

09 - THE SEXUALITY EXPERIENCE IN THE CONCEPTION OF SUBJECTS WITH SPINAL CORD INJURY

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INTRDUCTION

The annual worldwide incidence of spinal cord injury varies, for example in Portugal that has increased rates, with 57.8 / 1000, followed by Brazil remaining with high rates of 50/000 and with lower incidence in China, with 8.4 / 000 inhabitants, not considering deaths from this cause (Kirshblum, et al., 2011). In Brazil, it is estimated that more than 10,000 new cases of spinal cord injury occur every year in the country, with trauma being one of the main causes, which represents a very high incidence when compared to other countries (BRAZIL, 2012). The health problems associated with the consequences of the medullar lesion, acute and chronic, routinely involve multiple organ systems such as genitourinary, gastrointestinal, respiratory, epithelial, cardiovascular, autonomic nervous, neuromuscular as well as psychosocial, among which we will emphasize this to the damages caused to the sexuality of people with SCI (BRASIL, 2012).

The sexuality of people with spinal cord injury is maintained silent or in the invisibility of the discussions and practices of the modern world, so that social labels involving sexuality are established in view of the knowledge of the motor and sensory impairment that people with SCI have. In this way, Dall'alba (2004) says that people with physical disabilities have been marked by prejudice, marginalization and exclusion. The myths still present in society configure the ways in which a large part of the population is related to the different body configuration. In this context, the sexuality of these people is denied as a possibility, and sometimes it is not even addressed by health professionals.

Therefore, this study started from the assumption that, although there is a predominant meaning of "labels" that involve the sexuality of people with spinal cord injury, and regardless much the sexuality of these people is hidden, they are not asexual beings. Thus, society has no right to appropriate social definitions related to the meanings of the desirable body pattern to inhibit the expressions of sexuality.

For the reasons outlined above, it was intended to evaluate the sexual being conception of people with spinal cord injury.

METHODS

It was conducted a descriptive cross - sectional study. The sampling plan was used by reference chain, with a sample of 25 people with disabilities or permanent mobility restrictions. The inclusion criteria were: subjects of both genders, young and adults aged between 18-60 years, paraplegic with complete or incomplete spinal cord injury, independently of the injury time, related or not to the selected institutions that were willing to participate in the study. The study was developed in five institutions of support for people with disabilities in the city of João Pessoa. Data were collected in 2012, from April to July. Three instruments were used: I (Socioeconomic and Clinical Profile of Subjects), II International Classification of Functioning, Disability and Health: (Body Structure, Body Function and Activity and Participation) and III (Practice and Sexual Satisfaction), which were applied in a way of interview by the researcher. Specifically during instrument III application, it was used a small recorder, that provided the later transcription and analysis of the speeches. To guarantee anonymity and omit the subjects' true names, the recordings were identified using names of Gods (as) from the Greco-Roman mythology. It was also constructed a field diary, used as an observation recording instrument that was performed at the time of the interviews. For the data analysis of the semi-structured interviews of the third instrument, we created grids of interpretation from which the following analytical categories were defined: body concept and sexuality. The key informants were previously clarified about the research purpose. After the authorization for interview recording, they signed informed consent form, considering the ethical aspects related to human research recommended in resolution n. 196/1996 of the National Health Council of the Ministry of Health. The project was analyzed and approved by the Ethics Committee of Universidade Federal da Paraíba, according to decision No. 0178/12.

RESULTS AND DISCUSSION

Among people who were interviewed, 68% were men and the majority were between 25 and 40 years old; 92% are retired or receiving help and 44% have completed high school. Most of the interviewees (56%) are of black or brown race and predominantly Catholic or Evangelical / Protestant religion (88%).

For the purpose construction of this text, the categories body and sexuality will be considered. It is observed that people with spinal cord injury when questioned about their sexuality mention the concept of sexuality in its magnitude, highlighting two subcategories: sex and sexual practice.

(...) is active and nowadays I'm looking for ..., and it's getting more intense, that, the feeling is getting deeper, it's a different feeling, it's something that I can not explain because it's not a touch feel (ivy).

