

A pilot study on sexuality in rehabilitation of the spinal cord injured: exploring the woman's perspective

J Robinson B Occ Ther (UKZN)**

Occupational therapist in private practice, Durban

A Forrest B Occ Ther (UKZN)**

Occupational therapist, Livingstone School, Durban

C Pope-Ellis B Occ Ther (UKZN)**

Junior occupational therapist, Edendale Hospital, Pietermaritzburg

Angel T Hargreaves B Occ Ther (UDW/UKZN), M.ECI (UP)

Lecturer, School of Audiology, Occupational therapy and Speech language pathology, University of KwaZulu Natal

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ABSTRACT

This qualitative study was aimed at gaining an understanding of spinal cord injured women's subjective views and perceptions regarding the inclusion of sexuality in their rehabilitation.

A focus group comprising four women with complete spinal cord injuries who had received their injury not less than 2 years previously and who had been through a rehabilitation programme in the past 5 years confirmed the significance of the dialectical relationship between sexuality and self esteem. Self esteem had a great impact on the participants' ability to resume their lives as sexual beings and their receptiveness to sexuality being addressed in rehabilitation. Further, the participants' ability to resume their lives as sexual beings was impacted on by personal, partners and societal attitudes. It was also equated with their ability to engage in the physical acts of sex. This supports the theoretical constructs of occupational science which recognises the relationship between doing, being and becoming.

One of the significant shortcomings of rehabilitation was the failure to provide individualised and client-centred intervention when including sexuality. Therapists need to adjust the time and manner in which sexuality is addressed and consider the use of peer counselling, group discussion and access to detailed information and resources.

Key words: Activities of Daily Living, Female, Rehabilitation, Sexuality, Spinal cord injury

Introduction

Sexuality is an innate and multi-faceted dimension central to one's being. The perception that sexuality is only comprised of sexual intercourse and other physical acts is a common misconception. Literature tends to narrow sexuality to the physical capabilities of the individual. These capabilities may include sexual acts, positioning and sexual arousal, but from a holistic point of view, sexuality also

encompasses biological, psychological, emotional, social, cultural and spiritual qualities. These qualities may include among others one's sense of self; expression of self; relationships with others, intimate or otherwise; desirability and self esteem^{1,2}. Coulsdrick, cited in Sakellariou and Simo Algado, defines sexuality as a component of an individual which develops throughout one's life and is an integral part of everyday thoughts, feelings and behaviour³.

Sexuality refers to a whole spectrum of behaviours, attitudes and activities as well as shaping gender identity and contributing to self esteem and social role formation³. Sexuality further encompasses sexual identity and the sense of oneself as masculine or feminine. This is grounded on cultural and societal influences, self image and the beliefs of others. Sexuality is a significant part of human experience and it is viewed as the presentation of the self to others as a person, including gender representation², and how one acts, dresses and interacts with others in social and interpersonal relationships⁴.

There has been a growing interest in the inclusion of sexuality in the rehabilitation of disabled clients. However it seems that literature has focussed on males when exploring sexuality in spinal cord injured individuals whilst there is little knowledge regarding women and they have been largely excluded from studies concerning sexuality^{5,6,7,8,9,10,11}. The research conducted in this field on men has been merely extrapolated to include women¹. Research of spinal cord injured women carried out by Sharma and Sing⁷, focused more on the physical aspects of sexuality such as fertility, orgasm, contraception and pregnancy. Aspects such as intimacy, communication, romantic relationships and other emotional and psychological components of sexuality were largely neglected⁷. Considering women with spinal cord injuries have unique concerns and problems related to their sexuality, this focus has resulted in inaccurate research findings and perceptions of disabled women and their sexuality⁷ and the consequence of this is inadequate rehabilitation as far as sexuality is concerned. Furthermore research has found that men were twice as likely as women to receive sexual education or counselling in rehabilitation⁸. A phenomenological study of the sexuality and relationship experiences of 15 spinal cord injured women revealed that all the participants had little understanding of their sexuality needs as a disabled individual and that education and materials provided to them regarding sexuality were of a poor quality and focussed primarily on males¹.

