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Research Article

Experience of Sexuality by People with Spinal Cord Injuries in Maputo City-Mozambique

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ABSTRACT

Background: Sexuality is an integral part of life, constituting a form of interaction with the other and contributing to the individual's well-being and self-esteem. In the case of a person with spinal cord injury, this is affected by the level of the injury, complications caused by the injury itself, psychological issues and cultural aspects.

Objective: This study sought to know the sexuality experience of people with spinal cord injuries in Maputo city.

Methods: This is a qualitative research, with semi-structured interviews conducted with 20 people with spinal cord injuries, using content analysis as a methodological tool.

Results: Our observation revealed that most people with spinal cord injuries have great difficulties in experiencing their sexuality and there is a very large gap to approach the theme by health professionals.

Conclusion: We conclude that, there is a need of patient receives clear and precise guidance on possible changes and adaptive methods after spinal cord injury, which requires the training of health personnel on this topic.

Keywords: Sexuality; Spinal cord injury; Neurogenic sexual dysfunction

INTRODUCTION

Spinal Cord Injury (SCI) is the spinal cord involvement, whether due to trauma, pathology or congenital malformation, which results in impairment of the sensitive, motor part below the injury site and autonomic function together with a multiorganic systemic dysfunction [1,2].

Trauma represents the most frequent etiology of spinal cord involvement in the adult population [2-4]. Talking about sexuality or sex has always been taboo, a subject that is often repressed and generates insecurity and/or fear. In case of a person who has suffered a SCI, the restrictions and desires are greater because there is often misinformation and prejudice [5]. The World Health Organization (WHO) defines sexuality as a central aspect of human beings throughout life that encompasses sex, gender identities and roles, orientation, eroticism, pleasure, intimacy and reproduction [6]. Although everyone has the right to information, the expression of sexuality and to develop their maximum potential in all aspects of life, it is observed that little information is directed to people with SCI about their sexual and reproductive rights [7].

Given above, we asked the following questions:

1. How do people with SCI deal with their sexuality in Maputo city-Mozambique?
2. What problems do you face?
3. What solutions are presented to you related to your sexuality?
4. How to face and adapt to a new sex life after SCI?

The justification for the study originated from the experiences lived during the medical training specialized in Physical Medicine and Rehabilitation. Sexuality constitutes a relevant aspect of the losses suffered by patients with SCI; these losses at the level of the Department of Physical Medicine and Rehabilitation (DPMR) of

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Maputo Central Hospital (MCH) are empirically verified in the consultations by the rehabilitation team when the patient brings expectations and anxiety regarding their personal and marital problems. Therefore, its relevance is centered on contributing to the definition of adequate strategies for the formulation of rehabilitation policies and assisting professionals who work in this area, improving the quality of life of SCI patients and their families. To answer these questions, we established the following objectives: To understand how their sexuality was experienced before and after SCI; Identify the difficulties that people with SCI face in their sexuality; Describe changes in sexuality after SCI; Find out if patients receive any information and/or guidance regarding their sexuality from health personnel.

METHODOLOGY

We conducted a cross-sectional study of an exploratory and descriptive nature through semi- structured interviews. The treatment and interpretation of the data were carried out based on content analysis. The study involved 20 patients with SCI, followed at DPMR. Participants were selected for convenience. For the inclusion criteria we applied: Patients with SCI of any etiology; Patients with more than one year of disease evolution, which we believe is sufficient time for initial clinical stabilization and for the patient to have had the opportunity to experience situations related to sexuality; Patients aged 18 years or older; Patients who agreed to sign the informed consent form. Data collection took place in the months of November, December 2019 and January 2020.

The data collection instrument consisted of three parts. The first part consisted of socio-demographic information with characterization data of the subjects, identification variables. The second part consisted of clinical information / data related to injury and closed questions. The third and last part was a questionnaire about the affective, relational state, data related to their sexuality.

Each interview lasted an average of 30 to 45 minutes and we recorded the answers in the interview script. After a thorough reading of the interview scripts, the speeches of the study participants were subjected to thematic content analysis, allowing the identification of four thematic categories: 1st Experience of sexuality throughout life; 2nd Experience of sexuality after SCI; 3rd Difficulties in experiencing sexuality after SCI; 4th Health professionals and sexuality of the person with SCI. To preserve anonymity, the interviews were coded, we used the letter "M" followed by a number, to identify the participants' statements.