(...) So one day at home in bed I reached to fuck and she questioned why? You said you could not? And we managed to make it complete and I was feeling the super man (laugh) (Bacchus). (...)

If it is for me today, I would have intercourse relationship every day (Dionizio).

It is found that the subjects interviewed refer to the experience of sexuality by limiting its concept to the sexual act, fact that was observed in the undertones of the discourse, where it is clear the need to socially expose the possibility of the sexual

practice of people with SCI, since this is pointed socially as an impossible act. In this scope, it is verified that the speeches revere a possible and enjoyable sexual practice, which is unanimous among all the subjects interviewed, this way they socially explain that they are sexual beings and that sexuality is considered in their lives as a dynamic process and a right of all, although socially subjugated.

The conception previously expressed by the subjects confirms the social conception of sexuality, which means only the practice of sexual intercourse, associated with the fact that people with physical disabilities (PD) may have important functions for the sexual act. However, as Salimeni (1995) stresses, it is not necessarily the physical disability or spinal cord injury that make it impossible to manifest sexuality in its wider concept. This study aims to prove that people with spinal cord injury has an active sexuality, even when under evaluated, if observing only the sexual practice.

Previous studies such as *Feliz Ano Velho* by Paiva (1982) and *Minha Profissão é Andar* by Pecci (1980), bring experience reports that also overturn the thesis of the impossibility on exercising sexuality in people with physical disabilities, as well as demonstrate that they are capable of exercising sexuality, with the appropriate adaptations on the part of them and their partners. This way, people with physical disabilities are able to perform sexual acts and show that their sexuality has always been preserved. A study with men with complete spinal cord injury, conducted by Ishibashi, Oliveira and Costa (2005), revealed that 89% of the study participants reported that they continue to have sexual relations with their partners, corroborating that the person's adaptations allows the exercise of their sexuality even when living with some kind of physical disability.

The expanded understanding of sexuality makes it possible to put close the concept of sexuality defined by Merleau-Ponty (1999) which states that sexuality is an original intentionality that concerns vitality. The interviewees' speech illustrates this conception by focusing on social determinants of the sexuality experience, such as difficulty, prejudice, health problems, and bodily changes, among others; that were arranged into two subcategories - bodily and emotional changes, as these excerpts illustrate:

(...) is that sometimes I do not have the sensitivity in the legs, I think that sometimes the legs are going to break, the fear, right, of breaking because one day I may need it (...) (Demeter).

(...) and I spent some time lamenting myself, wondering if I was going to be me, if I still would be attracted to someone else, being charming in the case ... (Dione)

One of the passage we have quoted above refers to the reflection of the problem experienced by the study participants. People who, after a fatality, see a different body from the one constructed throughout their whole life history, but which, motivated by several signifiers such as God, children, wife and friends, begin to elaborate a new conception of self, and of his/her body. Ravagni (2007) on his PhD thesis, entitled "O que é sexualidade humana?" stated that the body carries with it feelings, sensations and emotions built from the experience and that these are explained in the gestures, attitudes and postures that each subject adopts, according to your personal way of being in the world.

In this regard, it is evident the difficulty found by the participants in the construction of a new body history, since these bodies historically served to express their sensuality and sexuality.

Another affected functional capacity is the emotional one, since the changes in emotional functions are common and result from the circumstances and changes in the life of these people. Venturini, Decésaro and Marcon (2007: 590) argue that "the loss of the healthy condition, roles and responsibilities causes changes in the individual's habits and lifestyle, and requires that they attribute new meanings to their existence, adapting to physical restrictions and new conditions." All these changes associated with possible emotional disturbances, interfere both in the rehabilitation process and in other aspects, including sexuality.

This investigation is in accordance with the study by Fischer et al. (2002), which says that emotional stress, low self-esteem, and feelings of inadequacy complicate intimate relationships, but these emotional aspects do not interfere in the interest and need of the person with spinal cord injury to express their sexuality.