Universally, there is a perception amongst healthcare professionals that women's sexuality following a spinal cord injury is less compromised than that of their male counterparts. This perception is evident in the statement by a health professional who asserted that "since females can still get pregnant and function well during coitus they have significantly fewer sexual problems than their male counterparts"⁸. This statement is congruent with the findings of a study by McKenna & Summerville¹², who asserted that women tend to experience fewer difficulties adjusting to their altered sexual function after sustaining a spinal cord injury (SCI) due to their perceived ability to more readily accept and adapt to a more passive sexual role¹². Allegations like these result in the assumption that women do not experience significant problems in the area of sexuality following a SCI when compared to men.

Women are perceived in society as being more private, passive and conservative when it comes to sexual expression¹¹. Due to this perception of women in society in conjunction with some cultural beliefs which require a woman to be private and submissive to a man when it comes to sexual expression and sexual intercourse, a woman's sexuality is frequently considered less important in comparison to the man. As a result, women are frequently overlooked in both research and rehabilitation.

Research has highlighted the significance of sexuality in the rehabilitation of disabled individuals and has shown that sexual expression may be of a higher priority to some individuals than other activities of daily living¹¹. Numerous studies have shown that spinal cord injured individuals tend to place greater importance on regaining sexuality than on early ambulation². The exclusion of sexuality from rehabilitation can, therefore, have a negative impact on various other areas of the individual's life. Individuals who experience inadequacy regarding intimacy and sexuality also feel unmotivated to engage in other aspects of life². It is, therefore, clear that sexuality forms an integral part of an individual's life. For this reason, health professionals need to adopt a holistic approach to treatment and should ensure that sexuality is included in the rehabilitation of spinal cord injured individuals.

The focus of this study is an attempt to close the gap in research concerning spinal cord injured women and the issues that they are

faced with regarding their adequate sexual rehabilitation. As such, the aim of this study was to explore spinal cord injured women's subjective views and perceptions regarding the inclusion of sexuality issues in their rehabilitation process. More specific objectives of the study were:

- ❖ to explore spinal cord injured women's understanding of the term sexuality;
- ❖ to capture their feelings as to whether rehabilitation prepared them to resume everyday life as sexual beings; and
- ❖ to identify the perceived barriers or supports to their comprehensive sexuality rehabilitation.

Methodology

A qualitative phenomenological research design was utilised for this research as this design yields valuable and informative findings that serve to portray the insider's point of view¹³. Considering that this study focussed on the personal beliefs and experiences of spinal cord injured women, this design enabled subjective views to be explored and discussed.

Qualitative research goes beyond the superficial to uncover the subjective emotions of the participants and serves to provide in-depth accounts of personal experiences¹³. As such, the researchers were able to unearth the personal views and accounts of spinal cord injured women with regards to their own rehabilitation. As qualitative researchers are personally involved in the study and display partiality and empathetic understanding towards the participants the design lends itself to the formation of close relationships between the researchers and the participants¹⁴. This "bond" encourages the sharing of more intimate information and is of particular importance to this study as the topic of interest is of a personal nature.

Sexuality itself is a personal and subjective issue which is difficult to measure using quantitative methods. As such, qualitative research which is inductive in nature and which makes use of the participants' feelings and perceptions to direct research will allow the researchers to gain insight into personal human experiences. This study adopted a descriptive mode of inquiry in that the researchers simply wished to describe the existing perceptions of spinal cord injured women regarding their sexual rehabilitation as opposed to investigating hypotheses.

Purposive sampling was used to select participants who were female and between the ages of 18 and 45 years. The participants were to have sustained an injury at any level of the spine and should have completed a SCI rehabilitation within the last five years. Purposive sampling was used in order to ensure a selection of participants who would be willing to participate in the discussions as a small sample was used¹³. The researchers contacted one private and one state owned spinal rehabilitation centre and the co-ordinators of associations and organisations for people with spinal injuries within the EThekweni district and requested contact details of potential participants. Participants who met the inclusion criteria were contacted telephonically by the research team and were informed about the study. An information letter outlining the nature, purpose and benefits of the study was faxed to those who were willing to participate in the study. The potential participants were also given the date, venue and time for the discussion group. Prior to commencing with the discussion, the participants signed a consent form and were informed of their right to withdraw from the discussion group at any time. Whilst confidentiality could not be ensured due to the nature of a focus group discussion, participants were assured that their names would not be released when disseminating the results of the study, thus anonymity would be maintained. Ethical clearance for the study was obtained from the University of KwaZulu Natal.

