

SEXUALITY IN THE MALE PARAPLEGIC

by

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DECLARATION

"I declare that: *Sexuality in the Male Paraplegic*, is my own work and that the sources that I have used or quoted have been indicated and acknowledged by means of complete references."

DEDICATED TO MY MOTHER

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SUMMARY

The aim of the study was to provide a platform for the male paraplegic to explore the implications of the disability on his sexuality.

A qualitative research method was utilised. In-depth interviews were conducted during October 1995 and February 1996 using a sample of ten black male in-patients at the beginning of their rehabilitation program and during their initial hospitalisation at Kalafong Hospital in Pretoria.

The results of the study indicated that the newly injured person has a great need to talk about the impact of the injury on his life. Three major areas of concern emerged: physical appearance, loss of control and independence and relationships. All three areas were perceived to have an impact on sexuality.

Rejection of the redefined intimacy by the able-bodied spouse, was perceived as a threat to sexual adjustment.

KEY TERMS

Black male paraplegic

Sexuality

Intimacy

Counselling

Rehabilitation

Spinal cord injury

Sexual dysfunction

Sexual adjustment

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CHAPTER 1

RESEARCH DESIGN

INTRODUCTION

There are few physical disabilities that are as complex and as challenging as the spinal cord injury. The injury threatens the individual's well being at many levels. Apart from physical restrictions, it carries a social stigma, has psychological and sexual implications and requires a radical revision of the persons self-image. With the progress in medical science, people with disabilities are now more concerned with the quality of their lives than with mere survival, thus the call for a revision of the rehabilitation programs. It is therefore a good time to allow the injured people themselves to describe what constitutes limitations in their world.

1. PROBLEM STATEMENT

The onset of a spinal cord injury introduces many physical impairments that change the persons ability to carry out activities such as ambulation, grooming, toileting and sexual activity. In addition there are psychological consequences that have a profound impact on the persons perception of himself (Trieschmann 1980: 4). The external requirements suddenly change necessitating adjustment.

Males with spinal cord injury experience disruption of sexual acts because of their motor paralysis and sensory deficit. The present rehabilitation programs at South African provincial hospitals do not address sexuality as part of the

rehabilitation process. Only mobility activities and daily living activities are included.

A survey of rehabilitation programs, by the researcher in 1992, revealed that of the six hospitals in the survey only one addressed sexuality. The reasons advanced for the omission were lack of personnel with knowledge and skills and the sensitivity of the issue. Very few people felt comfortable with the topic and the majority of the team in the spinal unit were females while the population of spinal cord injured were male. The female personnel did not feel confident to confront men about sexual dysfunction.

The failure to address the sex related problems and needs of the newly injured person, tend to confirm the individuals suspicions that as a person with a disability his sexual life is over (Miller, Szasz & Anderson 1981: 316).

In the past spinal cord injured persons who had completed their rehabilitation, left the hospital with their sexual concerns unanswered, making their sexual adjustment difficult.

2. REHABILITATION PROCESS

Rehabilitation is defined by Trieschmann (1980: 20) as the process of learning to live with ones disability in ones own environment. This learning experience is a dynamic process that starts at the moment of injury and continues for the remainder of a person's life.

Learning to live with a disability is a lengthy and often frustrating process. The spinal cord injured person has to deal with issues such as the devaluation of the person with a disability by society; the frustration and hard work associated with daily living activities of survival; the stress on family relationships and traditional roles; the altered sexual abilities and the loss of satisfaction from vocational and recreational activities.

Traditionally rehabilitation has focused on teaching techniques of mobility and activities of daily living. An area often neglected is sexual functioning. Mooney, Cole & Chilgren (1975: 8) attribute the neglect to either lack of knowledge or trained staff, or to the able-bodied persons attitude that the disabled are not sexual.

Recently the consumers of rehabilitation services have expressed a need to have their sexual concerns addressed by the rehabilitation staff. During group therapy at Kalafong Hospital in 1989, patients identified a need for sexual counselling. The results of an unpublished exploratory study by the researcher in 1990 and 1991 confirmed the identified need (Sishuba 1990).

The growing demand for a comprehensive rehabilitation care and for attention to all the disabled persons human needs, led to evaluation of the models used in rehabilitation in hospital. Two models were examined, the medical model which is widely used and the educational model.

2.1 THE MEDICAL MODEL

The medical model focuses on the injury. In the first weeks after the onset of the spinal cord injury, survival of the patient is the concern of the hospital personnel, the person becomes a passive recipient of the treatment designed to fix his body. When the medical stability has been achieved (when the person is no longer sick) but physically disabled, a rehabilitation program is outlined. At this point the person has to become an active participant in the process. The educational model differs in its approach.

2.2 THE EDUCATION MODEL

Trieschmann (1980: 26) points out that within this approach, rehabilitation is viewed as the process of teaching the person to live with his disability in his own environment. It is a learning process and everyone on the rehabilitation team acts as a teacher. The rehabilitation program is designed by staff with, not for, the person to meet his needs in terms of who he is and from what environment he will return. He becomes an active participant.

The medical model therefore concerns itself with some underlying pathology, while the educational model assumes that the person is healthy but must learn a series of behaviours so that he can return to the world outside the hospital.

The involvement of the injured person in the planning of the program gives the person an opportunity to give his input and to take responsibility for his rehabilitation.

The rehabilitation program should help the person to compete in a world designed for and dominated by able-bodied people. It should prepare the person for optimal functioning in the home and community settings. The preparation must include sexual health and adjustment considerations along with other factors of total human needs. Rehabilitation practitioners are beginning to be aware of the service gap in their rehabilitation programs.

3. MOTIVATION FOR THE STUDY

The idea of the study was conceived in 1989. In subsequent years, the researcher's activities confirmed that the issue of sexuality in the spinal cord injured person needed exploration.

3.1 The need to address sexuality issues following spinal cord injury was first identified in 1989 while conducting group therapy in the orthopaedic unit at Kalafong Hospital. Group members expressed a need to receive sexual counselling in view of the altered sexual abilities.

- 3.2 An evaluation of the rehabilitation program revealed that the program concentrated on activities of daily living and mobility techniques, neglecting sexual issues. An in-hospital community project conducted with the service providers comprising of doctors, nurses, physiotherapists, occupational thereapists and social workers in 1990, revealed that they lacked the training in this field, and thus did not feel confident to attend to the injured persons sexual concerns.
- 3.3 Literature review revealed paucity of material on sexuality and spinal cord injury. Most studies were done in western countries. There was a conspicuous lack of South African literature, particularly on Africans.
- 3.4 Statistics from the National Spinal Cord Research Centre in the United States, supported by the 1980 census of the Statistics Bureau in Pretoria showed that spinal cord injury occur in young males in their early adulthood. Early adulthood is described by Masters and Johnson & Kolodny (1986: 159), Goddard (1988: 240) and Dewis (1989: 389) as a critical period when the persons are confronted with developmental tasks one of them being the development of the capacity for intimacy.
- 3.5 Most studies were done after the hospitalisation period. Not enough is known about the sexual issues that plague the newly injured person immediately after the spinal shock period at the beginning of the rehabilitation program.
- 3.6 Most evidence in the area of sexuality and spinal cord injury comes from expert, clinical or professional sources.

The perspectives of the spinal cord injured people was lacking. A need to provide the spinal cord injured people, the beneficiaries of the services, with an opportunity to share the inner view of their life as disabled people was identified. The researcher felt it was time to listen to the true experts in this 'field' the persons who themselves have a disability.

- 3.7 An unpublished study by the researcher in 1989*90 found that most respondents in the study expressed a need to receive sexual counselling during hospitalisation (Sishuba 1990).

The findings of that study were presented at the Rehabilitation International Congress in Kenya in 1992.

The representation sparked interest among the disabled delegates. There was a call for more work to be done on the subject, especially from the African delegates.

It is hoped that involving people with spinal cord injury as informants in research, will provide pertinent data that will provide information needed to generate new research. The study might broaden the understanding of life as a disabled person.

4. RESEARCH GOAL AND OBJECTIVES

4.1 GOAL

To understand the world of the African male paraplegic and to put the importance of sexuality on the newly injured person during the initial hospitalisation into perspective.

4.2 OBJECTIVES

- 4.2.1 To provide a platform for the spinal cord injured male paraplegic to explore the implications of the injury on his sexuality.
- 4.2.2 To generate information to enable the service providers to design a sexual rehabilitation program, to address the newly injured persons concerns about sexual functioning.

5. RESEARCH QUESTION

While a research topic refers to the overall area of investigation, research questions and research hypotheses both refer to a specific aspect of the overall area. A general question may not always precisely identify all the variables which are the subject of the study. A hypothesis on the other hand, by definition, always contains specific independent and dependent variables (Grinnell, 1988: 436).

When we do not have enough knowledge in the study, then we use a general question.

The area of sexuality in the spinal cord injured person according to Fancoeur in Leyson (1991: 6) received attention in 1960 when Comarr initiated the scientific effects of spinal cord injury on sexual functioning.

It was not until the mid 1970s that male spinal cord injury related sexual dysfunctions were considered a problem treatable.

Mooney, Cole & Chilgren (1975: viii) believe that the neglect of sexual issues stems from the able bodied persons attitudes that the disabled are not sexual.

They point out that the disabled share with the rest of society, the misfortune of living in a society that has traditionally censured sex, but the people with disabilities are hit harder.

Sex is a primary drive as are hunger and thirst and avoidance of pain. Every person has sexual feelings, attitude and beliefs but everyone's experience of sexuality is unique because it is processed through a personal perspective.

According to Masters, Johnson & Kolodny (1986: 3) the individuals sexual personal perspective comes from both private, personal experience and public social sources. The authors describe sexuality as a dimension of personality rather than the individuals capacity for erotic response.

It is imperative for service providers to understand the multidimensional nature of sexuality and to guard against over emphasising the issue of sexuality more than the spinal cord injured persons themselves.

Trieschmann (1980: 94) cited studies by Hanson and Franklin that showed that the rehabilitation staff viewed loss of sexual function as more important than the injured persons themselves.

The study explored the perspective of the newly injured African male paraplegic with regard to sexuality during the initial hospitalisation.

