

Short Communication

No More Sex for You, Only for Men: Inequality in Right to Enjoy Sexuality for Women with Spinal Cord Injury

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Abstract

According to the medical model of disability (as explained also in the ICF), conceiving sexual activity by a person with a disability for a “normal body” population would mean admitting imagining an abnormal (monstrous) sexuality. It follows from this that “abled” people see the person with physical impairment as asexual, because their body condition affects the capacity to perform so-called normal sexual activity. These beliefs and attitudes inform the lives of people with spinal cord injury (SCI). However, these social barriers do not affect men and women with disabilities equally. More often than men, women with SCI's experience of sexual pleasure is neglected if not outright denied. Through reading the case of “She” and from a perspective of the right to pleasure of women with SCI, we reread data about the Love & Life project, which was carried out to enhance the psychological sexual health in a Unipolar Spinal Unit of in- and outpatients and their partners. The two studies reported here showed that men and women with SCI have experienced restriction to their right to sexual pleasure to varying degrees: women more than men are deprived of their right to enjoy their sexuality.

ABBREVIATIONS

BAI: Beck Anxiety Inventory; BDI-II: Beck Depression Inventory – II; ICF: International Classification of Functioning, Disability and Health; L&L: Love & Life project; SCI: Spinal Cord Injury; SIS: Sexual Interest and Satisfaction; USU-PG: Unipolar Spinal Unit of the “S. Maria della Misericordia” hospital in Perugia

INTRODUCTION

She was in her 30s when “She” was admitted to the neurosurgery unit due to an accident with her motorcycle. She felt no pain, but did feel fear! Just before She was anesthetized, the neurosurgeon told her, “And now, forget about having sex anymore” [1]. How much truth there was in those words of that distinguished male representative of a medical model of health, sexuality, and patriarchal, phallogocentric (penis-centered) culture [2]. According to this model and culture, “abled” people see the person with physical impairment as asexual because their body condition affects the capacity to perform so-called normal sexual activity. For a “normal body” population, conceiving sexual activity by a person with a disability would mean admitting to imagining an abnormal (monstrous) sexuality [3,4]. It should not surprise us, then, that from the perspective of a medical model of disability, psychiatry has a specific term for the sexual attraction to the body of a person with a disability: devotism [5]. This is a paraphilia, i.e. not a normal way to love; it is a suspect and, to a certain extent, pathological sexual attraction for *ab-normal*

bodies, according to the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition [6].

The myths of bodily perfection [7] and the asexuality [8] of disabled persons—emerging from a medical model of disability and sexuality—are not mere social constructions which influence attitudes and stereotypes. These myths emerge from psychological mechanisms that evolved to solve long-enduring adaptive problems characteristic of the ancestral human environment [9]. Mating with someone who is unhealthy could pose a range of adaptive risks to our ancestors, including transmitting communicable diseases or viruses, impacting survival and reproduction, infecting children and jeopardizing the children's chances of survival and reproduction [10,11]. Hence, human survival was guaranteed by an evolved psychological mechanism to avoid contact and sexual intercourse with persons with visible deformity [12-15].

But She was a woman, in a male-centered patriarchal culture [16], where the sex most people get to know is totally phallogocentric. As a result of the 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—the woman's experience of sexual pleasure is denied [17]. Women are, therefore, oriented to giving rather than receiving pleasure. Still, in a survey conducted in the United Kingdom, Thrussell et al. [18], in accordance with previous literature [19], reaffirm that for women with SCI

“satisfaction with body image was reduced. To look ‘sexy’ was difficult [...]. Lacking confidence and feeling sexually unattractive during rehabilitation was common; support and opportunities to improve self-confidence, self-esteem, body image and social skills were identified as essential” (pp. 1088–1091).

But what is more She was a lesbian, and as such, her sexual identity would disappear along with her sensitivity and mobility in her limbs.

“Non-disabled persons generally regard disabled persons as asexual beings. Although this falsehood degrades all disabled persons, it has especially humiliating effects upon disabled dykes. The reason it does so is this: if one assumes that disabled persons are asexual, then one cannot conceive the *existence* of disabled dykes. That is to say, if disabled persons are regarded as asexual beings, and if dyke identities are *sexual* identities, then disabled dyke identities are a conceptual impossibility (do not exist). Apparently, the category of ‘disabled person,’ and the category of ‘dyke,’ are mutually exclusive ones: one is either a(n) (asexual) disabled person, or one is a (sexual) dyke.” ([3], pp. 15–16, emphases used above are in the original).