We respect all ethical aspects throughout the study and the protocol was approved by the Institutional Committee on Bioethics in Health of the Faculty of Medicine / Maputo Central Hospital (CIBS FM & HCM) under the number CIBS FM & HCM/52/2019.

RESULTS AND DISCUSSION

Socio-demographic characterization of study participants

Table 1 contains the sociodemographic characteristics of the 20 study participants.

From the socio-demographic point of view, the following variables were collected: age, sex, education, profession/occupation before and after SCI.

Although we do not work with generalizations, we found that patients are spread over a wide age range between 21 and 72 years. Of the 20 interviewees, 8 were in the age group between 21 and 30 years old; 5 in the age group between 31 and 40 years old; 5 in the age group between 41 and 50 years old and 2 were over 60 years old, 1 with 63 years old and the other with 72 years old. Regarding gender, of the 20 study participants, 14 were male and 6 female. In terms of educational level, 13 participants had secondary education, 4 primary educations and 3 undergraduate educations.

Regarding occupation and/or profession, the data collected show that before the injury, all interviewees performed an activity: student 2, employees 15 and working on their own 3. After the LM, 10 participants became unemployed, employed 5 and self -employed 5.

Regarding the characterization of the study participants, the majority were men of working age and sexually active. The predominance of males, young adults, aged between 18 and 35 years confirms the data found in the literature [2,3], probably because men are more exposed to situations of risk and violence.

Most of the participants who were employed, exercising a profession that guaranteed them some dividend had to give it up and the student participants ended up dropping out of school, corroborating what we find in the literature that says, SCI is associated with lower enrollment rates education and economic participation [4] (Table 1).

Clinical characterization of study participants

As for the etiology of SCI, of the 20 participants, 14 were traumatic and 6 non-traumatic. When we declined the origin of the injury of

Table 1: Sociodemographic characteristics of study participants (n=20).

Variable	N	%
Age group		
21-30	8	40
31-40	5	25
41-50	5	25
51-60	0	0
>60	2	10
Sex		
Male	14	70
Female	6	30
Educational status		
Primary	4	20
Secondary	13	65
Graduation	3	15
Occupation before SCI		
Student	2	10
Employees	15	75
working on their own	3	15
Occupation after SCI		
Student	0	0
Employees	5	25
Working on their own	5	25
Unemployed	10	50

the individuals we interviewed, from the traumatic causes, twelve participants were victims of a road accident and two were affected by gunshot injuries. Of the non- traumatic causes, two were due to vitamin B12 deficiency, two due to Pott's disease and two due to an autoimmune process known as transverse myelitis (Table 2).

As for the neurological level of the 20 interviewees, 8 had complete paraplegia, 7 incomplete paraplegia and 5 incomplete tetraplegia. Still at the neurological level, 13 had injuries at the thoracic level, 5 cervical and 2 lumbar.

As for the clinical characterization of the study participants, most were of traumatic origin, with the road accident being the main cause of the injury. Pott's disease or vertebral tuberculosis remains a reality, especially in sub-Saharan Africa with a high number of TB cases. One third of non- traumatic SCI is linked to tuberculosis in sub- Saharan Africa. Regarding the neurological level, we found patients with a predominance of complete lesions of the thoracic level. These data from our investigation are corroborated by several authors [2-3,7-10].

Experience of sexuality before SCI

Before acquiring SCI, all participants had a fixed partner, among whom; twelve had boy/girlfriends and eight spouses/wives.

According to the interviewees' testimonies, before the SCI, no problems were identified in this health field, there is convergence in the speeches of all the interviewees regarding the perception of sexuality, as we can see in the testimonies of some of the interviewees presented below:

(...) It was normal, with love... (M- 01, 23 years old, male)

(...) Without complications, it was normal, I had many friends and I had a lot of fun... (M- 05, 32 years old, male)

(...) No problem, it was normal, I had a pleasant relationship and I practiced sex according to my disposition and opportunity.... (M-04, 37 years old, female)

(...) Always without problems, normal... (M-14, 42 years old, female)

We observed that before the SCI, all participants stated that they had a sexual life referred to as normal and some testimonies commented that throughout their lives they had an active sexual life and that this provided them great satisfaction as follows:

Table 2: Clinical characteristics of study participants (n=20).

