

A PHENOMENOLOGICAL STUDY INTO THE EXPERIENCE OF THEIR SEXUALITY BY MALES WITH SPINAL CORD INJURY

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ABSTRACT

On reviewing the literature on spinal cord injury (SCI) and sexuality in males, there was found to be a plethora of research in physical domains. Sadly, the psychological aspect of sexuality for men who experience SCI has been largely neglected. For this reason a phenomenological study was conducted to understand the experience of sexuality in its totality for the male who experiences SCI. Four males with SCI were included in the study. Central themes that emerged from the transcribed interviews included the establishment of an existential baseline, diminished independence and perceptions of masculinity post-injury. Participants also divulged needs pertaining to their (potential) relationships. Lastly, religion and certain coping mechanisms were found to either facilitate or hinder sexuality post-trauma depending on their rigidity and effectiveness respectively.

SAMEVATTING

Die studie van literatuur oor rugmurgbesering (RMB) en seksualiteit by mans, het 'n magdom navorsing oor die fisieke aspekte opgelewer. Ongelukkig is die sielkundige aspekte rondom seksualiteit by mans met RMB grootliks afgeskeep. Derhalwe is 'n fenomenologiese studie onderneem ten einde die man met RMB se ervaring van seksualiteit in sy geheel te ondersoek. Onderhoude is met vier mans wat RMB het gevoer. Sentrale temas wat uit die onderhoude voortvloei, sluit die vasstel van 'n eksistensiële basislyn in, asook verminderde onafhanklikheid en veranderde beskouings oor manlikheid na die besering. Deelnemers het ook hulle behoeftes met betrekking tot hulle (potensiële) verhoudings aangedui. Laastens is daar gevind dat godsdienst en sekere hanteringsmeganismes 'n positiewe of negatiewe impak kan hê op seksualiteit, afhangend van die rigiditeit en effektiwiteit daarvan.

INTRODUCTION

The consequences of spinal cord injury (SCI) are both multidimensional and chronic. These consequences occur on a physical, psychological, psychosocial, familial and sexual level. Unfortunately, the sexual consequences are the most ignored and appear to be disregarded by many medical professionals, rehabilitation programmes and by society at large. Pervin-Dixon (1988:31) has suggested that the reason for this is that of mere ignorance on behalf of those individuals who come into contact with the male who experiences SCI post-injury. Lemon (1993:73) also postulates that this ignorance is borne from the fact that society is blanketed in myths surrounding sexuality of men who experience SCI. These myths revolve around the theme of: disabled individuals are not sexual individuals (McCammon, Knox & Schacht, 1998:34).

Sexuality in itself is an extremely complex phenomenon, which encompasses physical, cultural and social dimensions (Wincze & Carey, 1991:10). Unfortunately, too many professionals who do address sexuality in the male who experiences SCI, focus only on the physical component. This state of affairs is sadly reflected in the research conducted in this area (Farrow, 1990:251).

Background

Griffith and Lemberg (1993:2) state that there are at least 10 000 new cases of SCI in the United States of America (USA) annually. Although there are no absolute figures given for the incidence of SCI in South Africa, it is estimated as many more pro rata than that of the USA due to violence and mining accidents.

On an individual level, the male who experiences SCI is confronted with numerous losses post-injury (Rabin, 1980:17). He is faced with the monumental task of attempting to adapt, integrate and cope with these losses. On a physical level, the male with SCI is often confronted with sexual problems such as an inability to achieve and sustain an erection (Rabin, 1980:3) and possible problems regarding fathering children. Other physical problems that may impact on sexual functioning and general well-being include loss of mobility, loss of bladder and bowel control, the

development of decubitus ulcers or pressure sores, breathing problems, lung and respiratory infections, kidney stones and pain (Rabin, 1980:1–26).

