

THE RIGHT TO PLEASURE OF PEOPLE WITH SPINAL CORD INJURY AND THEIR PARTNERS

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SUMMARY

People with spinal cord injury (SCI) must battle cultural and personal attitudes and stereotypes that reduce sexuality to genitalia's physiological functions. These psychological and social restrictions stem from cultural and models of disability that emphasize phallogentric primacy and the sexual appeal of beautiful bodies when it comes to sexual pleasure. In this paper, we look at the attitudes and stereotypes, conveyed by the medical model of disability, which are based on two widespread and interconnected beliefs (myths): bodily perfection and asexuality. The medical model is based on the normalization of sexual gender roles by male-centered patriarchal culture, which is characterized by unequal relationships between men and women according to the sex most people get to know as totally phallogentric (penis-centered). Finally, we observe the effects of a psychoeducational intervention (Love & Life Project) in a personal growth group on the sexual lives of two groups of people with SCI and their partners in terms of sexual interest and satisfaction, depression, and anxiety. The intervention dramatically increased the possibility and ability of the partner and patient groups to enjoy sexuality, allowing them to experience that "No injury, no matter how serious, can take away your ability to have a relationship, experience love, and experience the attraction between two people."

Key words: spinal cord injury - sexual health - attitudes

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STEREOTYPES AND PREJUDICES AFFECTING ATTITUDES AND SEXUAL LIFE OF PEOPLE WITH SCI

When someone has experienced spinal cord injury (SCI), the first question they often ask is, "Doctor, will I ever walk again?" Soon after - sometimes never verbalized - the thought emerges with equal urgency: "Will I be able to have sex?" This question is not answered easily, although the slogan of the American Consortium for Spinal Cord Medicine (2011) encourages to believe that "No injury, no matter how serious, can take away your ability to have a relationship, experience love, and experience the attraction between two people" (p. 3). People with SCI face many difficulties regaining their self-confidence and ability to experience intimacy and affection (Taleporos & McCabe 2001). These challenges do not just emanate from the genital dysfunction caused by the injury. They also arise because they must rediscover a new way of pleasure to themselves and others by learning to inhabit a body that in many ways is new, dissimilar, and requires a different way of touching, caressing, and exploring themselves and their partner (Hammond & Burns 2009).

In addition to this difficult adjustment to changes, like many other people with disabilities, people with SCI have to battle with their own and societal attitudes and stereotypes that deny individuals with disabilities are sexual beings (Hammond & Burns 2009; Tepper 2005). Such attitudes and stereotypes are the results of two pervasive and interrelated misconceptions (myths), which very often influence human thinking and behavior: bodily perfection (Stone 1995) and asexuality

(Milligan & Neufeldt 2001; Tepper 1999; Thompson et al. 2001; Tremain 1996). These two myths arise from a disability model that is often known as the medical model of disability (Altman 2001; Bickenbach 2012), whereby people are deemed disabled due to their medical condition or impairment (Federici and Meloni 2009; Meloni et al. 2015). Therefore, disability is understood as an individual inability to conform to a standard of normality, namely when the abnormality occurs within the person (Nagi 1964), making them different from most people (Friedman & Owen 2017).

According to this individual/medical disability model, people with SCI have a disability in sexual relations due to the limitation or lack (resulting from the injury) of ability to conduct sexual activity in the manner that is considered normal or ideal (Thomson 1997). Here, the interrelation between bodily perfection and sexual activity is closely and precisely related. Conceiving sexual activity by a person with a disability for a 'normal' population would mean admitting to imagining an abnormal (monstrous) sexuality (O'Toole and Bregante 1992; Tremain 1996).

The myths of bodily perfection and asexuality of disabled people are not merely social constructions that influence attitudes and stereotypes. As universal human convictions (Brown 1991; Ramachandran 2011), canons of body beauty and repulsiveness of an injured body have been evolved to solve long-enduring adaptive problems characteristic of the ancestral human environment (Tooby & Cosmides 1992). Mating with someone who is unhealthy could pose a range of adaptive risks to our ancestors in the Pleistocene, including transmitting communicable diseases or viruses, impacting survival

and reproduction, infecting children and jeopardizing the children's chances of survival and reproduction (Buss 2012, 2016). Hence, human survival was guaranteed by an evolved psychological mechanism to avoid contact and sexual intercourse with persons with visible deformity (Rozin & Todd 2016; Tybur et al. 2013). This theoretical evolutionary hypothesis could explain what emerges today about the relationship between an evolved disease avoidance mechanism and contemporary prejudices that affect individuals with physical disabilities found by Meloni, Federici, and Bracalenti (2012) and Park, Faulkner, and Schaller (2003). This human psychological mechanism and the influence of social stereotypes affect people regardless of their being with a disability or with nondisability. Like the non-disabled, most people with SCI have grown up believing that disability is deviance and that bodily perfection is the standard (Barnartt 2010).

The SCI is almost always a devastating event with many life-changing consequences, all of which require several changes during their post-injury lives (Burns et al. 2008; Taleporos & McCabe 2003). Sexual adjustment to SCI is one of those problems that is closely related to body image (Taleporos & McCabe 2001), general psychological health, overall self-esteem (McCabe et al. 2003; Romeo et al. 1993), and body attractiveness (Kettl et al. 1991; Milligan & Neufeldt 2001).