A focus group format for this discussion was used to gather data and was recorded using two digital voice recorders. Five open ended questions were used for the focus group discussion in order to gain detailed insight into the participants' experience⁶. The questions were formulated by the researchers and these were based on the gaps in knowledge identified when conducting a literature search. In order to ensure appropriateness of these questions, three

key informants were identified and were requested to critically evaluate the appropriateness and clarity of questions. Two of the key informants were occupational therapy academic members of staff who have extensive knowledge in the field of qualitative research and spinal rehabilitation. The last key informant was a woman who had sustained a complete spinal cord injury but did not meet the research criteria as she was injured more than 20 years ago. After feedback was given, changes in the questions were made. The recordings were transcribed verbatim by the three researchers.

The data were analysed using an open coding method. Themes were identified by recognising topics of discussion which were revisited or agreed upon using member checking by all participants or a topic which was frequently brought up by the same participant. Each of the three researchers individually analysed the data and categorised the codes before collectively discussing emerging themes. The researchers debated the interpretation of the data to reach non biased conclusions. This method is referred to as "researcher triangulation" and assists in improving the trustworthiness of the data obtained¹³. Trustworthiness of data was also ensured by the use of key informants and member checking as discussed above.

Results

Of the seven women who agreed to participate in the research only four able to attend the focus group discussion. The specific details of these women are recorded in the table below. See Table I.

Table I: Demographic information of participants

Participant	Age	Race	Marital Status	Time since injury	Injury Level	Duration of Rehabilitation
A	40	Indian	Married	5 years	T10-12	2½ months
B	27	African	Single	4 years	C6-7	6 months
C	23	Caucasian	Single	7 months	T12	2 months
D	51	Caucasian	Married	3 years	C5-7	3 months

Table II: Themes and Sub themes

THEMES	SUB THEMES
1. Sexuality is...	a) "Its how you feel about yourself" b) "Its about sex"
2. The Obstacles Experienced...	a) "It takes two" b) "Carer versus Sexual Partner" c) "Attitudes" d) "Accepting my new body"
3. My Rehabilitation Experience	a) "It should be about me" b) "Age is not just a number" c) "Timing is everything" d) "Positive Experiences"
4. What Women Want: My Ideal Rehabilitation	

The results of the research are reflected in the themes and subthemes which were identified during the focus group discussion. These have been outlined in the table below. See Table II. Each of the themes will be discussed separately.

Theme 1: Sexuality is

The first theme identified was "Sexuality is...." This focussed on participants own definition of sexuality which emerged during discussion. There were two sub-themes, one related to how the participants felt about themselves and the other to the sex component in sexuality. Participants defined sexuality according to certain factors. One of the primary factors that emerged was the inherent link between sexuality and attractiveness. This was supported by research conducted by Khan and Potgieter which revealed that women frequently perceived themselves as less desirable following a spinal cord injury¹⁵. Being wheelchair-bound contradicts society's

image of perfection, and led these participants to perceive themselves as flawed and unattractive which resulted in low self esteem. One of the participants reflected that, "I just feel unattractive... I feel disgusting because I'm in a wheelchair."

A dialectical relationship exists between attractiveness and self esteem. As such self esteem can be seen to contribute to one's concept of sexuality. According to Hammell women with spinal cord injuries feel unattractive and this results in their view of themselves as being asexual¹⁴.

Although the participants were able to recognise the psychological, emotional and spiritual aspects of sexuality, this idea was not revisited in discussion. This displays the participants' intellectual understanding of the varied and diverse facets of sexuality which become obsolete when one is no longer able to engage in the physical act of sex which is central to sexuality. Although probing enabled the participants to recognise the psychological, emotional and spiritual aspects of sexuality it was clear that the physical acts of sex weighed heavily in defining their sexuality and their ability to feel like a sexual being.