The pertinent question to be answered in the research study was:

IS SEXUALITY AN IMPORTANT AREA OF CONCERN TO THE SPINAL CORD NEWLY INJURED MALE (PARAPLEGIC) DURING THE INITIAL HOSPITALISATION PERIOD?

Literature search has revealed that information pertaining to the sexual concerns of spinal cord injured person at the onset of injury was very little, thus knowledge of this period is not enough.

6. RESEARCH DESIGN

In selecting a research design a number of aspects were taken into consideration.

The first aspect considered was knowledge on the subject. In South Africa little if any research is done in the field of sexuality and disability and in particular on sexuality in the spinal cord injured person. Most studies reviewed were done after the initial hospitalisation period, thus information on the importance of sexuality during the initial hospitalisation is not available.

Literature search revealed limited material there was a paucity of recent material, the researcher was compelled to utilise literature dating more than 10 years back.

The second aspect was the population studied in the past. Most studies were conducted in western countries, countries such as Sweden, United States of America, Israel and Canada have done extensive work. An inquiry at the Human Sciences Research Council in 1993 revealed that studies done in South Africa were limited in number especially studies on sexuality and spinal cord injury.

The third aspect was culture. Culture and ethnic background play an important role in psycho-social functioning, they influence the person pre and post injury. What is labelled as moral or right varies from culture to culture. Studies on sexuality attending to cultural traditions were not available. Thus information generated in this study may shed some light and illuminate cultural factors that come into play in sexuality issues in the African male paraplegic. This is not to imply that spinal cord injuries have a different impact on Africans than elsewhere in the world. There are reasons to

suppose that the impact on sexuality may vary according to factors such as religion or culture.

The study therefore aims to explore the issue of sexuality in the African male paraplegic.

6.1 EXPLORATORY DESIGN

Exploratory design was selected since the degree of conceptual development is low on this subject. The design is suitable for the study because the research participants can use their own language expressing their feelings and experiences to identify issues that are pertinent to them concerning their injury and sexuality.

According to Grinnell (1988: 188) detailed descriptions of social reality can be obtained by using qualitative methods; the descriptions can either serve as ends in themselves or they may be useful in generating hypotheses that can be tested at a later date.

The advantage of qualitative methods is that the description of the reality is from the point of view of the participant within the system studied. The respondents are actors in a social situation they can best describe their actions and the reasons for them.

Arkava and Lane (1983: 190) point out that often the practitioner possesses little objective information about the nature of the problem and the possible factors influencing it. In such instances, the best design to use is the exploratory design.

Bogdan and Bilken (1992: 29) cite five characteristics of qualitative research.

- (i) It has the natural setting as the source of data and the researcher is the natural key instrument.
- (ii) The qualitative researcher is concerned with the process rather than the outcome.
- (iii) Theory developed in this manner emerges from the bottom up. The researchers are not putting together a puzzle whose picture they already know. They are constructing a picture that takes shape as they examine the parts.
- (iv) The researcher is concerned with participant perspective. Qualitative research illuminates the inner dynamics that are often invisible to the outsider.

The selected research design will help with the generation of tentative insights which can be studied at a later date and verified at other levels of research. The study will provide the African male paraplegic with an opportunity to describe the impact of the injury on his sexuality.

For the purposes of the present study, the terms: research subject, research respondent and research participant were used interchangeably.

7. THE SAMPLE

The spinal cord injured population is scattered throughout the Republic of South Africa. Since the study proposed to concentrate on individuals in hospital during the initial hospitalisation at the onset of the injury, a non-probability sampling was used.

Grinnell (1988: 251) points out that non-probability samples are suited to exploratory studies where the researcher is interested in obtaining as much unique data on a research question as possible. The sampling is also useful in studies in which sampling units, paraplegic males, are in key positions to observe or experience the phenomenon being investigated.

7.1 AVAILABILITY SAMPLING

The first available sampling unit that meet the following description will participate in the study.

The incidents of spinal cord injury are high in young adults, thus the research subjects fell in the age category of between twenty and 40 years. Participation was voluntary. Ten newly spinal cord injured persons participated in the study. They were African males with a diagnosis of paraplegia (paralysis of lower limbs).

Registered in-patients, during the initial hospitalisation after the onset of the injury were involved. It was during the post spinal shock period at the beginning of the rehabilitation program.

The research subjects must have been sexually active prior to the injury. They must have been willing to have the discussion recorded on a tape recorder.

7.2 RECRUITMENT

Prior to approaching the respondents, permission to conduct a study involving hospital patients had to be obtained from the Superintendent and the Ethics Committee.

Medical and clinical particulars pertaining to the onset of the injury, cause of the injury, level of the injury and nature of the lesion were obtained from the sister-in-charge of the spinal unit.

Background information and details of the study were provided in a group setting. Volunteers were then interviewed individually to ensure that they met the criteria. At that stage details of their role in the study were provided.

In involving the people with disabilities as informants in research, in the matter of their own lives, as expert witnesses, who speak from a secure position of knowledge, increased the understanding of the world of the newly spinal cord injured African male paraplegic during the initial period of hospitalisation.

8. DATA COLLECTION

Several factors had to be taken into consideration before selecting a research instrument.

8.1 ACCESSIBILITY

The participants are easily accessible because they are registered as in-patients in the spinal unit. About 40 percent of patients admitted in public hospitals are illiterate, thus reading a questionnaire would pose problems.

The researcher is fluent in five African languages, Zulu, Xhosa, North Sotho, Tswana and Swazi, thus communication with the participants was easy.

Negotiating schedules with the rehabilitation team was facilitated by the good relationship between them and the researcher.

8.2 RESEARCH SUBJECT

The research topic was of an intimate and complex nature. Sexuality is a very sensitive and private aspect of a persons life. A good relationship must exist before one can be free to share intimate information. Privacy was of the utmost importance.

8.3 FOCUS OF THE STUDY

The subjective experiences of the spinal cord injured African male was the focus of the study.

The researcher hoped to gain an understanding, in considerable detail, of how the newly spinal cord injured persons developed the perspectives they held. The information was best obtained through personal interaction. The inner dynamics that are often invisible to the outsider can be brought to the fore by interaction with the research subjects.

8.4 RESEARCH INSTRUMENT

The interview schedule was selected because it affords personal interaction. Grinnell (1988: 267) points out that an interview has naturalness and spontaneity, it allows flexibility and control of the environment.

The presence of an interviewer allows for a more detailed set of questions. During the interview non-verbal responses can be observed and greater depth can be achieved through the use of probing questions. The interviewer can also ensure that the responses are from the respondent and not influenced by people around him. Rubin and Babbie (1989: 322) maintain that the interview is beneficial because the researcher is given an opportunity to clarify misunderstandings and to ensure that all questions are answered.

A semi-structured interview schedule was selected because it gave latitude to the interviewees to explore in their own way matters pertaining to the research questions being studied. Interviewees were free to introduce unanticipated answers that were important to them.

The interviewee is not limited in his exploration of the subject under discussion. This method was suited to the study, as the aim was to gather information that would help the rehabilitation team to gain insight into the private world of the newly injured African male paraplegic with particular interest in his view of the disability and its impact on his sexuality.

Biren and Deutchman (1991: 1) believe that when a person shares his life-story, he develops a sense of a stronger identity of who he is. It provides an opportunity to specify the elements of the self and how as an individual, one differs from others.

The interview provided the interviewer with an opportunity to listen to the respondents point of view. Booth and Booth (1994: 23) postulate that where the task is to understand the subjective realm of the lived life, it is essential for the researcher to listen to those who know.

It was hoped that the personal contact would facilitate the establishment of rapport and make it easier for the respondents to share their personal perspectives.

9. PRESENTATION OF DATA

Bogdan and Biklen (1992: 30) describe data collection in a qualitative research as raw material collected in the form of words rather than in numbers. They emphasise that it is important to analyse the data with all their richness as closely as possible to the form in which they were recorded. The direction the researcher will travel comes after collection of data and spending time with the subjects.

The authors describe the process of analysis as a funnel. Things are open at the beginning (top) and more directed and specific at bottom. The researcher uses the study to learn what the important questions are instead of assuming that enough is known before undertaking the research.

Literature review revealed that the period of initial hospitalisation has not been sufficiently explored. The researcher entered the field with the assumption that as much detailed information as possible needs to be gathered. She planned to lay a foundation for further research and to develop some understanding of the world of the newly injured African paraplegic.

The presentation of data will be in a narrative form. Themes were used with headings and subheadings. Description of the world of the African male paraplegic was presented in words, and quotations were utilised to illustrate and substantiate the information presented. The presentation grouped together the gathered particulars and put pieces that were interconnected together.

10. LAYOUT OF DISSERTATION

The dissertation consists of seven chapters. Chapter one deals with the research design, chapters two, three and four covers literature review with chapter two looking at sexuality and disability: conceptual issues; chapter three reviews previous empirical studies on sexuality and spinal cord injury and chapter four looks at treatment of sexual dysfunction in people with spinal cord injuries. Chapter five covers the research methodology. In chapter six the empirical research findings are presented and the seventh chapter outlines the conclusions and recommendations.

CHAPTER 2

SEXUALITY AND DISABILITY: CONCEPTUAL ISSUES

INTRODUCTION

The purpose of this chapter is to provide a clinical perspective of spinal cord injury from which the researcher can develop an understanding of the gravity of the implications of the injury on the individual's sexuality. This will be accomplished by describing the functioning of the spinal column, the physiological, psychological, sexual and social consequences of spinal cord injury.

A person with a recent spinal cord injury encounters a variety of barriers and adjustments during the rehabilitation process. In addition to the physical limitations, spinal cord injury has social and psychological consequences that have a profound impact on the person's perception of himself. Some authors argue that at the onset of the disability, three factors are uppermost on the injured person's mind, namely, the financial circumstances, the physical disability and sexuality. Literature review has shown that in recent years, the emphasis of rehabilitation has shifted from the physical well being of the person with a disability to include all his human needs. It was not until 1970 that sexual dysfunctions were considered in the rehabilitation programme in the United States of America.