	N	%
Causes of lesion		
Traumatic	14	70
Non-traumatic	6	30
Causes of traumatic lesion		
Road traffic accident	12	85.7
Gunshot injuries	2	14.3
Causes of non-traumatic lesion		
Vitamin B12 deficiency	2	33.3
Pott's disease	2	33.3
Transverse myelites	2	33.3
Neurologycal level		
Complete paraplegia	8	40
Incomplete paraplegia	7	35
Incomplete tetraplegia	5	25

(...) Very active, with a frequency of 3-4 times a week, with great satisfaction, I always had good experiences regarding sexuality... (M-07, 38 years old, male)

(...) Normal, very active, with a frequency of sexual intercourse of 4-5 times a week... (M-03, 23 years old, male).

The word normal was used in the interviewees' speech to express their perception of sexuality. There is a wide variety of sexual practices and attitudes among people, which makes it difficult to define what is "normal". According to the definition taken from the dictionary, normal is what follows the norm [11].

All respondents consider that before SCI their sexuality was experienced naturally and was not an object of concern.

It was also possible to observe, in the speech of some male interviewees, the use of the active word which is an aspect that culturally defines Mozambican men as having the role of being, in all relationships, an active being.

When talking about a sexually active man, ideas about sexual performance and virility are evoked [5].

Experience of sexuality after SCI

After SCI, eleven of the interviewees maintained the relationship before the SCI and nine ended.

Of the twenty study participants, eleven had no sexual involvement after SCI and nine did.

The interval to return to having sexual involvement ranged from 1 month to 2 ½ years, being that: 1-6 months: 2; 6-12 months: 6; more than 12 months: 1.

The initial concern is motor recovery, so most people think of sexual involvement after 6 months. This is corroborated by a study carried out in California, whose objective was to determine which areas of functional recovery are most important for the community of spinal cord injuries, which demonstrated that sexual function was the priority for paraplegic patients, and the second most important for quadriplegic patients, surpassed in the latter only by the recovery of the function of the upper limbs [12].

Among the causes that led people with SCI to end their relationships in most speeches was the abandonment of their partners for not being satisfied with the relationship and the destruction of self-image according to the speeches that follow:

(...) My boyfriend abandoned me when he found out how I was doing, I wear a diaper, I no longer feel attractive, I don't want to know any more about any man... (M-6, 29 years old).

(...) I have this tube that they say is forever, I don't feel like a man anymore... (M- M- 8, 41 years old).

(...) My wife abandoned me because the relationship was no longer satisfying; I use that tube, diapers... (M- 20, 38 years old).

(...) My fiancée cheated on me because our relationship was no longer satisfying, I use permanent catheter... (M- 18, 33 years old).

(...) My boyfriend abandoned me, I am no longer attractive, I no longer think of any man, I use disposable diapers, I use this tube... (M-10, 21 years old).

(...) My partner abandoned me, I have a lot of motor limitations in both my hands and legs, I use diapers, I wear a suit I don't feel like a man anymore (M-13, 30 years old).

The participants' speeches bring us the question of sexuality definition. As we see in the interviewees' speeches, the main issue is not being able to have sex because of the handkerchief and the use of a diaper that denotes the lack of bladder and bowel control. For men, the issue of sexuality is perceived as the ability to maintain a satisfactory sexual relationship, that is, based entirely on penis-vagina penetration and, when that fails, their self-image as a man is completely destroyed. For women, the question of self-image is fundamental, not being more attractive after SCI.

The consulted literature states that the imbalance in the relationship is common after serious disorders, especially those that generate sexual disorders such as SCI. Many are able to face the crisis situation with unity, but others are not adapted to the new situation, especially if the relationship is unstable. In a complicated relationship, an inability adds stress, leading to separation [13].

The literature also states that the factors that can affect the sexuality of any relationship are endless. However, if there is a healthy relationship prior to the injury, it can encourage the couple to focus on factors that support the relationship, such as love, communication, trust, intimacy, affection, romance, sensory stimulation, fantasy and self- concept [14].