Three of the participants felt that they were not able to resume their lives as sexual beings primarily because they were not engaging in the physical act of sex. This supports the theoretical constructs of occupational science which recognises the significant relationship between doing, being and becoming. For example, if a hockey player could no longer play hockey he would not define himself as a hockey player. Similarly, if a sexual being could no longer have sex he/she would no longer define himself/herself as a

sexual being thus contributing to occupational alienation. This is reflected in the response of one of the participants to the question "Do you feel you have been able to resume your life as a sexual being." The participant responded, "Definitely not... because I don't have sex... I am not a sexual being... Being is a verb. It means doing something..."

Theme 2: The obstacles experienced

One of the main concerns participants highlighted was their inability to resume the role of a satisfying sexual partner. This concern is focussed primarily upon their ability to respond to sexual stimulation from a lover in a way that would confirm his own feelings of competency as a sexual partner. It emerged in discussion that participants were particularly worried about their partners' feeling insecure about their ability to pleasure them. Although a review of the literature did not reflect the fear surrounding the issue of being in a relationship and thus involving another and burdening him/her, this arose as a significant concern as shown by the following comment made by one participant

"I think that's my whole issue involving someone else because its always just been my issue... but when it involves someone else that's where I get a bit shaky".

Participants reflected upon their experiences and expressed the opinion that they found it easier to overcome obstacles such as transfers on their own. Thus, when it came to surmounting the obstacle of being in a relationship they experience more difficulties overcoming any problems that arose. This was because the problem could not be tackled individually but required the spinal cord injured person to involve another individual in the struggles that they were facing.

A sexual partner who takes on the role of a caregiver may experience feelings of resentment and decreased lust or desire

for his or her sexual partner¹⁵. However, contrary to this the woman expressed feeling objectified, degraded and humiliated in the situation where their partner took on the role of a caregiver. These feelings were clearly portrayed in this statement by one of the participants, "*I literally cried...having the guy who I loved wipe my backside was horribly degrading for me.*" This resulted in a strain in the relationship due to the fact that the duties of caring for the partner had a tendency to dominate the relationship therefore the intimacy and sexual aspect of the relationship were lost.

Participants experienced difficulty contemplating issues of sexuality due to the need to adjust to significant changes in their physical body following their spinal cord injury. Levi and Westgren¹⁶ supported this in their research which found that spinal cord injured women experienced feelings of anxiety and insecurity as a result of a lack of understanding their new body and a lack of knowledge about how to control their body¹⁶. With reference to anxiety arising from lack of knowledge about how to control their body, participants expressed a significant fear surrounding bowel and bladder incontinence. One of the participants stated

"...because I don't have bladder control and um... like bowel control.. I have to like control it myself.. I'm TERRIBLY afraid of like.. if I was with someone and then I decide to pee on them or something (laughter), it's just like the thought just.. I'm way too afraid about that... so that's also very off putting".

This is supported by Leibowitz⁸ who found that women with neurogenic bladders fear the possibility of having an "accident" during a sexual encounter.

Theme 3: My Rehabilitation Experience

Although all of the participants reported that sexuality was addressed within their rehabilitation many of them had difficulty relating to the intervention provided as it did not recognise their personal context or address their specific needs. This theme is supported in the literature which stated that therapists need to consider the role that sexuality has in the life of the client and plan therapy accordingly in order for therapy to be maximally therapeutic⁶. Participants felt that their age played a significant role in how sexuality should be addressed by the rehabilitation team. Participants also emphasised the importance of addressing sexuality at an appropriate time in their recovery as they needed time to adjust to and accept their new circumstances after their injuries. Komisaruk et al¹ agreed that the majority of spinal cord injured patients regard the domain of sexuality as a low priority in the acute stage of recovery¹. Often education and materials provided to spinal cord injured individuals regarding sexuality are of poor quality and do not meet the specific needs of each individual¹. This was confirmed by participants in the focus group who felt that they were given outdated pamphlets and resource material. In addition books and/or pamphlets also tended to focus primarily on males and as such neglected the needs of women¹.

One of the participants reflected on her rehabilitation experience and indicated that sexuality had not been dealt with comprehensively due to the limited time allowed for rehabilitation which according to Komisaruk et al, often resulted in competing priorities and other matters taking preference over sexuality¹.

Although the negative aspects of sexuality and rehabilitation are largely reported in the literature, two of the participants who attended the same rehabilitation facility, highlighted some of the positive aspects of their sexual rehabilitation. One of these was the non-threatening manner in which sexuality was addressed which enabled the participant the choice of being involved in the intervention. The other participants had little to share regarding the positive aspects of their rehabilitation regarding sexuality.