The integration of human sexuality into rehabilitation practice, requires an understanding of the physiological, social, psychological consequences of spinal cord injury.

1. CRITICAL FACTORS IN THE REHABILITATION OF MEN WITH SPINAL CORD INJURIES

The person with an injured spinal cord can now expect to attain normal longevity given the appropriate medical supervision. The major emphasis has now shifted from helping the spinal cord injured fight for his life to providing a meaningful life for the individual (Rabin 1980: v).

According to Sha'ked (1981: ix) rehabilitation experts have realised that sexual adjustment is at the core of the total medical and psycho-social rehabilitation of people with disabilities. To attend to the aspects of sexuality and disability, the rehabilitation team has to have factual knowledge about the function of the spinal cord, as well as the physical and psycho-social implications of the paralysis on sexuality.

1.1 THE SPINAL COLUMN

The spinal column is made up of the vertebral column and the nerve supply to the body. The vertebrae consists of thirty three bones protecting the spinal cord. The neck has eight bones medically termed C1 - 8 or cervical level of the vertebral, and controls the diaphragm, arms, elbows, wrists, hands and fingers.

The thoracic termed T1 - 12 is responsible for the functioning of the chest and abdominal muscles. The lumbar area or L1 - 5 is in charge of leg muscles. The lower part the sacral region or S1 - 4 is responsible for the functioning of the bowel and the bladder.

Holmes (1987: 1) describes the spinal cord as consisting of a large nerve fibre tract which connects the brain with the muscles, skin, and internal organs of the body. The central nervous system (brain and spinal cord) is responsible for transmitting messages to and from the brain. If any of the spinal cord nerves are injured or damaged, the flow of messages to and from the brain will be hampered.

1.1.1 SPINAL CORD INJURY

An injury to the spinal cord may produce symptoms that are temporary or permanent as well as impairment that may be complete or incomplete.

An incomplete lesion is one in which certain amounts of motor and sensory function below the level of the injury will be intact. A complete lesion is one in which sensory and motor loss is total below the level of the lesion.

Implications for future functioning may be significantly different for two individuals who are injured at the same vertebral level, if one has a complete lesion and the other has an incomplete lesion.

Motor and sensory function will therefore vary depending upon the level of the injury on the vertebral column.

1.1.2 PARAPLEGIA

Spinal injuries in the thoracic lumbar and sacral levels will result in paraplegia, that is paralysis in the lower extremities.

Injuries between T1 and T8 will involve paralysis of the chest and trunk muscles, abdominal muscles and leg muscles. As a result balance and stability will be a potential problem.

Holmes (1981: 86) who has a physical disability (Paraplegia) describes it as one of the most difficult problems in rehabilitation. Physically the severity of the injury incapacitates some parts of the body while other parts remain intact.

1.2 PHYSIOLOGICAL CONSEQUENCES OF SPINAL CORD INJURY

Spinal cord injury results in physical complications that are distressing to the injured person, his family and friends. They are aggravated by the psychological and social implications that need to be considered.

At the onset of the spinal cord injury, it is the physiological consequences that receive immediate attention.

Studies by (Trieschmann 1980: 25; Holmes 1981: 22) have shown that the following physiological consequences have an impact on the person's sexuality.

1.2.1 SENSORY IMPAIRMENT

In complete lesions, there will be a loss of sense of touch, temperature, pain and position below the level of the lesion. The loss of touch and pain predisposes a person with spinal injury to pressure sores.

1.2.2 BLADDER DYSFUNCTION

Holmes (1981: 32) points out that after any traumatic lesion of the spinal cord, regardless of whether the lesion is complete or incomplete the bladder enters a state described as spinal shock. During this stage the bladder remains non-functional, emptying only small amounts of urine periodically.

Initially an indwelling catheter in the bladder will provide for drainage of the urine. Following spinal cord injury the person has to take certain steps to maintain a healthy urinary tract system.

The urine needs to be acidified either through medication or diet, a lot of fluid intake is essential each day. The probability of bladder infection is increased by the presence of an indwelling catheter.

Holmes (1987: 8) states that it is important for the professional involved in the rehabilitation process, to have a basic knowledge and understanding of the urinary complications together with the various methods of incontinence control, as they play a role in the individuals ability to cope with altered body image following the onset of trauma.

1.2.3 BOWEL DYSFUNCTION

Bowel incontinence introduced by injury on the spinal cord is a cause for concern as it interferes with an individuals social and vocational life.

As in bladder control, defecation is dependent on the co-ordinated action of an opening and closing mechanism and in this respect the anatomical connections of the rectum are analogous to those of the bladder. These connections are dependent upon the intactness of the spinal centre in the lumbosacral cord (Holmes 1987: 9).

Life as a spinal cord injured person loses much of its flexibility and spontaneity. A bowel program is planned in order to train the bowel schedule. Maintenance of a proper diet becomes essential to avoid disruption of the bowel schedule. Adherence to diet and bowel schedule avoids socially embarrassing accidents.

1.2.4 SEXUAL FUNCTION

Sex is a primary drive, as are hunger, thirst and avoidance of pain. These primary drives are expressed through the complex interrelationship of bodily receptors, hormonal balance, the autonomic nervous system and the central nervous system.

Males with spinal cord injuries experience disruption of sexual acts because of their motor paralysis and sensory deficit. In addition there will be an interference in the ability to obtain an erection. The level of the injury and completeness of the lesion will be the key factor in the ability to have erections.

According to Trieschmann (1980: 9) although erections may occur on a reflex basis not psychogenically, intercourse is still possible for spinal cord injured men.

Despite the physical interference with sexual function, many men have satisfying sexual experiences with their partners (Holmes 1987: 44; Berkman, Weisman & Froelich 1978: 20).

1.2.5 FURTHER COMPLICATIONS

There are several other factors that need to be considered when describing the physical consequences of the spinal cord injury and its impact on sexuality.

Depending on the level of the injury, the issues of pain, muscle spasms, autonomic dysreflexia, temperature regulation and respiratory function may have a significant impact on a person's daily life.

1.3 PSYCHOLOGICAL FACTORS

The loss of function of body parts has an impact on the person's motivation, body image and self-concept.

The onset of disability, such as spinal cord injury often affects a person's ability to function "normally" and may lead one to evaluate his masculinity. Sex may not be the most important issue facing the newly injured person, however, it is a significant one that affects an individual's gender identity and ability to establish and maintain relationships.

1.3.1 MOTIVATION

Motivation is a critical factor in the rehabilitation process.

According to Trieschmann (1980: 57) there are three approaches to motivation. One approach considers motivation to be those rewards in the environment for which the person will work, the other approach considers motivation to be a dynamic force within the individual and the last one is a combination of the two, postulating that the individuals locus of control in interaction with environmental rewards will be the key to

motivation.

A study by Diamond, Weiss & Grynbaum in 1968, cited in Trieschmann (1980: 57) found that participants in the rehabilitation programme for persons with spinal cord injuries were positive, hopeful and future orientated, while the non-participants were negative, resigned and past-orientated.

The rehabilitation team must know the locus of control of the injured person in order to develop a successful intervention method. For a person who has an internal locus of control it would be best to concentrate on what the program will do for him. For example such a person will engage in activities that will benefit him, such as daily living activities that will help him to regain his independence. It is also important to allow such an individual to set his goals because he will select the issues that are important and relevant to his situation. On the other hand an individual with an external locus of control views the external world as responsible for what happens to him. For him the reward is in the environment. He may select activities that will impress his partner or his friends.

Motivation can therefore be external or internal to the patient. The rehabilitation team and significant others must have knowledge of the locus of control of the injured person in order to steer him in the right direction.

1.3.2 BODY IMAGE

Body image is a term that refers to the body as a psychological experience and includes one's feelings and attitudes towards one's own body, body parts and body functions (Trieschmann 1980: 65).

Studies of body image as a personality variable in persons with spinal cord injuries have not produced much information that is helpful in understanding the process of sexual adjustment to spinal injury.

According to the Consumer Conference 1977, persons with spinal injury described increased efforts to look attractive in contrast to a lesser concern with personal appearance prior to injury. They believed that how they look and the attitudes that they communicated about their bodies to others was a big factor in coping with the social world following a spinal injury (Trieschmann 1980: 65).

Studies by Manganyi (1970) of black paraplegics and non-patient control groups, found that both the experimental and normal control group had equally disturbed body concepts.

While information on body image and spinal cord injury is not sufficient, body image remains an area that is vital to self-concept.

It is important that the patient integrate his disability into his body image. His image of himself must now include the lifeless lower limbs as well as the aids and appliances that assist him to cope with his environment.

Body image is critical when addressing the issue of sexuality because the individual's image of himself will determine his ability to establish and maintain relationships and his view of himself as a sexual person.

1.3.3 SELF-CONCEPT

Injuries to the spinal cord frequently cause partial or complete loss of sensory and motor function below the lesion. People with disability have to face many difficult physical and psychological problems including the belief of the patient or his family that he has completely lost his sexual function.

Stubbins (1977: 453) maintains that it is especially important to correlate the positive relationship between self-concept and sexual attitudes. He stresses that if counsellors were to know a person's self-concept there is a greater chance that they could learn how the person feels about himself and the world around him. If problematic sexual attitudes are a result of a negative self-concept, the person could be assisted to work towards acceptance of a positive self-concept.

Sing (1977) as cited by Stubbins (1977: 453) describes self-concept as "all that a person is" and serves as a super-moderator of his functioning. What an individual feels, how he acts or reacts and how others react to him is a direct result of his individual self-concept. Cooley as cited in Stubbins (1977: 453) described the self as three basic elements.

- the imagination of ones appearance to the other person
- the other person's appraisal of that appearance
- some kind of self-value (feelings such as pride or shame)

A person with an injured spinal cord must make an adjustment and integrate the disability into the body image. Sometimes the victim will take a dim view of himself because he has not integrated his disability into his body image. His body may look ugly to him, so he may feel that a person as unattractive as he is, should forego sexual relationships.

Any effective rehabilitation must consider the whole person, for the greatest resource in the rehabilitation of any individual, is that individual himself.