Another problem with the abandonment found in the study was the use of catheter by most patients with neurogenic bladders. It should be noted that in Mozambique the intermittent bladder catheterization technique is not used for clean bladder management, and all patients with SCI without urinary control use permanent catheter contrasting with what we find in the literature in which the recommended technique is catheterization intermittent bladder using a clean technique [15,16].

One of the participants made a statement that differed from the other participants as follows:

(...) After SCI, I kept my relationship for 8 months and whenever I was with my partner, I spent the night with him, walked with him, family and friends were always asking me: but what are you going to do with him, while you are in a wheelchair, I ended the relationship... (M-08, 40 years)

The interviewee refers to the pressure that society puts on a person with a disability. Society has a great influence so that the person is able to overcome or not the challenges imposed by SCI and it is the same that limits the sexuality experience of the person with SCI, these individuals tend to be stigmatized by society.

The statement of the interview confirms what is found in the literature, which says that the person with SCI presents difficulties generated by the body's own limit, but it is society that imposes, in particular, this condition of being asexual [17]; in addition, other changes occur in relation to self- image and prejudice perceived by society [18].

What are the difficulties faced in experiencing sexuality

Of the 20 participants, only 9 reported that they have experienced their sexuality.

The consulted literature reveals that spinal cord injuries do not necessarily lead the individual to the loss of their sexuality, it is known that an injury or disease does not restrict sexual desire, changes and limitations occur at the sensory and motor level, which generates a difficulty in the response of the stimulus, but the individual is still sexed [13].

As we can see in the interviewees' statements, the main complaint for the majority was issues related to difficulty in erection, ejaculation, lack of orgasm, immobility and its consequences.

For men it was related to issues related mainly to the difficulty in erection and ejaculation as we can see below:

(...) I have learned to adapt to the situation, but the difficulty in erection and ejaculation has been very frequent, I have already masturbated but I cannot ejaculate... (M-02, 23 years old).

(...) Difficult erection, I don't always ejaculate, my legs don't help suddenly become stiff, they shake... (M-03, 26 years old).

(...) At first I didn't feel anything, but with my boyfriend's insistence I feel different pleasure than before the injury but I feel pleasure, satisfaction (M-30 years old).

(...) I have had problems with erection, ejaculation, and certain positions that I liked, I can’t do it anymore, and my partner helps me a lot... (M-04, 37 years old).

(...) The erection is not satisfactory and I usually use pills to help have an erection capable of satisfactory penetration... (M-05, 46 years old).

(...) Very difficult, I have no movements in my legs, my hands are not 100%, my erection is weak and I don't always ejaculate, my wife is afraid because I once had spasms, without bladder and bowel control... (M-11, 43 years).

For women, in addition to issues related to immobilization and its consequences, the main complaint was “not feeling anything”, starting with the comparison before and after SCI;

(...) I try to do it and I don't feel anything, it is very different from before the injury ... (M-12, 40 years old).

(...) Very difficult for not being able to move my legs, I try to do it but I feel very little pleasure... (M-07, 30 years old).

The interviewees' statements are supported by the consulted literature which says that the changes caused by SCI vary according to the level and degree of the injury. You can see decreased sperm, difficulty maintaining an erection, ineffective ejaculation. In women there is a reduction in vaginal lubrication and difficulty in reaching orgasm; other changes occur in relation to self- image and prejudice perceived by society [18].

The sphincter repercussions, spasticity, autonomic dysreflexia and therapies associated, in particular, with antidepressants, also contribute negatively to the experience of sexuality [19].

According to the speeches of the interviewees, we see that most of them compare the experience of sexuality before and after SCI. The consulted literature advises that people with SCI should be encouraged not to compare their sexual performance with previous sexual performance (especially one based entirely on penis-vagina penetration), as this can result in disappointment and limit their ability to explore a wider aspect sexuality and achieve satisfaction [20].

Health professionals and the issue of sexuality of the person with spinal cord injury

Among the 20 study participants, only 6 commented that they talked to a health professional about their sexuality, with 13 of the interviewees not talking to anyone and only 1 talking to 1 friend about the subject. As we see, most respondents did not receive any information from health personnel.

When analyzing the interviewees' statements, we found that the 6 interviewees who received some information, this was not clear and sufficient about the relationships that exist between the exercise of sexuality and SCI.

(...) I talked to my attending physician who just said not to stop having sex, otherwise my boyfriend would abandon me, he said nothing more, I learned from my boyfriend and he has helped me a lot... (M-07, 30 years).