Theme 4: What women want: My ideal rehabilitation

Participants identified fundamental aspects of 'their ideal rehabilitation.' They agreed that the preferred way in which sexuality should be addressed in rehabilitation was in group discussion, with individuals in a similar position. One on one discussion was found to

be daunting whereas a group discussion would allow them to recognise that they were not alone thereby giving them the confidence to share their experiences. Group discussion would also allow for development of a support system between members of the group which was reflected within the focus group itself.

Peer counselling was also identified as a preferred means of addressing sexuality as participants expressed the benefits of talking to others who had successfully overcome similar barriers. In particular participants felt that an able bodied therapist would have difficulty understanding the needs and feelings of a spinal cord injured individual and that this could be overcome by peer counselling.

The participants also identified the necessity for rehabilitation to be client centred, reporting that their own rehabilitation failed to address their individualised needs. This was identified as one of the main barriers to sexuality being adequately addressed in rehabilitation.

Conclusion and Implications for Occupational Therapy Practice

This research has highlighted the inherent link between sexuality and self esteem. This dialectical relationship was evident in the responses and behaviours of participants throughout the discussion. In addition, the dominant factor that impacted upon participants being able to perceive themselves as sexual beings was their ability to engage in the physical acts which characterise sexuality.

Although there is evidence of a growing awareness of sexuality, results from this study as well as others reflect that, despite it now being addressed in rehabilitation, there are shortcomings to the way in which it is done. Findings from this research indicated that the predominant factor which contributes to sexuality being inadequately addressed was the tendency for therapists to provide generic intervention that was not based on the client's specific needs. Therefore occupational therapists working in the realm of spinal cord injury rehabilitation need to identify the client's specific needs and problems and allow this to direct the intervention provided.

Participants of the focus group came to agree on some of the fundamental aspects of 'their ideal rehabilitation.' The participants agreed that the preferred way in which sexuality should be addressed was through discussion, involving individuals in a similar position. For example, a group of in-patients in a rehabilitation facility or a support group of spinal cord injured patients. Although the topic is of a personal and intimate nature the participants felt that groups allowed less focus on the individual and her problems. One on one discussion was viewed as more threatening whereas it was felt that a group discussion would create a more open and accepting environment where all of the participants shared experiences and were able to relate to one another. These findings have implications for occupational therapists and their approach to sexuality within rehabilitation programmes. Due to the highly personal nature of the topic of sexuality, the subject tends to be dealt with on a one-on-one basis. However this study indicated that, in fact, the preferred approach is to address sexuality in a group setting.

The inability of an able-bodied therapist to understand the needs and feelings of a spinal cord injured individual was highlighted as both a concern and barrier to adequate rehabilitation. Participants felt that this could be overcome by introducing peer counseling into rehabilitation. Participants expressed the benefits of talking to others who have been in a comparable situation and have successfully overcome similar barriers. Having themselves been through the process of recovery and adjustment after a spinal cord injury, the personal experiences and advice offered by peer counselors would be more meaningful and would motivate and inspire newly injured people who were struggling with issues regarding sexuality.

This study clearly emphasises the need for sexuality to be addressed effectively within rehabilitation programmes and highlights the role that the occupational therapist should play in ensuring this. As such it is recommended that specific guidelines



for sexuality in rehabilitation for women should be formulated and included in the role and the scope of practice for occupational therapists.

In addition, further research on the occupational therapists preparedness for undertaking sexuality rehabilitation should be conducted as it is the health professionals' lack of skills and knowledge in this area which contributes significantly to the sexuality of women with SCI being inadequately addressed in rehabilitation. To address such shortcomings practically, more comprehensive input on sexuality in rehabilitation should be included in the curriculum for occupational therapy students. Topics should include: physical changes in sexual functioning after a spinal cord injury; preparation for and engagement in sexual activities; bladder and bowel hygiene; approaching the subject of sexuality with a client; ways to facilitate group discussion about sexuality and the importance and benefits of peer counselling. Continued professional development courses are indicated to provide further training to professionals to enable sexuality to be effectively addressed in rehabilitation.

