a variety of alternative solutions (implants, medication or vacuum pumps among others) and positioning can be negotiated with one's partner. Sensation cannot be usually regained but erogenous zones can be remapped. As Nick said: "Some parts of me have become more sensitive, my bosom for example. My nipples are very, very sensitive to touch ... I feel a bit like a woman when this happens". The disabling societal beliefs and attitudes however prove harder to control.

### *Some Further Concerns*

Financial problems, inadequate sex education and dubious motives for initiation of sexual relationships should all be added to the issues already discussed. Although not a concern for the informants of this study, existing literature suggests that these are all factors that should be taken into account when examining issues of barriers to one's sexuality [24].

Having to live on a social security check may mean that one cannot go out much, thus reducing the chances of meeting potential partners. It may also mean that he has to depend on family members for personal assistance, with all the incurred problems outlined previously in this chapter [11, 24]. Moreover, financial hardship may prevent somebody from getting married and having a family [1]. Dimitris, highlighted the importance of financial resources to being sexual:

My attitude changed when I got my own car, got myself a job, became financially independent ... I could get my girlfriend and go for a ride and go and spend the night at a hotel or some other place ... that was out of the question before becoming independent.

Physical barriers leading to inaccessibility can also be a major problem. If one cannot get out of his house because he lives in a walk-up apartment, or can't use public transportation then his chances of becoming independent and enjoy a satisfying sexual life are dramatically reduced. Nick said that: "It's definitely different—the way I experience a sexual relationship—because I have to plan before I do anything, think about where I will go and whether it's accessible".

Inadequate or inappropriate sex education leads to perpetuation of current societal beliefs regarding sexuality, masculinity and disability. Moreover, lack of education could lead to dangerous sexual practices, unplanned pregnancies or unrealistic expectations. Sex education in Greece has gradually started being introduced in schools during the last years, but not in a consistent way. Pavlos commented that: "There is no kind of sex education, which would provide support to the disabled persons and eliminate current social beliefs".

Finally, disabled people may find that some people are attracted to them not because of who they are but because of their impairment. Men with spinal cord injury may attract persons willing to devote their lives to somebody, wheelchair fetishists or persons of a dominating disposition. Men with spinal cord injury should be wary, without of course going to the other end and being suspicious toward everybody; they need to know whether it is a true interest in them or some other reason that attracts a particular person to them [24].

## Discussion

Men with spinal cord injury often report an unsatisfying sexual life, with limited chances to express their sexuality [22, 26]. While this may be an acknowledged fact, the reasons for it are far from clear. Until quite recently health professionals and the society at large, adopted a strict essentialist approach, where the body and its frailties were to blame for any sexual problems; lack of erection or inability to walk accounted for not meeting sexual partners or not achieving an orgasm. Although this may depict some people's experience, it seems it is not the main reason for the reported sexual problems.

The disability rights movement brought about the notion of a social model of disability, which propagates that it is not the person but rather the society that is the source of disability [5]. We may all be different, but whether our varying characteristics will be disabling or not depends on the social reality around us [27]. In this paper we examined the social processes that lead to an unsatisfying sexual life, without overlooking problems caused by the physical environment or the impairment.

Sexuality is thought of as being universal, automatic and heterosexual [28] and is conceptualized in terms of normality. Consequently, any behavior deviating from the normative sexuality is deemed as abnormal [29]. Masculinity is embodied in one's physical presence and performance, so that body and gender identity become inseparable [30]. The male body is seen under the light of instrumentality and man is predominantly thought of as *homo faber* [31]. Men are expected to be active and strong and physically independent, all of which are cultural expectations from the engendered body, conditional upon physical performance and thus threatened by the arrival of impairment. In a similar vein, Murphy [10] suggested that physicality is destiny rather than possibility and viewed erection as an indispensable element of the "male active lover" role. Moreover, the body beautiful doctrine is increasingly becoming an ordeal for men, who, just as women have for decades now, are bombarded by unrealistic images of the body.

Men with physical impairments may be viewed as castrated and emasculated, unable to engage in the sexual drama. Furthermore, it is not only their penis that has lost its functionality and rendered them emasculated; but more importantly the loss of social power, independency and all the other traits traditionally attributed to the male gender, equals a metaphorical castration. As Murphy said:

After all, being a man does not mean just having a penis, it means having a sexually useful one. Anything less than that is indeed a kind of castration, although I am using this lurid Freudian term primarily as a metaphor for loss of both sexual and social power ([10], p. 96).