In short, this study is in line with an interesting and current statement, described by Merleau-Ponty (1999, 122), which points out that the body as being "the vehicle of being in the world, and having a body it is, to a living being, to join a defined medium, be confused with certain projects and continually engage in them". Thus, what stands out is that people with spinal cord injury actually "wake up" after a "tragedy" with a difference in their vehicle and with an impairment in very important functions, causing a huge transformation in their lives. So, these people have to accept and know this new vehicle so they can give continuity to their lives. This different body has changed in its image, so that they confer the presence of stigmas facing the new reality.

CONCLUSION

The sexuality conception present in the discourse and practice of the interviewees is restricted because it is still limited to the sexual act itself. However, it is observed that they are looking to reinvent themselves, rediscovering their body, seeking knowledge about the subject and extending this concept according to their new reality.

Another issue that deserves attention is the difficulty of people to deal with the transformations in their body image, as well as with the functional limitations of this new body that came up after a fatality, and they have to rediscover themselves with this point of creating a new corporal history. This process of body discovery attends with emotional stress, low self-esteem and a sense of nonconformity, in order to affect the sexuality of these subjects; but not to the point that they deny this sexuality, since they continue to experience different forms of experiencing their sexuality, as was emphasized in the speeches presented.

This research has limitations due to the fact that only a small sample has been studied, emphasizing the need for new studies at the national level, so that it can boost the development of public policies aimed at the attention of people with spinal cord injury.

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THE SEXUALITY EXPERIENCE IN THE CONCEPTION OF SUBJECTS WITH SPINAL CORD INJURY ABSTRACT

The sexuality of people with spinal cord injury is maintained silent or in the invisibility of the discussions and practices of the modern world, so that social labels involving sexuality are established in view of the knowledge of the motor and sensory impairment that people with SCI have. Goal. To evaluate the impact of the spinal cord injury (SCI) under the people's sexuality experience with spinal cord injury. Methods: This is a descriptive cross-sectional study with a qualitative approach. The research scenarios were public and philanthropic rehabilitation institutions in the city of João Pessoa-PB, in which participated 25 young people and adults who suffered spinal cord injury and accepted to participate in the study. Data were collected in 2012, from April to July. Three instruments were used: I (Socioeconomic and Clinical Profile of Subjects), II International Classification of Functioning, Disability and Health: (Body Structure, Body Function and Activity and Participation) and III (Practice and Sexual Satisfaction), which were applied in a way of interview by the researcher, as well as it was constructed a field diary. The interviews and the field diary were analyzed based on the discourse analysis method. The categories of analysis were: conceptions of body and sexuality. Results and discussions: It was noticed that the interviewees had a limited concept of sexuality, which directly influences their conception. However, it is observed that they can overcome their body and sexuality conceptions, reinventing themselves to experience their sexuality in a satisfactory way with indications that this is a daily challenge experienced in a particular way.

Keywords: Body, Sexuality and spinal cord injury.

L'EXPÉRIENCE DE LA SEXUALITÉ À L'AVIS DES SUJETS AVEC LÉSION MÉDULLAIRE RÉSUMÉ

La sexualité des personnes souffrant de lésion médullaire (LM) demeure en silence ou dans l'invisibilité des discussions et pratiques du monde contemporain, de façon que les labels sociaux par rapport à la sexualité sont établis face à la connaissance de la détérioration motrice et sensitive des personnes souffrant de LM. Objectif. Évaluer l'impact de la lésion médullaire (LM) dans l'expérience de la sexualité des personnes souffrant de lésion médullaire. Méthodes. Il s'agit d'une étude descriptive avec une approche qualitative. Les champs de recherche ont été des institutions publiques et philanthropiques de réhabilitation, adressées dans la ville de João Pessoa-PB, avec la participation de 25 jeunes et adultes souffrant de lésion médullaire et qui ont accepté à participer de l'étude. La saisie des données a utilisé trois instruments (I – Profil socioéconomique et clinique des sujets ; II – CIF : Structure du corps, Fonction du corps et Activité et participation ; e III – Pratique et satisfaction sexuelle) lesquels ont été appliqués sous forme d'interview par la chercheuse ; aussi on a élaboré un journal de terrain. On a analysé les interviews et le journal de terrain fondés sur la méthode de l'analyse de discours. Les catégories d'analyse ont été : conceptions de corps et de sexualité. Résultats et discussions. On note que les interviewés avaient un concept limité de la sexualité, ce qui influence directement leur avis. Cependant, on a observé qu'ils réussissent à surmonter leurs conceptions de corps et sexualité, en se réinventant pour qu'ils puissent vivre leur sexualité d'une façon satisfaisante ; on a noté des indices qu'il s'agit d'un défi quotidien vécu de mode particulier.