The findings of this study should be used with caution, keeping in mind that they cannot be generalised to all spinal cord injured women.

Specific limitations of this study include the following:

- ❖ The topic of sexuality is of a personal and intimate nature. As such, the women participating in the study may have felt embarrassed voicing their opinions within a group setting. However, this did not seem to be the case. Interestingly, although focus groups are perceived to be primarily designed for low involvement topics, research has shown that focus groups are useful when investigating sensitive, intimate or high involvement topics such as sexuality¹⁷.
- ❖ Due to time constraints, the researchers were unable to conduct a second focus group or individual interviews in which to gather additional data or confirm interpretation of the results obtained from the original focus group.
- ❖ Whilst seven women had agreed to participate in the study, only four participants attended the focus group discussion. The results were therefore limited to the experience of only these women and should not be generalised to people from other spinal rehabilitation facilities.
- ❖ While participants that were interviewed included women with paraplegia and quadriplegia, the differences in concerns were not highlighted in this study. Further concerns that could arise when looking at the different classifications.
- ❖ Including the demographics of the participants may compromise the anonymity of the participants as they can be recognisable based on this information and also because of the small number of participants.

References

1. Komisaruk B, Richards E, Tepper M, Whipple B. Women with complete spinal cord injury: A phenomenological study of sexuality and relationship experiences. *Sexuality and disability*, 1997; 5 (4): 271- 281.
2. Chard G, Northcott R. Sexual Aspects of Rehabilitation: The client's perspective. *The British Journal of Occupational Therapy*, 2000; 63 (9): 412- 418.
3. Sakellariou D, Simo Algado S. Sexuality and Occupational Therapy: Exploring the Link. *The British Journal of Occupational Therapy*, 2006; 69 (8): 350-354.
4. Hammel KW. *Spinal Cord Injury Rehabilitation*. London: Chapman and Hall, 1995.
5. Albo M, Dunn K, Joseph A, Phelps J. Spinal cord injury and sexuality in married or partnered men: Activities, function, needs, and predictors of sexual adjustment. *Archives of Sexual Behaviour*, 2001; 30 (6): 591-603.
6. McAlonan S. Improving Sexual rehabilitation Services: The Patient's Perspective. *American Journal of Occupational Therapy*, 1996; 50 (10): 826-833.
7. Sharma S, Singh R. Sexuality and Women with spinal cord injury. *Sexuality and disability*, 2005; 23 (1): 21-32.
8. Leibowitz RQ. Sexual rehabilitation services after spinal cord injury: What do women want? *Sexuality and disability*, 2005; 23 (2): 81-105.
9. Sakellariou D. If not the disability, then what? Barriers to reclaiming sexuality following spinal cord injury. *Sexuality and disability*, 2006; 24: 101-111.
10. Hess MJ, Hough S, Tammaro E. The experience of four individuals with paraplegia enrolled in an outpatient interdisciplinary sexuality program. *Sexuality and disability*, 2007; 25: 189-195.
11. Pollard N, Sakellariou D. Sex and occupational therapy: Contradictions or contraindications. *The British Journal of Occupational Therapy*, 2007; 70 (8): 362-364.
12. McKenna K, Summerville P. Sexuality education and counselling for individuals with a spinal cord injury: Implications for occupational therapy. *British Journal of Occupational Therapy*, 1998; 61: 275-279.
13. McMillan JH, Schumacher S. *Research in education. A conceptual introduction*. 5th ed. Pretoria: Van Schaik, 2001.
14. Glesne C, Peshkin A. *Becoming Qualitative Researchers: An Introduction*. Vermont: Longman, 1992.
15. Khan G, Potgieter CA. Sexual self esteem and body image of South African spinal cord injured adolescents. *Sexuality and disability*, 2005; 23 (1): 1-19.
16. Levi R, Westgren N. Sexuality after injury: Interviews with women after traumatic spinal cord injury. *Sexuality and disability*, 1999; 17(4): 309-318.
17. Aronsson K, Hyden M, Overlien C. The Focus Group Interview as an In-Depth Method? *Young Women Talking About Sexuality. International Journal of Social Research Methodology*, 2005; 8 (4): 331-344.

Corresponding author

Angel Hargreaves

Email: hargreavesat@ukzn.ac.za