A study by Koehler cited in Nordqvist (1986: 24). using the Tennessee Self Concept scale on 175 subjects with spinal cord injuries, revealed that there was a strong positive relationship between the self-concept and a successful rehabilitation. It must be remembered however, that self-concept is only one of many factors.

Wright (1960) cited in Holmes (1987: 128) postulates that the self-concept of the individual with an injury to the spinal cord becomes very important because of the changes undergone after the onset of the injury. These physiological and psychological effects can result in the individual feeling abnormal and not accepting himself.

Self-esteem is a vital component of the male's capacity for sexual performance. An individual with low self-esteem will be inhibited in the formation of sexual relationships. The injured person will imagine what their sexual partner thinks of their appearance and the perceived appraisal of that appearance by the sexual partner will influence the injured persons self-evaluation.

Self-concept is an important factor to consider when dealing with sexuality and disability.

2. SEXUALITY AND SPINAL CORD INJURY

The potential for expression of sexuality is present throughout the lifespan, however certain situations, such as spinal cord injury, may interfere with the expression of this drive.

According to Dewis (1989: 389) the young are especially prone to spinal cord injury, and it occurs at a time when critical developmental tasks are being confronted.

These injured people are faced with an enormous task of coping with the multiple sequelae of the injury.

It is now generally accepted among professionals (and partially by society) that the onset of physical disability does not eliminate sexual feelings and that the injured individual continues to be a sexual being. Kaplan (1979: 4) concurs by pointing out that sexual adjustment is being increasingly viewed as an integral and necessary part of the total psychological adjustment of the individual.

Mooney, Cole & Chilgren (1975: viii) who are proponents of studies in sexuality and disability, emphasise that the disabled are people, and people are sexual. They explain that much of the individual's personhood comes from the ability to play a sexual role. In essence nobody is too disabled to derive some satisfaction and personal reinforcement from sex. The authors believe that when a disabled person is unable to enjoy sex, the greatest obstacle to enjoyment is the social contention that sex consists of putting the penis in the vagina and that all the remaining range of human and mammalian sexual responses; oral, manual and skin stimulation, are abnormal. They strongly believe that sex is widely versatile and hardly limited to the genitalia.

Individual beliefs and attitudes are important factors in coping following spinal cord injuries. Frank and Elliot (1989: 251) believe that individuals vary in their beliefs about responsibility for and control of events and situations. It is therefore timely to allow the people with spinal cord injuries to describe what constitutes limitations in their lives themselves.

In order to understand the impact of spinal cord injury on sexuality, it is imperative that the rehabilitation team should understand sexual function. It is important to look at the whole spectrum namely, the sex drive, the sex acts and sexuality.

Trieschmann (1980: 127) differentiates among sex acts, sex drive and sexuality as part of sexual functioning.

2.1 SEXUAL FUNCTION

2.1.1 SEX ACTS

Sex acts are those behaviours involving the erogenous zones and genital areas that may, but need not, include sexual intercourse. There are a variety of sex acts that involve motor behaviour and that produce pleasurable sensory responses. Through sex acts we express our sex drive.

2.1.2 SEX DRIVE

The sex drive as a primary drive is expressed through the complex interrelationship of bodily receptors, hormonal balance, the autonomic nervous system and the central nervous system.

2.1.3 SEXUALITY

Sexuality is the expression of a sex drive, through sex acts, within the context of the sexual identity of the person. Berkman and associates as cited in Trieschmann (1980: 135) define sexuality as a dynamic process based on developmental learning experiences which has three components:

- The psycho-social component in which the individuals self-concept is central.
- Socio-sexual component which characterises relations with others.
- The behavioural component which focuses on specific sexual behaviour.

They state that sexual development like other human growth, is an ongoing process in which new learning occurs throughout life. Thus sexual expressions can change because of personal needs, interpersonal experiences and as a result of physical limitations.

2.2 THE ANATOMY AND PHYSIOLOGY OF MALE SEXUAL RESPONSES

The physiological male sexual responses is a complex interaction of various bodily systems

Sha'ked (1981: 67) describes the physiological male sexual responses as the three 'E's', erection, emission and ejaculation.

2.2.1 ERECTION

The ability to have an erection is controlled by the central nervous system and three levels are involved, cerebral centres, thoracolumbar outflow (sympathetic system) and the sacral cord (parasympathetic system).

The cerebral afferents pathways connect with the thoracolumbar and sacral erection centres of the spinal cord.

It is believed that the psychogenic erotic stimuli may release a thoracolumbar vasodilator impulse, resulting in erection of the penile corpora.

Tactile stimulation of the penis and stimuli from the rectum are carried as sensory afferents via the pudendal nerve to the sacral cord segments S2 - 4. Efferent parasympathetic impulses are conducted from the sacral via pelvic nerves to the penile corporal arterioles resulting in a reflex erection.

Actual erection of the penis is a vascular phenomenon. When the penis is flaccid the erectile bodies contain very little blood. During erection the vascular spaces fill and distend with blood.

The arterial inflow is greater than that of venous return and the penis becomes erect.

2.2.2 EMISSION

Emission is a function of the sympathetic nervous system. During sexual stimulation, the sympathetic outflow causes contraction of the smooth muscle of vas deference transporting sperm to the ampula of the vas.

2.2.3 EJACULATION

At the time of emission, the seminal bolus sets off sensory afferents from the posterior urethra via the pudendal nerve to the sacral cord (S2 - S4).

Orgasm is thought to be the conscious perception of the contraction of both the smooth muscles of the internal sexual organs and the striated pelvic muscles.

Clonic contraction of the striated muscles, together with completion of bladder neck closure, results in projectile ejaculation through the urethra.

2.3 SEXUAL FUNCTION AFTER SPINAL CORD INJURY

The capabilities of sexual response in men who have injured spinal cords vary depending on the cord level of injury and the completeness of the lesion. The upper motor neuron lesions refer to the spinal cord lesions which preserve the sacral cord. Persons with these lesions will

have external anal sphincter tone and reflex. The majority of such lesions are above T12. Lower motor neuron lesions imply disruption of the sacral cord. Patients with these lesions will have a lax anal sphincter and absence of a bulbocavernosus.

2.3.1 ERECTION

Sha'ked (1981: 70) maintains that erection incidents are greater in patients with incomplete lesions and those with upper motor neuron.

Since erection is a condition vital to traditional coitus, problems in this regard do exist for a number of males with spinal cord injuries (Holmes 1981: 13).

Studies done on sexuality and men with spinal cord injuries have described two types of erection. The reflexogenic erection occurs by reflex and is not associated with sexual stimuli. The second type is the psychogenic erection in which the cognitive activity causes erection.

Maintaining an erection can pose a problem after spinal cord injury depending on the level and the completeness of the lesion.

2.3.2 EJACULATION

According to Sha'ked (1981: 70) ejaculation is a more vulnerable component of sexual function than erection.

Studies have shown that the incidence of ejaculation is greater in persons with

- i) incomplete lesions vs complete lesions
- ii) lower motor neuron lesions vs upper motor neuron lesions
- iii) lower cord lesions vs upper cord lesions

Gott as cited by Sha'ked (1981: 72) points out that the vast majority of men with spinal cord injuries with complete upper motor neuron lesions will be unable to ejaculate. With incomplete upper motor neuron lesions, 25% have been reported to ejaculate. Ejaculation was noted in up to 35% of men with spinal cord injuries with incomplete lower motor neuron lesions.

Chigier (1976) points out that because of a weakness of the internal vesical sphincter, many men with injured spinal cords experience retrograde ejaculation (into the bladder) rather than external ejaculation.

2.3.3 ORGASM

Holmes (1987: 62) cites Geiger as making a distinction between ejaculation, a pelvic event in so far as activity can be isolated to a particular part of the body, and orgasm as a cerebral event.

Orgasm ranges from two to sixteen percent in men who have spinal cord injuries. In those with complete upper motor neuron lesions orgasm is non-existent.

Comarr (1970) is of the opinion that the intensity of orgasm seems to be dependent mainly upon the intactness of the sensation associated with muscle contraction of ejaculation.

Studies reviewed seem to indicate that incidence of orgasm is greater in men with incomplete and lower motor neuron lesions than men who have complete and upper motor neuron lesions.

The phenomenon of phantom orgasm has been reported by a number of people with spinal injury. They describe a build up of tension with pleasurable sensations (although not genital in sensation) which may be followed by a feeling of relaxation, perhaps with temporary reduction of spasms.

Comarr and Vague (1978) reported that the ability to fantasise was related to an ability to have orgasm in a group of males and females with complete spinal injuries. However women in their group far exceeded the males in ability to fantasise. Thus strategies to teach males to use fantasy became one focus for sexual counselling (Trieschman 1980: 131).

One may conclude that the level of the lesion as well as a well developed ability to fantasise are significant factors in determining interest in sexual activity. may be a significant factor in interest in sexual activity.

2.3.4 FERTILITY

Fertility in men with spinal cord injuries is markedly impaired. The cause of this predominant infertility may be due to the fact that emission and ejaculation are preserved in a small percentage of men with spinal cord injuries.

Sha'ked (1981: 71) maintains that impaired spermatogenesis is common with spinal cord injuries in men.

A study of 529 men with spinal cord injuries by Bors and Commarr (1960) revealed that of men with complete upper motor neuron lesions only one percent fathered children and six percent of those with incomplete upper motor neuron lesions sired children. Five percent of men with complete lower motor neuron lesions sired children and finally 10 percent of men with

incomplete lower motor neuron lesions sired children.

One can thus conclude that the ability of men with spinal cord injuries to father children lies between one and ten percent.

2.4 DESIRE DYSFUNCTION

Upon first regaining consciousness or a clear understanding of the extent to which a spinal cord trauma has damaged the body, the injured are full of queries about three basic areas of their lives, physical survival and limitations, economic capability and sexual functioning (Hotchner) cited in Leyson (1991: 115)

The sexual concern centres on several important questions

- i) can I still satisfy my partner?
- ii) can I be satisfied sexually?
- iii) will I be desirable?

The fact that sexual capability is so prominent in the minds of the disabled indicates the centrality of sex in the lives of people. Sexual interest and functioning is a deep and pervasive aspect of personality and one that is essential to an integrated self and to a sense of general well being.