(...) He just told me there are alternatives to explore... (M-11, 43 years old; M- 14, 49 years old).

(...) There are no viable alternatives, I must forget this issue, it will no longer be possible... (M-08, 41 years old; M- 10, 21 years old).

(...) it is still too early to think about it, we will focus first on recovering your movements (M-13, 30 years old)

As we see in the interviewees' speeches, there is a complete lack of information about sexuality after a SCI and patients want to receive this type of information. We also noticed that there is a great lack of holistic care for patients with SCI, with an increasingly fragmented assistance and that the issue of sexuality is not included in the treatment plans, neither during the first periods of treatment nor during rehabilitation, revealing complete lack of information about sexuality after a SCI.

The interviewees' speeches differ from what we find in the literature according to which even in the acute phase, it is important to show the patient that it is possible to have a satisfactory sexual life, that SCI is not an impediment to reproduction, leaving the door open for a discussion a more detailed future, and from the first hospitalization to outpatient follow-up, it is necessary to encourage the maintenance of sexual identity to preserve basic human needs [21,22].

According to some interviewees, health professionals are concerned with technical assistance itself and never ask about sexuality, being perceived the unpreparedness of health professionals on this topic as follows:

(....) It is the first time of my 7 years of injury that someone asks me how my sex life is... I wish I had the opportunity to talk to someone who is better oriented in this issues I had and I have in the sphere of sexuality... who knows, I might have separated from my wife... (M-09, 38 years old).

(...) They only talk about it as it is; there is some movement, what medications are you taking, it is very difficult for us to ask these questions of sex, a very intimate and embarrassing subject and often the environment do not help, there are other patients ... (M-20, 38 years old).

(...) these matters are not mentioned in the consultations ... how good they are asking will help more people. We also want to date, get married, and have children... (M-12, 40 years old).

(...) I would have liked to have had the opportunity to talk to someone who is better informed about the problems I had in the sexual sphere... (M-09, 38).

We believe that prejudices and taboos still exist that prevent health professionals to work on issues related to sexuality, as well as professional unpreparedness in this area. Patients rarely initiate this type of conversation because it is still an intimate, personal nature, which creates embarrassment in people. If health professionals do not address these issues, they will not collaborate to face one of the problems that the person with SCI will have to face sooner or later.

The consulted literature emphasizes that rehabilitation is still very much focused on the physical part. Today, there is still a great deficiency in information that supplies the lack of care for sexual rehabilitation of people with SCI. It is necessary to improve the assistance of the multidisciplinary team to work the whole and, thus, educate this citizen holistically [5].

In addition, the development of this fundamental facet for the human being (Sexuality) has been neglected, silenced and disregarded by both families and health professionals [23].

Currently, in the context of health care, we are experiencing a change in the cartesian paradigm, that is, the individual ceases to be seen in parts and starts to be observed and recognized in its entirety [5].

CONCLUSION

With this study we could see that most people with SCI do not experience their sexuality. The few individuals who experience their sexuality, they have a level of sexual dissatisfaction after SCI influenced not only by physical changes and by the use of permanent catheter but also by issues related to their self-concept and the consequences of an affective relationship.

There is a need of introduction of intermittent bladder catheterization in the management of the neurogenic bladder at the country level to remove the permanent catheter that is one of the major obstacles for men and women with SCI to experience their sexuality in addition to being a source of infections.

The topic of sexuality is a neglected topic, which is not routinely addressed in the follow-up of patients with SCI, revealing that it is necessary to improve assistance in this area in the commitment of the multidisciplinary team that even today still forgets the commitment to holistic care.

It is necessary for the patient to receive guidance on possible changes and adaptive methods, as the information can effectively contribute to clarify doubts and reduce fears to face the new condition. Thus, there is a need of training rehabilitation staff in matters related to sexuality in SCI and the creation of consultations on Neurogenic Sexual Dysfunction (NSD) at the country level. Rehabilitation services can offer courses and opportunities for discussion and updating on the topic.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

AUTHORS' CONTRIBUTIONS

LP, TJ and ES participated in the study design, data collection and analysis and preparation of the manuscript. LF and TT participated in the preparation of the manuscript. All participants read and approved the final version of the manuscript.

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