It is often very early during hospitalisation that his concerns regarding his sexuality arise (Althof & Levine, 1993:527). These sexual concerns cover areas ranging from societal roles imposed on men, for example: how will he now protect and provide for his family's future; to physical dimensions, for example: will he be able to achieve an erection; to psychological factors such as: how will anyone find him attractive in a wheelchair? Naturally, it follows that due to the lack of research and resultant ignorance in this regard many of these questions remain unanswered for males who experience SCI (Lemon, 1993:73).

Human sexuality

"Human sexuality is a complex and multifaceted concept. The various elements of human sexuality include sexual self-concept, behaviours, thoughts, values, emotions, anatomy and physiology, interpersonal relationships, and diversity" (McCammon *et al.* 1998:4). Moreover, according to Griffith and Lemberg (1993:1): "Human sexuality is the sum of all those biological and psychological factors relating to our capacity to love, to be loved, and to reproduce".

Sexuality is formed during childhood and continues to develop throughout one's life. The new and profound physical deficits encountered after SCI affect sexuality and feelings of masculinity. Following injury, men who experience SCI no longer perform usual social and vocational roles or they cannot perform them as they used to. This has profound effects on self-worth, body-image and potential or existing relationships (Althof & Levine, 1993:527).

In rating the importance of sexuality to males with SCI, Comarr (1971:378) states, "These men do think of sex, I believe (after nearly 25 years of observation) that the paralysis of the limbs among these patients would be secondary if they could carry on a normal sex life".

Research has shown that a variety of factors may however influence the experience of sexuality of the

male with SCI. These include changes in the sexual response cycle such as a diminished interest in sex (due to various factors such as depression and medication), inability to achieve or sustain an erection and an inability to ejaculate (Lemon, 1993:35; Rabin, 1980:5). The sexual encounter may also change due to a lack of spontaneity that arises from numerous physical preparations prior to sexual encounters. These preparations include bowel and bladder emptying, removal of external catheters, the use of penile prostheses, penile injections and the use of vacuum erection devices (Rabin, 1980:34; White, Rintala, Hart, Young & Fuhrer, 1992:226).

Perhaps one of the largest hindrances of sexual functioning post-trauma for the male experiencing SCI is the destructive societal and individual held stereotypes/misconceptions about sexuality. It follows that if these myths constitute a large hindrance to sexual functioning. It may be an area that requires the most adaptation on the part of the male experiencing SCI and society around him for his effective sexual adjustment post-trauma (Althof & Levine, 1993:531; Lemon, 1993:88).

Some of these myths surrounding males experiencing SCI are that disabled persons are not sexual beings, they are not interested in sex and sexuality, the male must initiate sexual activity and encounters, love and intimacy is expressed through sexual activity, masturbation is considered sinful and dirty and that sexual activity weakens the effects of medication (Lemon, 1993:89; McCammon *et al.* 1998:5; Persaud, 1986:11; Pervin-Dixon, 1988:32; Rabin, 1980:60).

Singh and Magner (1975:7) emphasise the destructiveness of these myths to the male who experiences SCI. They state that sex and sexuality for the individual experiencing SCI is just as important as it is for the able-bodied. They even went as far as to state that the male experiencing SCI would rather be able to perform sexually than walk. Farrow (1990:255) remarks that disability does not eliminate sexual feelings and that individuals experiencing SCI still continue to be sexual beings and to have the same sexual desires as found in any other individual (Stein, 1992:54).

Rationale

This phenomenological study was conducted to address the problem regarding the severe lack of insight into the sexuality of men who experience SCI (Lemon, 1993:81). The study attempted to incorporate all aspects of sexuality as experienced by the individual. Because of the multifaceted dimensions of sexuality, a phenomenological framework was utilised for the study in the hope that full acknowledgement can be accredited to the experience.

AIMS AND OBJECTIVES

The aim of the study was to assess the life world of the male with SCI regarding his experience of sexuality post-injury. This was done in order to reveal structures of experience and meaning in this phenomenon. The research question that this study attempted to answer is: What is it like to experience sexuality post-injury as a male with SCI? As such the study is descriptive in nature and therefore the aim is to capture the meaning of this experience in the most rich and holistic manner possible. The investigation was conducted within a phenomenological framework, as it was believed that only a qualitative approach to this phenomenon would justify and capture the entirety and the diversity of this phenomenon (Wincze & Carey, 1991:84). The data was gathered via open-ended interviews till the data were saturated.