It should be pointed out here that this asexualisation process is two-fold; men with spinal cord injury were socialized in a world that favors conformity and non-disability, believing in one and only masculinity and a rigid model of sexuality. They enter the disability arena with a skewed perspective, believing that disabled men either cannot be sexual or if they are, then they cannot possibly have a satisfying sexual life. However, they eventually find out that they do have sexual feelings and so they are torn between a social script that does not bear any resemblance to their life and a personal will that contradicts the social imperative of asexuality.

The incorporation of the dominant societal values regarding sexuality, masculinity and disability can lead to internalized oppression, where disabled people fail to acknowledge the non-conditional nature of sexuality. This is vividly illustrated in the personals section of the Greek Disability Now magazine, where people with a certain impairment are looking for somebody who has a similar one or they specify the range of acceptable impairments. None of the informants of a previous research [18] reported having had a relationship with a person with spinal cord injury or any other impairment and internalized oppression was probably one of the reasons.

No matter how secure they may feel about their manhood, men with spinal cord injury occasionally find themselves in situations where their male status is submerged by the impairment; the “a guy in a wheelchair cannot possibly be a proper man” attitude. One manifestation of this could be the approachability of women who feel it is safe, i.e. there is no imminent sexual threat present, to talk to or go out with men with spinal cord injury. Murphy [10] observed that after becoming paralyzed, women would increasingly talk to him in elevators or smile at him if their eyes happened to meet. This change of attitude though is not necessarily undesirable; for some of the informants the increased approachability of women was welcome. Some others, like Manos, though found it very difficult to be perceived as men and not as disabled:

When a girl sees I have a problem she kind of dumps me. They don't mind being friends with me but I when I try for something more they go saying: 'but, we are so different!'

Similarly, Tepper [3] said that although it was very easy for him to make female friends, the transition from a friendly to a sexual relationship was very difficult to achieve. Shakespeare ([32], p. 148) stated, “in general, the problems of disabled sexuality are not caused by impairment itself but by the way people are viewed and treated”. Indeed, without denying the influence of physical impairment as such on sexuality of men with spinal cord injury, the results of this study suggest that several societal attitudes and metaphors act in disabling ways. These are important factors that should be taken into consideration when examining sexuality of individuals with spinal cord injury.



## Implications for Change

Lack of information can lead to misinformation, prejudice, misconceptions and potentially dangerous behavior. A comprehensive sex education program implemented in schools would be very useful in dispelling myths and teaching the inclusive and non conditional nature of sexuality. This would not only mean that people with impairments would still be viewed as sexual beings but also that the reported internal oppression and feelings of inadequacy that they feel especially in the initial period after the injury would be effectively diminished.

Changes should also be made with regard to personal assistance. According to Shakespeare, Gillespie-Sells and Davies [24], assistance should be exactly that, assistance, and no judgments regarding the nature of assistance required should be made. This would ensure that men with spinal cord injury get the help they need in order to engage in sexual activity, date or otherwise pursue their sexuality. Even in the cases where family members are the primary carers of individuals with impairments, it is suggested that paid personal assistance be available at the client's request. Indeed, as John also experienced, when personal and intimate issues are involved, it may be difficult to ask help from a family member.

Elimination of physical barriers is also believed to be vital in facilitating the expression of sexuality of men with spinal cord injury. It would enable them to go anywhere they wish, without the need for extensive planning beforehand, which may rob spontaneity off a relationship. Enhanced accessibility of the physical environment would also mean that it would be easier for men with spinal cord injury to pursue paid employment out of their houses, something that would not only provide the necessary income to be sexual (dating and grooming do cost money) but would also lead to increased encounters with potential partners.

Important though as all the above suggested measures may be, it is believed that challenging the current disabling societal attitudes is believed to be the single most important step towards a more accepting and enabling living environment for disabled people [33].

## Conclusion

Sexuality has been a taboo for a very long time with reactions toward manifestations of desire ranging anywhere from mere disapproval to imprisonment. Nowadays, in the western world we are proud to say that sexuality is no longer a taboo and expression of sexuality is deemed indispensable to the well-being of the individual.

Several groups of people however would recount different versions of this story. Elderly people, homosexual people and disabled people among others, may find that their sexual needs are not taken into account or are not respected; in other words they are denied one aspect of their personal identity. Reasons vary from political to social and economical and they form a nexus of assumptions, beliefs, barriers, policies and constraints that disable and disempower disabled people and annihilate their right to sexuality. What is more, disabled people themselves, being acculturated with the oppressive ideas of hegemonic masculinity and dominating sexuality, they are led to a form of internal oppression; although they want to be sexual they feel they are not entitled to be sexual.

Men with spinal cord injury however, and disabled people in general, are not inherently asexual, they are asexualized; it is due time they regained their right to being sexual.

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