She was a participant in the Love & Life project (L&L), which was carried out to enhance the psychological sexual health of the in- and outpatients of Unipolar Spinal Unit of the “S. Maria della Misericordia” hospital in Perugia (USU-PG) and their partners, before the COVID-19 outbreak. By forming a psychoeducational personal growth group, L&L promoted a pathway in which people with SCI and their partners could experience, express, and rework thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, roles and relationships about sexuality [20]. She shared her experience as a woman, a lesbian with SCI, within the growth group in which she participated with her partner.

The aim of this paper is to reread data about the L&L from the perspective of the right to pleasure of women with SCI [21].

MATERIALS AND METHODS

Study 1

PARTICIPANTS: The inclusion criteria for attending the L&L personal growth group on sexual life were the folloAge ≥ 18 years;

- Provide voluntary written informed consent;
- USU-PG in- and outpatients with a traumatic SCI (para- or tetraplegic), with or without a partner;
- Current partner (wife, husband, sexual partner) of in- and outpatients of USU-PG who attended the Love & Life personal growth group.

I use “participants” (Study 1: $N = 11$; Study 2: $N = 7$) to refer to all those who attended the growth group on sexual life and “patients” (Study 1: $N = 7$; Study 2: $N = 6$) to refer to both inpatients and outpatients.

MEASUREMENTS AND PROCEDURES: A sociodemographic questionnaire and three outcome measures were self-administered (see below) by participants during the recruitment process. The outcome measures were administered again at the end of the last group meeting.

Sociodemographic questionnaire. This form was developed ad hoc to collect data on participants’ age, sex, sexual orientation, type of SCI (para- or tetraplegia), civil status, children, education, employment, citizenship, political orientation, and religious beliefs.

Sexual Interest and Satisfaction (SIS) scale. This measure is a six-item scale designed to measure sexual adjustment after SCI [22]. It is used to assess interest in and satisfaction with sexuality before and after injury. Participants are asked to give answers on a scale of 0 (nonexistent/very dissatisfying) to 3 (increased/very satisfying).

Beck Depression Inventory – II (BDI-II). In its current version, the BDI-II is a 21-question multiple-choice self-report inventory [23]. Scores for statements ranged from 0 (e.g., “I do not feel sad”) to 3 (e.g., “I am so sad or unhappy that I can’t stand it”). Higher total scores indicate more severe depressive symptoms.

Beck Anxiety Inventory (BAI). This measure was designed to differentiate anxiety from depression [24, 25]. Respondents rated each symptom on a scale ranging from “not at all” (0) to “severely” (3). Higher total scores indicate more severe anxiety symptoms.

RESULTS OF STUDY 1: Sample. Eleven participants (female: $N = 6, 54.5\%$; male: $N = 5, 45.5\%$), 4 males had complete paraplegia, 1 female had complete tetraplegia, and 1 female and male each had incomplete paraplegia. All of them were outpatients during the group activity. For all participants, the cause of SCI was traumatic (years from injury: $M = 38.1$; min = 26; max = 50; $SD = 9.44$). All four partners of the participants with SCI were females. The 11 group participants included 4 couples (8 individuals). One female participant with SCI reported not having a romantic or sexual partner.

Outcome measures. All participants ($N = 11$) improved significantly on SIS Scale item 5 (“What opportunity and ability do you have to enjoy sexuality yourself?”; $z = -3$; $p < 0.01$), SIS Scale total score ($z = -2.53$; $p < 0.05$), and BAI scores ($z = -1.99$; $p < 0.05$). The effect size was high in all cases ($r = 0.90$, $r = 0.76$, and $r = 0.60$, respectively). There was no difference in the scores for the SIS general satisfaction after injury or BDI.