In a male-centered patriarchal culture (Code 2002) - characterized by unequal relationships between men and women (polarization) and power distribution (androcentrism), and biological essentialism (i.e., sex/gender and roles vary by nature) (Bem 1993) - the sexuality most people get to know is phallocentric (penis-centered). According to Freud (1925/1959), around the age of five, children become aware that they either possess a penis or do not possess a penis and that having a penis is "a proud possession" (Freud 1924/1959, p. 271). Conversely, for women, the absence of a penis makes them "victim to envy for the penis" (Freud 1925/1959, p. 191). For Freud, the recognition that one has or does not have a particular set of genitals is tantamount to recognizing the gender to whom they belong. "I have a penis" means "I am a boy" and "I do not have a penis" means "I am a girl". In this system, the gender identity is a genital (penis-centered) identity. Therefore, the phallocentric view of sexuality (and culture) assumes an apophatic way (i.e., negatively involving knowledge obtained by negation) to know the sex/gender identity. The female is but an absence. In a recent study conducted by Federici and colleagues (2021) to investigate which sexual characteristics (penis/vulva, short/long hair, male/female face, flat chest/breasts, narrow/long hips, body hair/no body hair) are most salient in the cognitive process of sex detection. The participants attributed male gender 86% of the time when the penis was shown, but only the female gender 67% when the vulva was shown. The male external genitalia overshadow any other features that might rather suggest a

female identity. This study has confirmed Kessler and McKenna (1978) already found that the penis makes the difference in sex/gender recognition.

This penis orientation relates to the awareness that having and using erections has something to do with masculinity (Zilbergeld 2013). Therefore, "males are in constant danger of losing their manhood and their identities" (Zilbergeld 2013, p. 20) when the erectile functions are compromised.

Extensive research on erectile functions and male sexuality has largely overlooked the female sexuality of women with SCI (Ferreiro-Velasco et al. 2004; Kettl et al. 1991; Lombardi et al. 2010). This phenomenon is not surprising within Judeo-Christian androcentrism that restricts the sexual role of a woman to a reproductive function within the family and the ability to stimulate and satisfy a man's own sexual appetite (Bem 1993). This view denies women the experience of sexual pleasure (Ranke-Heinemann 1990). Given that SCI neither compromises the receptive function of female sexual organs nor a woman's reproductive capacity (Consortium for Spinal Cord Medicine 2011), the biggest issues for women after SCI is usually focused on the perceived attractiveness of their bodies (Kettl et al. 1991), that is, as a function of male sexuality. In an androcentric, penis-centered sense of sexuality characterizing Judeo-Christian androcentrism, loss of genital sensation does not compromise a woman's sexual role; indeed, the loss of genital sensation of women with SCI would ensure their virginal and chaste role.

Alexander and Rosen (2008) and Komisaruk and Whipple (2011) provided other evidence of a different focus on the sexuality of women with SCI compared to men. Women are oriented to giving rather than receiving pleasure. Given that the sexual role of a woman in patriarchal cultures is restricted to the attractiveness of their body as a function of male sexuality, in a reverse sense, this factor can also be their shame. In fact, a woman's attractiveness is perceived similarly to penis erection, that is, a sexual behavior: When a male finds an attractive body, then sex is allowed because the former is a function of the latter. Golden reported (Golden et al. 2001) that an action by an attractive male-directed toward an unattractive female is more likely to be identified as not harassing. From a recent survey conducted by the Italian National Institute of Statistics (ISTAT (Istituto Nazionale di Statistica) 2019) on stereotypes on gender roles and the social image of sexual violence, the prejudice that blames the woman for their suffered sexual violence still persists. For instance, 23% (without gender differences) believe that women can cause sexual violence with their way of dressing (read, their attractiveness). Therefore, it is not surprising that the main sexual concern of women with SCI is to have a body that is no longer attractive, no longer capable, that is, of giving their partner the 'right' sexual pleasure, and run the risk of deserving violence.

ENHANCING PSYCHOLOGICAL SEXUAL HEALTH OF ITALIAN PEOPLE WITH SCI

Further evidence of how the human psychological mechanism works in recognizing sex differences - to which myths about the sexuality of people with disabilities are a consequence - was provided by Federici and colleagues' (2020; 2019) studies on the sexual behavior of people with SCI. These studies were based on data collected from two interventional studies (Love & Life Project) performed in the Unipolar Spinal Unit of the 'S. Maria della Misericordia' hospital in Perugia (USU-PG) to improve the sexual health of twenty-three in- and outpatients of the USU-PG and their partners.

The three themes that emerged from the qualitative analysis showed that sexuality appeared as closely linked to one's own and others' perception of the functioning and image of the body. A disabled body has disabled sexuality (Shakespeare 2000). It was also clear from the qualitative analysis that stereotypes did not only concern nondisabled people toward patients with SCI; they also affected the patients themselves ("I was the first one to call myself asexual or disabled") (Hammond & Burns 2009; Tepper 2005).

CONCLUSIONS

"Now is the time for action concerning sexual and reproductive health of persons with disabilities" (WHO, 2009, p. 1). We make this World Health Organization's statement our own, acknowledging the right of every individual to sexual pleasure, whatever their physical and psychological condition. Furthermore, we believe that there is no sexuality "of" the people with disability as if their psychological architecture was distinct from any other human being. Man or woman, healthy or sick, disabled or not, with disability or nondisability must come to terms with their own sexuality, which clashes with cultural myths and evolved psychological mechanisms that often thwart the achievement of sexual pleasure and health. "No injury, no matter how serious, can take away your ability to have a relationship, experience love, and experience the attraction between two people" (Consortium for Spinal Cord Medicine 2011).

Acknowledgements: None.

Conflict of interest: None to declare.

Contribution of individual authors:

All Authors have worked together and contributed equally to this manuscript.

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