Thus, the study aimed to understand part of the life worlds of these four participants as they subjectively experience it. The objective was then to elicit common and central themes from all four these men's life worlds in order to attempt to capture significant thoughts and feelings pertaining to the experience of sexuality post-injury for men who experience SCI.

METHOD

An existential phenomenological framework was utilised to elicit a comprehensive understanding of the lived experience of sexuality for the male who experiences SCI. Human sexuality constitutes such a complex phenomenon in that social, cultural, psychological, physical, personal and spiritual

dimensions are all intertwined (Wincze & Carey, 1991:10). As Duniluk (1993:55) who conducted a phenomenological study on the experience of female sexuality states, "Phenomenological methods are particularly appropriate for the examination of meanings and experiences about which little is known or that are fraught with erroneous assumptions and misinformation". Thus, this approach will enable the researcher to understand the experience from the point of view of the individual.

The open-ended interview

The aim of phenomenological investigation is to allow a phenomenon to reveal itself in its full intensity and that the most common and appropriate method that succeeds in allowing the phenomenon to show itself is the open-ended interview (Helgeson, 1992:342). The phenomenological interview can be likened to a conversation. It is an interaction which takes place in the context of a relationship. This interaction seems to provide a rich data source of human structures of experience. To facilitate openness and generosity in divulging information, the participant needs to feel comfortable and trusting toward the researcher (Polkinghorne, 1985:382).

Sample

Four participants were selected by an adapted version of snowball sampling until the data were saturated. As it was extremely difficult to find suitable participants for this study a process of networking was used to source participants who fulfilled the prerequisites stated below. Due to the lack of support groups as associations for males with SCI in South Africa, participants were not easy to come by. It neither helped to approach hospitals with spinal units or rehabilitation centres as they cannot divulge the names of past patients and current patients have been recently injured. Therefore, given the prerequisites listed below, it was decided that four participants would be sufficient to complete this initial research project.

Only males were utilised for this study. The rationale for this is that males constitute the majority (82%) of the spinal cord injured population (Donahue & Gebhard, 1995:22; Solomon, 1982:126; White *et al.* 1992:230). All the participants were required to be

19 years or older, as Louw (1991:542) states that 83% of males have been sexually active by the age of 19. Participants were required to be wheelchair-bound due to SCI caused by accidents or trauma, and not due to congenital or other neurological disorders. Further, it was a prerequisite that SCI had occurred at least one year prior to the interviews, as White *et al.* (1992:225) found that sexual activity in males with SCI resumed up to six months post-injury. Also, within one year the male is usually discharged from hospital, has undergone rehabilitation and has dealt with some of the physical and psychological consequences of his injury (White *et al.* 1992:225).

Data collection

The raw data of the study were obtained through face-to-face phenomenological interviews. These interviews were recorded and transcribed verbatim with non-verbal cues noted in the appropriate places. The interview was largely unstructured in order to afford the participant the opportunity to direct the content of his experience and to express it in his own unique manner, which is consistent with phenomenological methodology (Becker, 1987:63). Confidentiality and anonymity were assured prior to the interview and again reiterated following the interview.

Data analysis

The transcriptions were analysed using a six-step phenomenological process as proposed by Giorgi (1983:192) and Wertz (1983:197). These steps included gaining an understanding of the data as a whole, utilisation of an existential baseline, emergence of natural meaning units, first- and second order profiling in order to synthesise natural meaning units and transferring individual experience to general experience. The individual interviews were analysed using an intra-individual approach to identify the natural meaning units. An intra-individual approach allows the researcher to find natural meaning units within each participant's interview. Following this an inter-individual approach was utilised to elicit the common themes of the experiences. An inter-individual approach allows for a comparison of themes between different participants.