Leyson (1991: 115) in his study identified four phases of human psycho-social sexual response.

- Transition (the psycho-social urge to arrange or go out on a date and have a sexual encounter.)

- Preliminary desire (libido)
- Sexual arousal / excitement and
- Orgasmic - resolution phase

Hochner cited in Leyson (1991: 115) maintains that when sexual functioning is called into question or is feared to be irretrievable, a lack of interest in sex can become a protective mask for an overwhelmed ego. Sexual interest can be affected by other psycho-social ramifications of spinal cord injury.

Leyson (1991: 116) concludes that lack of sexual interest, strikes at the very foundation of what is important to people, to be normal, to be adequate, to love and to be loved.

The extent of sexual interest or disinterest in the person with an injured spinal cord is difficult to assess since various studies report different findings.

2.5 SOCIAL FACTORS

The onset of a disability, such as spinal cord injury has tremendous social implications for the disabled person. He perceives himself as different and this is confirmed by others reaction to him. Thus to cope, he will need to learn a variety of social skills in order to combat the devaluation and rejection he will experience. The social and ethnic background from which he comes and to which he will return influences the outcome of his sexual adjustment (Trieschmann 1980: 86).

Issues on social factors cannot be excluded when discussing sexuality and disability. The process of adjustment has been shown to be influenced by such variables as age, severity of disability, duration of disability, sex, family relationships, socio-economic status and culture, urban or rural residence and the task of socialisation.

The onset of spinal injury changes a persons social stimulus value and this change will be reflected in all areas of his life. The world is designed for and populated by able-bodied people who become constricted and uncomfortable in the presence of a person with a disability (Treichmann 1980: 110).

It can be concluded then that skills in social interactions are important to the success of a persons reintegration into society and in establishing and maintaining relationships.

The injured person finds himself re-entering a world familiar to him, a world he knew as an able-bodied person. He becomes a stranger in a world he knew so well because he now enters it as a person with a

disability.

All the social skills he learnt, he did so as an able-bodied person. He is not the only person who has to learn, he also is faced with an enormous task of sharing his world as a disabled person with his loved ones and significant others. His verbal skills are in demand more than ever before.

In establishing or reestablishing sexual relationships, he has to verbalise his needs, his abilities and his limitations. The reaction of and acceptance by others becomes crucial to his sexual adjustment.

The discussion of the effects of spinal cord injury on sexuality, cannot be limited to physical, psychological and social factors. The behavioural, spiritual and cultural factors also come into play. According to Masters, Johnson & Kolodny (1986: 5) sexuality means a dimension of personality instead of a persons capacity for erotic response alone. They emphasise that sexuality should be studied from the biological, behavioural, psychological, clinical and cultural perspectives in order to deepen understanding.

In understanding the multi-dimensional nature of sexuality one will be able to evaluate the effects of the impaired sexual function on the male paraplegic.

The individuality of each person has to be respected because though every person has sexual feelings, beliefs and attitudes, the experience of sexuality is unique, it takes place in a personal perspective.

Masters, Johnson & Kolodny (1986: 3) maintain that sexual experience comes from both private, personal and public social sources.

2.6 BEHAVIOURAL DIMENSION

The behavioural aspect involves not only what people do in the context of their sexuality. It also involves how and why they do it. This dimension is a product of both the biological and psycho-social forces.

Individuals express their sex drives through sex acts. The sex acts involve behaviour. The behaviour of the individual is guided by his beliefs, attitudes and norms pertaining to sexuality.

It is important to know the individual sexual behaviour prior to injury and to understand the rationale for the behaviour. Thus understanding will be a foundation for appreciating his choice of the types of behaviours after the injury.

Masters, Johnson & Kolodny (1986: 9) caution that one must not measure other people's behaviour by one's own values and experiences. The rehabilitation team's objectivity must not be clouded by their subjective sexual experiences.

The task faced by the person with the spinal cord injury is enormous. Adjustment does not mean a change overnight, it is an extensive process that is influenced by multiple factors such as religious and cultural traditions.

2.7 CULTURAL DIMENSION

There is no sexual value system that is right for everyone and no single moral code that is universally applicable. Masters, Johnson & Kolodny (1986: 10) point out that what is labelled as 'moral' or 'right' varies from culture to culture.

Ethnic background and cultural traditions play an important role, they influence the persons sexuality prior to the injury and continue to do afterwards. Cultural differences need to be taken into consideration in dealing with sexuality and disability. There is no viewpoint that is shared by all people in all places. Individual differences exists even in the same family. People from the same ethnic background will also differ because culture is not static it changes from time to time.

Literature review revealed a paucity of studies on sexuality and disability with special emphasis on cultural issues. Trieschmann (1980: 104) maintains that more research needs to be done and that future studies should specify the nature of the subject population more precisely to enable the researchers to assess the role of culture as a factor in the adjustment of spinal cord injury.

The author cautions that such statements as follows: 'Males with spinal injuries from cultures in which masculinity is equated with physical prowess, success with females and fathering of many children may have a more difficult time in adjusting to spinal cord injury' have yet to be confirmed.

Should the above statement be found to be correct through research, then the males from that culture would indeed have a mammoth task in adjusting. Their masculinity would be questioned because of the erectile, ejaculatory and orgasmic dysfunctions. Fertility would also be a problem because studies cited previously have shown that fertility among males with injured spinal cords ranges between one and ten percent.

Cultural and religious beliefs have an impact on an individual's sexuality, thus the spiritual dimension needs to be examined.

2.8 SPIRITUAL DIMENSION

The Christian viewpoint postulates that the human person is a unified being thus the body cannot be indulged without affecting the essential person. Man is created as an embodied person, thus cannot relegate the sexual dimension if his existence, as having no bearing on his relation with God.

Genz (1990: 6) quotes Genesis two which includes the human procreative potential. God creates humankind as male and female from the beginning and he commands them to 'be fruitful and multiply'. This implies the presence of reproductive capacities as corollary of their existence as male and female.

The author concludes that our sexuality is given by God. That sexuality is an essential feature of each human being and is a central aspect contributing to the identity of each as a person.

The spiritual dimension of sexuality plays an important role in the sexual adjustment of a man with an injured spinal cord. For example certain religions may frown upon specific acts or sexual behaviours.

Procreation is emphasised for example by the Catholic Church. With the reduced chances of procreation, the injured male maybe severely disturbed by his infertility.

The strong religious convictions may limit the sexual options available after spinal cord injury. For those individuals whose religions prescribe specific actions in their sexual lives, adjustment may be difficult.

Sexuality is a sensitive issue and in order to explore all its dimensions, it is important to understand what it means to the individual and what it represents to the total relationship. Another important factor that needs considering when dealing with sexuality and disability is intimacy.

3. INTIMACY

3.1 INTIMACY AND INTIMATE RELATIONS

The word 'intimacy' comes from the Latin word 'intimus', which means innermost or deepest. Masters, Johnson & Kolodny (1986: 234) define intimacy as a process in which two caring people share as freely as possible in the exchange of feelings, thoughts and actions. It is generally marked by a mutual sense of acceptance, commitment, tenderness and trust.

The authors emphasise the distinction between intimacy and romance. They point out that casual sex without exchange of feelings may have been intimate sexually but have not experienced the sharing and caring as defined.

Intimacy is influenced by the person's firm sense of self, based on a realistic self-knowledge and a degree of self-acceptance. Such a person will be able to form intimate relationships.

Masters, Johnson & Kolodny (1986: 235) postulate that people who do not like themselves or who feel ashamed of who they are often have a difficult time establishing and maintaining intimacy because they are preoccupied with trying to prove themselves to others or trying to gain recognition or respect.

Most people search for at least one feeling, caring person with whom to share their private time.

Physicians point out that loving enhances physical health, while psychologists insist that loving is essential for emotional survival. It helps confirm a person's sense of individual worth (Lamanna and Riedman 1988: 84).

Everybody needs love. Love is a deep and vital emotion resulting from need satisfaction, coupled with caring for and acceptance of the loved one and resulting in an intimate relationship.

The person with a spinal cord injury may battle with issues of self-acceptance because his body is now different, his abilities may be affected. He now deals with intimacy at a different level, that of a person with a disability. He may have fears that his loved one may not accept him or care for him as a disabled person.

A study by Robert Sternberg, a psychologist cited in Lamanna and Riedman (1988: 92) on relationships found that the qualities most important to a lasting relationship are not visible in the early stages. He studied relationships varying in length from one month to thirty six years.

He identified three components of love: passion, intimacy and commitment.

Passion: this component peaks early in the relationship but continues at a stable lower level and is important to the long-term maintenance of the relationship.

Intimacy: the second component includes understanding each others needs, listening and supporting each other and sharing common values. In its most emotional form, intimacy may not always be visible. When things are running smooth, intimacy is taken for granted. In the event of a crises such as illness, when the relationship is interrupted, intimacy takes on a real meaning.

Commitment: the third component is an outgrowth of the caring, sharing and trust that develops in the early stages of an intimate relationship.

All three elements of love are essential. Human beings need recognition and affection thus love meets a basic need. It involves caring and acceptance. Individuals are accepted for themselves, for who they are. Love permits freedom to expose feelings, strengths and weakness without fear of rejection.

Intimacy is the capacity to share one's inner-self with someone else and to commit oneself to that person despite some personal sacrifices (Lamanna and Riedman 1988: 94). For example, an able bodied partner may make a commitment to remain with the injured person despite the fact that their sexual life will be altered.

Commitment that develops in the later stages of the relationship entails committing oneself to another person, it involves the determination to develop the relationship. In such a relationship, problems are worked through, conflict is seen as a normal part of the growth process and the relationship is seen as worthwhile.

Commitment requires both partners to work willingly to maintain their intimacy through periods of crisis, frustration, prosperity and excitement. Committed partners share both the good times and the difficult times. They work to maintain the relationship in spite of difficulties. They express themselves freely and honestly.

3.2 THE IMPACT OF DISABILITY ON INTIMACY

Spinal cord injury can create a crisis in the relationship. It can test the ability of the partners to remain intimate and committed in the relationship. The affectionate ties composed of trust, mutual respect and caring, an open sharing of feelings, experiences, love and sexual expression can be disturbed, because of the drastic physical and emotional changes at the onset of the injury.