A significant effect was found on SIS scale item 5 (“What opportunity and ability do you have to enjoy sexuality yourself?”) for both patients ($N = 7$; $z = -2.24$; $p < 0.05$) and partners ($N = 4$; $z = -2$; $p < 0.05$) with a high effect size ($r = 0.84$ and $r = 1$, respectively). There were no effects for the total score or general satisfaction after injury for the SIS scale, BDI-II, or BAI. Further, there were no significant differences between sexes or patients and partners. See [1] for more details on the pilot data of Study 1.

Study 2

In this second study, our purpose with respect to the Study 1 was to also collect data for a qualitative analysis of participant dialogues. Recruitment procedures and eligibility criteria, measurements and procedures were the same as in Study 1. A Sony ICD-PX312 audio-recorder was added to record the dialogues of each meeting.

RESULTS OF STUDY 2: Sample. Seven participants (female:

$N = 1$); 2 males had complete paraplegia, 2 males had complete tetraplegia, 1 male had incomplete paraplegia, and 1 male had incomplete tetraplegia. Five of them were outpatients during the group activity. For 5, the cause of SCI was traumatic (years from injury: $M = 8$; $\min = 0.75$; $\max = 11$; $SD = 3.03$). The participating female was the partner of a male with SCI, the only couple in the group. Three male participants with SCI reported not having a romantic or sexual partner.

Outcome measures. Although not significant, there was an increase in the raw values for all participants ($N = 7$) on SIS Scale item 5 (“What opportunity and ability do you have to enjoy sexuality yourself?”; $M = 1.29$ to 3.57), SIS Scale total score ($M = 10.86$ to 13.14), and SIS Scale general satisfaction after injury score ($M = -1.57$ to -2). The effect size was medium in all cases ($r = 0.36$, $r = 0.46$, and $r = 0.60$, respectively). There were no significant differences in the scores for BDI-II and BAI and between genders or patients and partners.

Qualitative analysis assisted by Atlas.ti 8. The software was used to process all participants’ on the base of the grounded theory [26]. Three main themes were identified, supported by seven categories: (1) disabled sexuality (e.g., “I don’t know how your body can react to my caress, it’s not like before”); (2) influences of family and social environment (e.g., “I’ve seen them look at me differently”); and (3) effects of psychoeducational intervention (e.g., “I have discovered that sexuality is not only physical, but there is also the more satisfying aspect, which is, really, that which goes beyond the physical part”). These three themes can be assumed to represent three stages of the same process—each one inextricably influenced by the others—and resulting in the ultimate purpose of the intervention, namely to achieve sexual health after SCI. See [27] for more details of the qualitative data analysis.

Limitations of the studies

Future research might overcome some limitations of the present studies. These include, for example, increasing the sample size, given that the sample of participants observed in the present studies prevents us from generalizing the results as representative of the Italian population of SCI. In addition, a randomized controlled trial might reduce bias when evaluating psychoeducational intervention.

As the reader may have noticed, several references provided are over 10 years old some up to 20 years old. Although scientific research has never stopped conducting research on the topics of this article, some of which very recent (such as those conducted by the author), nevertheless, the main concepts underlying patriarchal culture and androcentrism concerning sexuality and disability have not substantially changed despite the sexual revolution of the 1960s and the feminist movement [28]. Therefore, I have preferred to cite the “classics” of literature relevant to our topic.

CONCLUSION

“She” opened this paper, casting a glance at a woman who, behind the expressed question, “Doctor, will I ever walk again?” hid an untold and censored one, “Will I be able to have sex?” There is no place for sexual pleasure when She is forced

to give thanks for a life that has been given back to her but no longer contemplates sexual health. A disabled body has disabled sexuality [29]. But what was surprising was not so much the well-known condition of a woman with an (unattractive) body as much as that of males with SCI. They were affected, indeed they themselves possessed the same attitudes and stereotypes towards themselves that emerge from the medical model and the patriarchal culture [30]. Having erectile dysfunction and inhibited ejaculation, loss of sensation and physical impairment meant that their sex life is over [31]. In a phallogocentric world, a man with SCI is a half-man [32]. The male participants in two growth groups were reluctant to even imagine the possibility of talking about an (psychological) orgasm or talking about masturbation, as their penises were no longer sensitive and were turgid. The myth of the bodily perfection and the “fucking ideology” [29] in the path of L&L hit males and females indiscriminately, accumulating both in the disabled category, as abnormal, depriving them equally of the right to pleasure.

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