Methods for validity and reliability

Approaching the question of validity and reliability of a phenomenological study, Register and Henley (1992:472) state: "The best measure of generalisability, reliability and validity in (phenomenological) research, however, is ultimately in the correspondence between the results obtained and the experiences you, the reader, yourself have had". To achieve an acceptable level of validity, reliability and trustworthiness, it was ensured that in this study the transcriptions and the results have been made transparent so that the reader may scrutinise them and consequently pass personal judgement on the credibility of the study (for full interviews refer to Walter, 2000:118–240). These results were also given to the participants of this study in order to ascertain validity and reliability through correspondence of actual experience and of results. Furthermore, the final description of the phenomenon can be verified by comparing it to the transformation and transcriptions as a test for validity.

Ethical issues

The very nature of the aim of a phenomenological study, to understand the individual's life world, is obtrusive. In this study, this obtrusiveness is further exacerbated by the sensitivity of the topic of sexuality. First and foremost, the researcher has a responsibility to respect the rights, needs, values and wishes of the participants (Rosnow & Rosenthal, 1996:237).

In order to protect the participant's rights, the following safeguards as listed by Creswell (1994:184) were employed:

- The research topic and objectives were articulated clearly in order to be well-understood by the participants.
- Each participant had to give his/her consent to participating in the study.
- Transcriptions, interpretations and reports were made available to the participant if they wished to scrutinise them.
- In any decision-making process in the study, the researcher firstly considered the rights and protection of the participants.
- The researcher honoured participant anonymity and maintained complete confidentiality.

The study further employed the ethic of offering the participants a debriefing session if they so required. The participants were informed of this session prior to the actual interviews and they were contacted telephonically a few days after the interview in order to ascertain how they felt after the interview and if they required debriefing.

FINDINGS

The study elicited central themes that were common to the participants regarding their experience of sexuality post-injury. These themes related to topics such as the decrease in independence post-injury, altered perceptions of masculinity and changes in sexual relationships. These commonalities or themes may be viewed as the essence of the phenomenon and are listed and discussed below.

Existential baseline

All four participants established an existential baseline by reflecting on their sexuality pre-injury and contrasting this post-injury. They perceive their sexuality post-injury to be frustrated by numerous limitations imposed on them by the nature of his injury. One participant described his loss as follows: *"...before the accident, uhm, I did have quite uh good sex uh, what's the word that I'm looking for? Sexual relationship with women and that. And uh that's gone, so you can't have, have that anymore, and so that is very frustrating"*. All the participants compared sexuality pre-injury to post-injury on a physical dimension, one participant also utilised a social dimension (in his altered ability to attract partners), while two utilised a psychological dimension (loss of independence).

According to Althof and Levine (1993:533) males with SCI may need to broaden their definitions of sexuality or alter the relative importance of various dimensions with respect to sexuality. This may, in turn, lead to an alleviation of feelings of loss and frustration. The results seem to support the finding of Althof and Levine (1993:533) in that participants spoke of a new-found mental sexual stimulation.

Loss of independence

The experience of decreased independence frequently

negatively impacts on the male who experiences SCI and the perception of his masculinity. It appears that the more independent the man who experiences SCI becomes, the more masculine roles he can fulfil and the easier it becomes for him to function on a sexual level (Lemon, 1993:90).

The results seem to suggest that independence and masculinity are directly proportional in relation to each other. In response to a question on how his losses have affected his sexuality or feeling of being a man, one participant responded: *"The physical things like not being able to drive. That your wife has to drive for you. Drive you where you want to go. She has to load you in the car. She orders at the restaurant. She pays the bill. Those aspects, yes."* Three of the participants presented with a desire for independence post-injury.

It also seems that the participants view any gain in independence post-injury as extremely valuable and relate their gradual gain of independence to changes in their sexuality: *"I'm very fortunate, in that I feel very independent. I pretty much do, **whatever**, I want to do, **whenever** I want to do that..."*. On elaborating how his independence is boosting him in sexual areas, one participant stated: *"Because you can independently do what you want to do without somebody, depending on somebody else"*.