The injured individual can question the strength of the special quality of emotional closeness that bound them prior to the injury. He may question whether he can still trust his partner to accept him as he is, with a disability.

He may begin to have doubts about the maintenance of the physical and psychic intimacy that prevailed before the injury.

Literature review has shown that most individuals with spinal cord injuries find that they must deal with five problem areas regarding their disability and sexuality.

They have an impaired body image; decreased self-esteem, difficulty with gender identity and role; difficulty with decision about sexuality and parenthood and finally sexual experiences that are different from those of the able-bodied person.

It is apparent that the problems that emerge post-injury, calls for a redefinition of intimacy for the injured man. The definition of the self has to incorporate the disability. Their physical intimacy has to

accommodate the disability which involves impaired limbs, assistive devices, such as the catheter, altered sexual functioning and limited mobility.

A crucial dimension of any relationship is the extent to which the partners are prepared to reveal all aspects of themselves, experiential, emotional and physical, to each other: Physical intimacy demands a willingness or some degree of self-revelation.

The sharing of aspirations, desires, strengths and weakness' to each other is important. Both the injured partner and the able-bodied partner have to share their inner most feelings in relation to the injury to each other.

The decreased self-esteem may make it difficult for the injured party to share with his partner. The challenges for both partners is to revise the elements of love such as passion and intimacy which were established prior to the injury, to incorporate the disability in their new definition of intimacy.

One of the key steps in developing an intimate relationship is self-disclosure, the willingness to tell another person your thoughts and feelings. For the person who is injured, the thoughts and feelings may involve doubts pertaining to the able-bodied partner's willingness to accept the redefined intimacy.

Injuries to the spinal cord affects intimacy as defined for the able-bodied person. For a person with a disability the physical intimacy involving sexual intimacy undergoes a drastic change which calls for redefinition.

The process of redefining affects the psychic intimacy, involving sharing of thoughts and feelings.

We can therefore conclude that a successful sexual adjustment after the injury will be influenced to a degree by the ability of the partners to incorporate the changes, and to maintain their intimacy through the crisis and to commit themselves to each other despite some personal sacrifices. Sharing uncertainties and other problems is essential for the growth of intimacy.

Summary

This chapter gave the researcher an overview of the sequelae of spinal cord injury, forming a vital basis against which the empirical study was conducted.

Literature review has shown that the onset of spinal cord injury introduces many changes, necessitating adjustment. The consequences of the injury impact upon the physical, psychological, social, sexual, cultural and spiritual development of the individual.

Professionals are increasingly viewing sexual adjustment as a necessary part of the rehabilitation of the spinal cord injured person.

Sexuality has many dimensions, thus it should be studied from the biological, psychological, behavioural, clinical and cultural perspectives. Each individual must be treated as a unique person, because the experience of sexuality is unique. The rehabilitation teams' objectivity must not be affected by their own values and experiences.

The onset of spinal cord injury calls for a redefinition of intimacy to accommodate the disability and the resulting limitations and alterations.

The resolution of problems created by the changes in sexual functioning rests with the mutual communication and relationship of the sexual partners.

CHAPTER 3

A REVIEW OF PREVIOUS EMPIRICAL STUDIES ON SEXUALITY AND SPINAL CORD INJURY

INTRODUCTION

This chapter has three major aims namely:

- i) To review previous empirical studies with a view of studying the trends in research methodology, areas of sexuality and disability studied.
- ii) To formulate a number of empirically derived guidelines, to serve as a basis for the present study.
- iii) To identify commonalities and differences between previous studies and the current study.

Literature review revealed that interest in the field of sexuality and disability was first developed in European countries such as Sweden, England and Holland. According to Leyson (1991: 6) it was Comarr in the United States of America who initiated the scientific study of the effects of spinal cord injury on sexual functioning in the 1950s.

A literature search conducted by the Human Science Research Council in 1993, showed that there was paucity of South African studies and that the field of sexuality and disability remains unexplored.

In order to improve the quality of life of people with disabilities, their needs must be identified and met. Practice based on the latest research findings is the first step in the right direction to deal with the dilemmas and opportunities related to sexuality of spinal injured males.

1. RESEARCH FINDINGS

Literature review revealed that previous research studies in the area of sexuality and spinal cord injury included topics such as self-image, rejection by spouse, sexual desire, perceptions on sexuality and disability, the meaning of body changes, the need for sexual counselling, sexual adjustment and locus of control.

1.1 SELF-IMAGE

Spinal cord injury threatens the individuals well-being at a number of levels. He is confronted with a variety of stressors.

In simple terms self-image refers to the way one sees himself in relation to his world. This self-view may be related to reaction from others, ones perceived capability and perception of oneself in comparison to others around him.

Koehler (1989: 1) describes self-image as how one views his own importance in relation to others. She points out that this view is a decisive factor in how one acts in interpersonal relations. Self-image encompasses concepts of self in terms of satisfaction, confidence, esteem and importance.

The extent to which positive self-image exists among people with injuries to the spinal cord has not been assessed directly, although research has examined factors related to self-concept. For example,

Green, Pratt & Grigsby (1984: 751) studied 71 people who had been injured for at least four years using the Tennessee Self Concept Scale. Their findings revealed that the respondents had a very positive self-concept. They warn that the results could be attributed to the fact that the respondents participated voluntarily; thus those with the poor self images may not have been identified because they did not participate.

In another study Conomy cited in Leyson (1991: 182) studied the disturbances in body image occurring in eighteen people with spinal cord injuries. He found that body image disorders involved included disordered perception of the body in space, of posture, movement and size.

Eisenberg in Leyson (1991: 183) cites a study by Cogswell of 36 young adult paraplegics from a variety of socio-economic background. He found that they all experienced a marked reduction in their social contact and frequency in entering community settings, as well as in the number of roles they played. He also made a very interesting observation, that as people with injured spinal cords assumed social relationships, they seldom resumed relationships with pre-trauma friends, but rather associated with individuals of lower class status, decidedly younger or older or less attractive in other ways.

Research in the formation of relationships after injury, would perhaps help to establish the reasons for the injured persons choice of relationship. It could be possible that the injured persons terminated relationships because they found that their associates found it

difficult to adjust to their new status as people with disabilities.

Injury to the spinal cord impairs the persons ability to function in a variety of ways. He loses his independence, thus the dependent positions he experiences following the injury may have a devastating effect on his self-image. More studies are needed to establish the impact of the injury on the person's self-image.

1.2 REJECTION BY SPOUSE OR PARTNER

The spinal cord injury affects young adults during the most productive years of their lives and it can have a far reaching effect on their ability to function in society.

Individual beliefs and attitudes as well as society's attitudes are important factors in coping following spinal cord injury.

Eisenberg in Leyson (1991: 83) maintains that one of the most pervasive fears of the injured persons, is that the spouse or sexual partner may reject them because they cannot function satisfactorily. He cites a study by Berkman et al of 148 spinal cord injured out-patients. The Index of Sexual Adjustment was used. An instrument that measures factors such as adaptation to sexual limitations, partner satisfaction, sexual self-concept and regularity of sexual contact.

Of the 148 persons in the Berkman study, 33 reported no sexual relations since the injury. Forty one percent rated their sex relations as satisfactory, 36 percent indicated that they were somewhat satisfied, and 23 percent stated they were dissatisfied. In contrast, 76 percent thought their partners were satisfied. Since sexual partners were not interviewed, the accuracy of the reports could not be verified. Leyson (1991: 83) points out that Berkman's findings are significant, since they refute the myth that individuals cannot engage in sexual activity after spinal cord injury. Of the group studied, 97 percent had sexual experiences and 79 percent felt they were desirable as partners.

The researchers also found that high scores on the index were positively correlated with better physical functioning, higher income, the role of worker and community participant, higher morale and age at the time of the study.

The findings in Berkman's study indicate that various factors play a role in the adjustment of a person with an injured spinal cord. The fears of the injured person may be justified because of the myth that the injured persons are condemned to a life devoid of sexual experience. It is therefore important to be open and communicate feelings after the injury. Both partners have to make an effort to communicate and understand the implications of the injury.

1.3 SEXUAL DESIRE

Sexual interest and functioning is a deep and pervasive aspect of personality and one that is essential to an integrated self and to a sense of general well-being.

Hotchner in Leyson (1991: 115) points out that upon first regaining consciousness or a clear understanding of the extent of the injury, the injured person's concerns evolve around three basic areas of their lives, physical survival and limitation, economic capability and sexual functioning. Sexual functioning centres on several important questions:

- i) Will I still be desirable?
- ii) Can I still be sexually satisfied?
- iii) Can I still satisfy my partner?

This perhaps is an indication that sexual capability is prominent in the minds of the people with a disability, thus it is central in the lives of people.

Hotchner further argues that when sexual functioning is called into question, a lack of interest in sex can become a protective mask for an overwhelmed ego. He further points out that inhibited sexual desire exists among able-bodied people as shown by a study by Lo Piccolo in 1980, who reports that of the 39 cases treated at The Stony Brook Sex Therapy Centre in New York, 69 percent included a diagnosis of low sexual desire.

The extent of sexual disinterest in the injured person is difficult to assess since various studies report different findings. According to Leyson (1991: 116) Bors and Comarr (1960) found no change in desire in their study while Weiss and Diamond (1966), Hohmann (1966) findings show that a slight decrease in sexual desire in men is apparent. Jochheim and Wohle (1970) report a marked decrease.

It is important to establish the source of inhibited sexual desire, because the lack of interest may have well existed before the injury. Leyson (1991: 117) points out that there are normal dips in desire that tend to parallel the passages of marital development. This statement is supported by Hotchner (1991) and Masters, Johnson and Kolodny (1986) who point out that these tend to come in the first year of marriage after the hormonal highs of courtship wane, during the rearing and careering years when other priorities and responsibilities and a broadening of the affection network make sex less urgent; at middle age when boredom, body image concerns or malaise and depression common to mid-life crisis take a sexual toll; and in old age as the myths, physiological changes of sexual functioning and depression to becoming a valueless person in our society erode interest.