Mots-clés : Sexualité ; Lésion médullaire et corps.

LA VIVENCIA DE LA SEXUALIDAD EN LA CONCEPCIÓN DE SUJETOS CON LESIÓN MEDULAR RESUMEN

La sexualidad de las personas con lesión medular (LM) es mantenida de forma silenciosa o en la invisibilidad de las discusiones y prácticas del mundo contemporáneo, de forma que los rótulos sociales que envuelven la sexualidad se establecen en vista del conocimiento del compromiso motor y sensitivo que las personas con LM poseen. Objetivo. Evaluar la repercusión de la lesión medular (LM) bajo la vivencia de la sexualidad de las personas con lesión medular. Métodos: Se trata de un estudio descriptivo de abordaje cualitativo. Los escenarios de la investigación fueron instituciones públicas y filantrópicas de rehabilitación, ubicadas en la ciudad de João Pessoa-PB, con la participación de 25 jóvenes y adultos que sufrieron lesión medular y aceptaron participar del estudio. Los datos fueron recolectados utilizando tres instrumentos: I (Perfil Socioeconómico y Clínico de los Sujetos), II (CIF: Estructura del cuerpo, Función del Cuerpo y Actividad y Participación) y III (Práctica y la Satisfacción sexual), que fueron aplicados bajo la forma de una encuesta por la investigadora, así como fue construido un diario de campo. Las entrevistas y el diario de campo se analizaron con base en el método de análisis de discurso. Las categorías de análisis fueron: concepciones de cuerpo y de sexualidad. Resultados y discusiones: Se percibió que los encuestados tenían un concepto limitado de sexualidad, lo que influye directamente en su concepción. Sin embargo, se observó que los mismos logran superar sus concepciones de cuerpo y sexualidad, reinventándose para vivir su sexualidad de forma satisfactoria con indicios de que éste es un reto diario vivido de forma particular.

Descriptores: Sexualidad, Lesión medular, Cuerpo.

**AVIVÊNCIA DA SEXUALIDADE NA CONCEPÇÃO DE SUJEITOS COM LESÃO MEDULAR
RESUMO**

A sexualidade das pessoas com lesão medular (LM) é mantida de forma silenciosa ou na invisibilidade das discussões e práticas do mundo contemporâneo, de forma que os rótulos sociais que envolvem a sexualidade são estabelecidos em face do conhecimento do comprometimento motor e sensitivo que as pessoas com LM possuem. Objetivo. Avaliar a repercussão da lesão medular (LM) sob a vivência da sexualidade das pessoas com lesão medular. Métodos: Trata-se de um estudo descritivo de abordagem qualitativa. Os cenários da pesquisa foram instituições públicas e filantrópicas de reabilitação, localizadas na cidade de João Pessoa-PB, com a participação de 25 jovens e adultos que sofreram lesão medular e aceitaram participar do estudo. Os dados foram coletados utilizando-se três instrumentos: I (Perfil Socioeconômico e Clínico dos Sujeitos), II (CIF: Estrutura do corpo, Função do Corpo e Atividade e Participação) e III (Prática e a Satisfação sexual), que foram aplicados sob a forma de entrevista pela pesquisadora, assim como foi construído um diário de campo. As entrevistas e o diário de campo foram analisados com base no método de análise de discurso. As categorias de análise foram: concepções de corpo e de sexualidade. Resultados e discussões: Percebeu-se que os entrevistados tinham um conceito limitado de sexualidade, o que influencia diretamente sua concepção. No entanto, observou-se que os mesmos conseguem superar suas concepções de corpo e sexualidade, reinventando-se para vivenciar sua sexualidade de forma satisfatória com indícios de que este é um desafio diário vivenciado de forma particular.

Palavras-chave: Sexualidade, Lesão medular, Corpo.