The physical sexual relationship

The physical sexual relationship for the male who experiences SCI is fraught with changes, losses and needs (Althof & Levine, 1993:530). Males with SCI encounter losses such as the inability to initiate sex (Althof & Levine, 1993:532), the loss of spontaneity (Rabin, 1980:56) and the loss of physical satisfaction. Centrally, the male who experiences SCI tends to redefine or refocus physical sexuality to include a 'mental' component that elicits a mental satisfaction (Donahue & Gebhard, 1995:74).

The results indicate that the three participants who are quadriplegic or tetraplegic (the fourth participant is paraplegic and therefore more able to initiate sex) expressed frustration over their inability to initiate sexual encounters, for example: *"And it's also nice uhm for instance, like uhm, if you've got a girlfriend...to*

initiate the sexual act, and whereas like this (injured state), you can't really do that. You've got to say like, come here, or uhm, which sometimes spoils the mood. It's nice just to go there and initiate it, ja... (sounds sad)".

The same pattern was found for the theme of mental rather than physical sexual satisfaction. All three participants expressly stated that their sexual satisfaction is mental, for example: *"... I ...experience the sensation, in my mind"*.

This study elicited an important theme regarding the loss of and need for intimate physical contact which was lacking in the literature review. Two participants stated that their inability to display intimate physical contact such as holding hands or hugging constituted one of the greatest and most painful losses of sexuality post-injury. They also expressed the need to receive intimate touch from their partners. One participant stated that he *"still gets such a thrill out of it"* when his wife touches his head or face. The paraplegic participant (not included in the above two) addressed the need for foreplay such as oral sex which can probably be regarded as a similar theme of need for intimate contact other than sex.

Religion

It appears that the more rigorous the male who experiences SCI's religion is and the more active he is in this regard, the more impact this frame of reference has on his sexuality post-injury. This was indicated especially with one subject who claimed to be active in his religion and would not engage in premarital sex any more. He stated *"I took religion more seriously, and – all aspects of it"*, just after commenting that before his injury he did not worry about premarital sex. Now, he stated *"Premarital sex is wrong"*. Thus, the individual may base his sexual behaviour and values on his religious beliefs (Castillo, 1997:251; McCammon *et al.* 1998:36).

Coping

Central to dealing with sexuality post-injury is the employment of a variety of coping strategies by the male who experiences SCI. These may be effective or ineffective and are highly individualistic. Strategies com-

mon to the participants of this study include (examples included):

- Intellectualisation: *"I did a lot of reading, lot of studying about it (sexual issues) and, it can be normal...halfway, ja"*.
- Generalisations (for example, speaking in the third person): *"...the best way to get over your physical hang-ups basically is, independence. Get yourself as more independent as possible"*.
- Direct actions: *"I actually insist that if there is a situation like that (inaccessibility to his daughter's functions), they arrange for the meetings to take place at a point where it is accessible..."*.
- Humour: *"Not gonna cope. If you can't laugh at yourself, life's not worth living"*.

These central themes of the phenomenon of sexuality for the male who experiences SCI are generated and influenced by broader contexts. The male who experiences SCI is a being-in-the-world with physical, psychological and social dimensions, all which impact on and shape his experience, the meanings he derives from it and the decisions he makes in regard thereof.

Limitations of the study

The following limitations of the study can be identified:

- The homogeneity of the sample in terms of culture may limit the ability of the study's results to be generalised to other cultures, although generalisation is not generally a goal of phenomenological research. The study did not intentionally set out to utilise only white males, it remained open to participants from any cultural group. The sampling procedure elicited the most convenient and accessible candidates.
- The study may be criticised on the modest sample size. Perhaps a replication of the study with different participants may elicit differing results. This point is, however, consistent within the phenomenological framework and as such the results should be interpreted within the research's limited context.
- The researcher as a subjective being-in-the-

world may well have exerted some influence on the collection of data and the analysis of the results. The researcher attempted to avoid this potential bias and subjectivity by adopting strategies such as bracketing of her pre-suppositions and theories, verbatim transcriptions of interviews, validation of themes through justification from raw data by way of direct quotations, inclusion of the researcher's impressions and qualifying and supporting the findings by the literature study where possible.