Alexander, Sipski and Findley (1993: 219) cite a study by Berkman et al (1978). They studied 104 males veteran with spinal cord injuries and found that thirteen percent reported their sex lives as better than before the injury, ten percent as the same and 77 percent as worse than before the injury.

The study however, did not provide details of neurologic information and the subjects remaining sexual ability.

Other studies conducted in 1983 by Phelps et al found that of the 50 spinal cord injured males studied, twenty percent described their sexual desire to be very weak as compared to pre-injury, and 42 percent were dissatisfied with their sexual functioning. The researchers caution that these figures should be compared with studies done by Shaver and Freedman in 1976. They found that 35 percent of the 52 000 men in the general population reported dissatisfaction with their sex lives. They urge that in view of these results in the general population, the need becomes apparent to compare the spinal cord injured persons degree of satisfaction with their own level of satisfaction prior to injury (Nordqvist 1986: 35).

Findings of a study cited by Alexander et al in 1993 revealed that desire for sexual activity was rated high by 97 percent of the 50 male sample as compared to 78 percent of the post-injury sample. Post injury sexual desire correlated with age, sexual experience pre-injury, severity of injury and pre-injury sexual desire.

Studies cited by Alexander et al also found that most individuals return to sexual involvement within twelve months of injury. However, following spinal cord injury, the pre-injury frequency of sex decreased dramatically, the reduction seemed to be related to the sexual desire of both the individual and his partner pre-injury, however post-injury only the partners desire for sex was related to frequency of sex.

The level of injury did not seem to be a major factor in frequency of sexual activity.

The above findings by Alexander et al indicated two major factors associated with pre-injury sexual satisfaction, namely: frequency of sexual activity and the partners perceived desire for sex. In post-injury both factors are decreased. They recommend that future studies should include issues such as physiological factors (erectile dysfunction and fertility) and psychological factors (depression, self-esteem, social skills, communication, family functioning and expanding one's personal definition of sexuality).

It is apparent from the cited studies that in studying sexual desire other aspects come to the fore. Hotchner's postulation cited in Leyson (1991: 115) should be kept in mind that "sometimes a lack of interest can be displayed to protect one's self-esteem and to divert attention from the sexual function that is altered due to injury".

1.4 STAFF AND PATIENT PERCEPTIONS OF THE CONCERNS OF PEOPLE WITH SPINAL CORD INJURIES

Health care of the injured person requires consideration of the patient's psychological readjustment, as this aspect of the patient functioning bears significantly on the patient's total rehabilitation.

The reactions and expectations of significant others including the rehabilitation team have an important bearing on the patients adjustment. Trieschmann (1980: 70) states that if the staff of a rehabilitation centre tend to have certain perceptions of persons with spinal cord injuries, these perceptions form part of the psychological climate of the hospital.

Badenhamer (1983: 148) reports a study with 46 spinal cord injured persons and 30 staff members drawn from two rehabilitation centres in Dallas, Texas. The study was developed to delineate the perceptual discrepancies or similarities between attending staff and the spinal cord injured patients. Results of comparisons of patient and staff responses add support to the growing body of evidence that serious discrepancies exist between the perceptions held by rehabilitation personnel and what the patients actually reported. The results are consistent with Taylor's findings that the rehabilitation staff overestimate the psychosocial distress that the patients feel.

The results of the study indicated that the rehabilitation personnel over-estimated the psychosocial distress of the patient, than did the patients themselves. There was a discrepancy between the perception reported by the rehabilitation personnel and the perceptions reported by the patients.

The data from the Badenhamer study could be considered consistent with Trieschmann's (1980: 102) interpretations that rehabilitation personnel carry preconceived notions of how the persons do or should react to spinal cord injury and that staff consider the patients to be more demoralised than they in fact are.

It would seem that the staff's negative expectations are a continuation of the same negative stereotypes that the general public holds. Perhaps further study on this subject could shed more light as to the cause of the discrepancies.

The present study will hopefully gather first hand information on the private world of the spinal cord injured person. The information may help the rehabilitation team to gain insight into what constitutes the limitations of the spinal cord injured person's world.

1.5 THE NEED FOR FORMAL SEXUAL COUNSELLING

Since the early seventies literature has emphasised the need for sexual counselling and information giving as part of the rehabilitation programme.

Trieschmann (1980: 142) maintains that if health care professionals are going to be receptive to the needs of persons with spinal cord injury, sexual functioning must be included as part of a rehabilitation program.

Cushman (1988: 66) studied 25 spinal cord injured persons and 25 able-bodied persons, they were asked whether they felt the concerns about sexual functioning were an important issue during their stay on the rehabilitation unit. 40 percent of spinal cord injured and twenty percent of the non-injured patients answered affirmatively. 48 percent of each group respectively did not answer.

It is interesting that the majority of subjects in both Cushman's groups did not respond. It could be that the subjects were reluctant to discuss this very sensitive issue.

In an unpublished study by the researcher in 1990 (Sishuba 1990), all twenty respondents felt that sexual functioning should be included as part of the rehabilitation program. All subjects were male, had been sexually active pre-injury and were on the rehabilitation program.

However, the response may be an indication that the subjects become more concerned about sexual functioning as they prepare to reunite with their partners the first time since the injury.

1.6 THE MEANING OF BODY CHANGES

Spinal cord injury is one of the most catastrophic events that may befall a human being. The injured person changes from an independent, self-sufficient, contributing individual to a patient dependent on mechanical devices and trained medical personnel. The physical sequelae of the injury include impaired mobility and sensation, bowel and bladder dysfunction requiring a lengthy rehabilitation for the relearning of self-care skills.

Spinal cord injuries primarily affects those aged 15 - 29 years. The injury occurs at a time when critical developmental tasks are being confronted. Dewis (1989: 389) conducted an exploratory study to examine the effects of spinal cord injury on the young people

involved.

The study had two purposes, to describe the personal meaning of body changes resulting from spinal cord injury from perspectives of the young adult, and to describe the coping strategies used to respond to the changes.

The methodology used was qualitative and descriptive to allow the subjects to describe the body changes from their own perspective. The study found that two dimensions of explanation were common to all individuals as they described their experiences. The first of these was a concern with normalcy and being valued and the second was the use of deliberate strategies chosen and acted upon to maintain a sense of normalcy. Three major areas emerged as the ones in which maintenance of normalcy was a consistent phenomenon. These were physical appearance and functioning, physical and emotional independence and social skills and interpersonal relationships.

All subjects conveyed acute awareness of their loss of previous independence and their striving towards some degree of control over assistance with activities of daily living and relearning basic skills, almost all expressed feelings of helplessness and anger.

The study helped to identify a range of behaviours and strategies related strongly to efforts to normalise. Many of the behaviours identified reflect the findings of studies of adaptation to and coping with other long term illnesses and disabilities.

From the findings of the study by Dewis (1989), service providers can take actions to help the injured persons find meaning in their lives.

1.7 LOCUS OF CONTROL

Internal and external locus of control refers to the extent to which individuals perceive contingency relationships between their actions and their outcomes. Holmes (1987: 92) describes locus of control as the degree to which an individual perceives success and failure as being contingent upon personal initiative. People who believe that they have some control over their destinies are considered to be internally orientated. They believe that some control resides within themselves. Externally orientated people, on the other hand, believe that their existence and ultimate destiny is determined by factors outside themselves.

Individual beliefs and attitudes are important factors in coping following spinal cord injury. It has been found that individuals vary in their beliefs about responsibility for and control of situations and events. Rotter (1966) in Frank and Elliot (1989: 250) described persons who believe they have a high degree of personal control over events and situations as having internal locus of control. In contrast those who believe they have little personal control were defined as having external locus of control.

Frank and Elliot (1989: 252) conducted a study using the Multidimensional Health Locus of Control scale to measure individual's beliefs about control of health along the dimensions of internal, chance or powerful others. They also used the Beck Depression Inventory, a twenty one item self-report measure of depressive symptoms.

53 Patients with injured spinal cords were assessed. The researchers found that spinal cord injured patients who believed that they are primarily responsible for their health, evidenced less depression and displayed more adaptive behaviours than those with externalised beliefs.

Psychological adjustment after injury is influenced by a number of factors, personal, social, psychological and physiological. Frank and Elliot (1989: 254) believe that those patients who have more fatalistic beliefs about their health may require psychosocial intervention to help them towards psychological adjustment.

Rotter (1966) cited in Holmes (1987) and Elliot and Frank (1989) pointed out that beliefs about control were learned over a period of time, after substantial interactions with the environment. From the study we can conclude that since beliefs about health control can be learned and can be modified, perhaps patience with fatalistic beliefs can be taught to use medical personnel as a resource and see how their own actions are necessary to obtain and maintain their health.

In relating the locus of control construct to the present study, it is important to identify the locus of control of the subjects. This may help the researcher to understand their view of their present circumstances and events in their situation.

1.8 SEXUAL ADJUSTMENT FOLLOWING SPINAL CORD INJURY

Rehabilitation efforts, particularly in developing countries, have paid little or no attention to sexuality and the disabled. The need of the disabled for sexual expression have often been ignored by the health professionals, firstly because the disabled are perceived to be asexual and secondly by the professionals inadequacy to deal satisfactorily with the subject.

The discussion of sex and sexuality is frequently neglected in health care delivery system, although research has shown that physical disability does not decrease sexuality and the libidinous drive (Anderson and Cole 1975, Conine and Evans 1982, Lotmer 1981, Vemirreddi 1973, Wallace 1980).

Sexuality appears to play an important role in the individual's ability to cope with his disability. According to Novak and Mitchell (1988: 105) several authors have described a relationship between a persons sexuality and self-esteem.

Tepper (1992: 16) maintains that sexual education and sexual counselling may help to diminish the impact of the changes accompanying spinal cord injury on a persons self-esteem. A study by Tepper was conducted of 458 spinal cord injured persons, to determine trends in the provision of sexual education and sexual counselling services in rehabilitation programs.