RECOMMENDATIONS

In reviewing the literature and the findings of this study, it follows that three main recommendations may be made to the male who experiences SCI who is addressing his sexuality post-injury.

Education

All the participants of this study expressed the lack of education regarding their sexual functioning during their hospitalisation and/or rehabilitation. In this area the subjects all expressed their need to attain such information by becoming active in this regard. It appears that the dismissal of sexual education leaves the male who experiences SCI with much uncertainty, frustration and concern about his sexuality. Once the male is educated, his sexual functioning becomes more predictable and he is able to make more informed choices.

The education would require initiation of information regarding sexuality in the rehabilitation of the male who experiences SCI and may do well to include, where applicable, the partner. It appears that the attainment of concrete facts regarding his sexuality provides a strategy for coping for the male who experiences SCI. This was evident in this study in that all participants utilised intellectualisation and the active seeking out of factual information to cope with their sexuality post-injury. The subjects gathered information either by consulting a nurse and neurologist or via independent research.

Independence

The nature of SCI will render the male who experiences SCI less independent post-injury. The male may need to rely on others to bath, change and feed him, to move him around and to conduct his toilet functions. He may also no longer be the breadwinner or the family protector. The study found that the greater the level of independence post-injury, the greater the individual's self-esteem, confidence and perceptions of masculinity. This was found in particular with one subject who is paraplegic, has no caregiver, has a good career and who is independently mobile and felt that SCI has not greatly affected his masculinity due to this independence.

It appears that the more independent the male who experiences SCI can become, the better he can integrate his experience of sexuality post-injury. It follows that the areas mentioned above will be positively influenced. Thus, it is recommended that the male who experiences SCI attains employment and conducts as much of his life as independently as possible. Autonomy is also promoted by familial support and relationships that are not based on sympathy but on mutual respect (Bamford & Grundy, 1986:215; Grundy & Swain, 1986:32; Lemon, 1993:52; Persaud, 1986:11; Rabin, 1980:65; Siosteen, Lundqvist, Blomstrand, Sullivan & Sullivan, 1990:292).

Support relationships

It was found that a supportive relationship is also influential in many aspects of the male who experiences SCI's sexuality. A supportive relationship may serve to foster in the male who experiences SCI's improved self-esteem, body image and independence.

It may be necessary for the male who experiences SCI and his partner to attend some type of intervention therapy, supportive therapy or psychotherapy. This may facilitate factors such as mutual respect, understanding and, most importantly, open and honest communication. Communication is also key to the physical sexual relationship. Partners need to be completely transparent to each other in terms of their fears, desires, limitations and needs.

CONCLUSION

It is believed that this research has fulfilled its objective of obtaining an in-depth description of the experience of sexuality for the male who experiences SCI. The rich descriptions of this phenomenon serve to demonstrate the complexities and interplay of sexuality, SCI and individuality and the ultimate uniqueness of this experience. Despite this uniqueness, certain important commonalities appear to weave their way through the phenomenon, for example, a quest for independence. The research has demonstrated the complexities, contrasts and commonalities of the experience.

Sexuality for the male who experiences SCI is one that is pervasive and ever-present. It is one that is always influenced by the individual's broader context. It is a process that the male has been thrust into, a process that requires continual confrontation, courage and strength. It stands that for the able-bodied individual, there is no room for him/her to hold myths or judgements regarding the male who experiences SCI and his sexuality. Indeed, able-bodied individuals can derive humbleness and motivation in their sexuality and have great admiration for the male who experiences SCI as a sexual being.

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