The findings revealed that 48 percent of the respondents who received such services felt the services met their needs. The study revealed an obvious gap between the services offered and the services desired. Perhaps it is an indication that the consumers of the services should have an input when the content of the program is planned.

There is also a need to look at sexuality in a broader sense and include all the dimensions and to break away from the genital function confines.

Nwuga (1982: 77) conducted a study to investigate sexual adjustment among upper class Nigerian male paraplegics. The conceptual framework for his study included sexuality as a dynamic phenomenon based on developmental learning experience.

The subjects in the study were senior executives working in commercial establishments, successful business men and senior civil servants.

The findings of the study revealed that the younger the subject the better the chances for sexual adjustment. The researcher concluded that there was a close relationship between good sexual adjustment and the ability to perform role activities, high morale, relative independence and general satisfaction about life.

The positive correlation between sexual adjustment and psychosocial functioning shown by Nwuga is corroborated by the conclusion made by Cole, Chilgren & Rosenberg (1973: 82). They pointed out that sexual satisfaction had a positive effect on self-esteem and the ego and it encourages the subject to engage in his world.

Sexual inadequacy is a factor which can influence overall adjustment in view of the way it affects psychological and social needs. Self-concept is an organising principle in a person as a sexual human being. Sexual inadequacy as a result of injury to the spinal cord for instance will endanger sex identification and injure self-concept (Nwuga 1982: 79).

The study by Nwuga (1982) points out that sexuality is on the one hand a physiological need, on the other hand it is intimately related to societal norms, personal needs and cultural values. When the subjects becomes a rehabilitation issue, conflicting opinions regarding solutions come to the fore. This presents a problem to the care-givers. In many quarters, open discussion of the subject is taboo.

According to Nwuga (1982: 79) the Nigerian culture has reinforced the myth that men instinctively know how to satisfy women. They therefore play a dominant role in sex. A change of roles as made necessary by the sequelae of spinal cord injury is not easy to achieve because of cultural attitudes. Thus communication between the partners becomes essential to dispel mistrust and resentment.

Nwuga's study involved upper class subjects. It would be interesting to use lower class subjects in future studies, in view of the possible cultural differences between the upper and lower class subjects. The lower class probably share traditional values that may be different from their upper-class group who have a western view of the world.

Involvement of the spouse or partner would be helpful in determining whether the responses of male subjects are corroborated by their female partners. All the attention on this issue of sexuality in the spinal cord is given to the male. Newman (1979: 287) supports the statement by pointing out that literature on the subject is devoid of research on the women in the relationship. At the Rehabilitation International Congress in 1992 in Kenya, women delegates with spinal cord injury called for studies on women as all the papers presented seem to concentrate on men.

In another study, Pochalski and Pachalska (1984: 238) developed a program involving active education in which not only those with paraplegia were participating but also their families. 38A group, paraplegics and their families, was treated under this regime and another, 38B group, paraplegics, was involved without their families.

The program had a positive effect in the therapy of the paraplegics. Before the treatment, the majority in both groups believed themselves to be unadapted socially. After the rehabilitation the results changed, in group A.

An examination after treatment showed a change in the situation. More patients from group A saw before them a future, found a goal in life and evaluated positively their worth, feelings of guilt and threat decreased as did fear. In group B there were no significant differences in these areas after treatment.

The support and attitudes of family and significant others play a role in the adjustment of spinal cord injured people. Becoming a paraplegic impairs a persons ability to function sexually in a variety of ways. The attitudes of spinal cord injured persons towards their own sexuality is an important factor in determining adjustment after injury.

Page, Cheng, Pate, Mathus, Pryor & Ko (1987:115) conducted a study to examine the attitudes of spinal cord injured persons towards their own sexuality and the various sexual options that are open to them. The Marital Adjustment Checklist for the disabled was used.

The results revealed that the spinal cord injured persons thought they had the right to experience some type of sexual satisfaction. Ninety two percent were permissive in many of their sexual attitudes and were willing to try different sexual options open to them.

The subjects brought other issues to the fore. Many reported being frustrated, disappointed, hurt and embarrassed at the thought of having sex with someone who was not injured.

They also pointed out that it was difficult to form and maintain relationships with members of the opposite sex. Some felt their disability made it difficult for them to have sex with the same frequency as before they became disabled. A small percentage, 10 percent were concerned about being pitied by able-bodied sexual partners.

The researchers point out that the fact that the results were based on a self-report data is one possible limitation of the study. The subjects may have exaggerated their pre-injury sexual capabilities in order to maintain their self-image to themselves and to significant others.

The study has shown that if spinal cord injured persons can maintain a positive and open attitude about functioning sexually within the parameters that are available to them. They might be able to achieve some level of sexual satisfaction.

It goes without saying that there are many factors that influence adjustment after injury. Pearson and Klock (1989: 286) point out that people with disabilities formed ideas about sex and the nature of sexual satisfaction at a time when they were able-bodied and they tend to retain those attitudes even when they acquire a disability. Sexual disability is thus compounded of the interaction between the social environment and their own construction of the new situation.

Pearson and Klook (1989) conducted a study on paraplegics in Hong Kong to examine the sexual needs of people with physical disabilities.

The subjects had partners and at least one year had elapsed since the injury in each case, they had all gone through a rehabilitation program.

The researchers point out that Hong Kong is still a sexually conservative society. The Cantonese language does not possess a middle range of words to communicate directly about sexual matters.

The subjects were interviewed by an interviewer who is confined to a wheelchair. All respondents agreed that people with disabilities should have a right to enjoy sex. Some respondents because of misconceptions and lack of correct knowledge about sexual matters induced attitudes of avoidance. All respondents regarded insertion of an erect penis into the vagina and ejaculation as essential and normal practice and ultimate goal of sexual activity. Failure to perform these sexual acts was regarded as occasion for great sadness and regret and an indication of a total or partial cessation of sexual life. The variety of sexual practices adopted was narrow.

The results of this study indicate that the problems faced by people with disability in Hong Kong are similar to those faced elsewhere but they are aggravated by certain cultural and environmental factors.

While for some paraplegia will bring about a change for the worse in their self-image, others will experience a positive change, associated with a new self-awareness and appreciation for life, heightened sensitivity and compassion (Ray and West 1984: 249).

No one form of coping can be claimed to be superior to another. The effectiveness of each will depend on many factors, the nature of the demands that are being met, the character of the person who is doing the coping and the optimal way of adjusting to disability.

In dealing with sexuality it is important to remember the physiological as well as the psychosocial factors that come into play. Rieve (1989: 266) postulates that sexuality and sexual behaviour for an individual are determined by a multiplicity of interacting factors, including, but not limited, to the following:

- Preconceived notions
- Knowledge and education
- Personal and observed experiences
- Value systems which includes morals, religious beliefs, prohibitions or taboos
- Cultural and societal attitudes and health status
- Physical capabilities and self image.

Other variables such as current age, age at onset of injury and time lapsed since injury are related to several sexual issues.

Developmental stages and developmental issues are also important variables.

The ratings of the participants of their satisfaction with sex and of the importance of this area in their lives are helpful in placing results in perspective.

In a study by White, Rinkala, Hart, Young & Fuhrer (1992: 229) compared with other areas of life, sex was rated as moderately important, but there was a strong degree of dissatisfaction. These findings are consistent with studies by Hanson and Franklin (1976) on veterans. 88 percent of paraplegics ranked the use of their legs higher than sex, and 96 percent of quadriplegics ranked the use of their arms and hands above sex.

It is thus important that the injured people should themselves indicate what areas of their lives are most affected by the injury. This indication would help the rehabilitation team to focus on those areas in order of importance from the perspective of the injured person.

SUMMARY

Spinal cord injury impairs the person's ability to function in a variety of ways. Attention on sexuality and disability had increased and research has become more broadly focused attending to psychosocial aspects of sexuality.

In the studies cited it became apparent that spinal cord injury has an impact on the persons sexuality.

Multiple factors play a role in a person's sexuality, namely physiological, psychological, cultural, religious and social. It is the interaction of these factors that determine adjustment after injury.

In this chapter the most outstanding conclusion is that most studies were done on spinal cord injured persons after the period of hospitalisation and that the methodologies used revealed that the professionals approached the subject from their own perspectives and experience.

The present study will give the subjects a platform to describe their own life world, immediately after the injury during hospitalisation. It is hoped that the meaning of sexuality and the effects of the injury on their lives will emerge.

CHAPTER 4

TREATMENT OF SEXUAL DYSFUNCTION IN PEOPLE WITH SPINAL CORD INJURIES: A LITERATURE REVIEW

INTRODUCTION

In the previous section empirical studies were reviewed, this chapter offers a conceptual framework for the treatment of sexual dysfunction resulting from spinal cord injury.

Individuals with injuries to the spinal cord were often assumed to be incapable of, uninterested or inactive sexually. Sexual adjustment is now being viewed as an integral part of the total psychological adjustment of persons with spinal cord injuries.

Leyson (1991: 6) points out that it was not until 1970 that males with spinal cord injury-related sexual dysfunctions were considered a medical problem that was treatable.

In recent years more and more spinal cord injury rehabilitation professionals have integrated sexuality into the rehabilitation program. The programs encompass a large variety of treatment techniques, such as information giving sessions, sexual attitude readjustment workshops, individual or group counselling, behavioural training on the multiple parameters of sexual interaction and the use of mechanical sex aids.

1. TREATMENT TECHNIQUES

Whether the injured person chooses to remain sexual or not, he must try to think of his abilities and not disabilities. The important thing is to feel good about ones choice and about oneself.

While sexual expression is usually shared with another person, Mooney, Cole & Chilgren (1975: 98) believe that the responsibility and the decision to be and remain sexual is the individuals. Sex is one part of the total sexuality, and choosing not to engage in sex acts does not mean that the person is not sexual.

1.1 SELF-IMAGE

The attitude of the injured person toward his own sexuality is one of the most important factors determining the success of treatment.

Comfort in Mooney, Cole and Chilgren (1975: viii) points out that the disabled person's first hurdle in overcoming the obstacles created by a society that regards people with disability as asexual, is to deprogram themselves and to reject the idea that he is not a potential sexual person and is not loveable. He believes that with special counselling and a minimum of physical help, all people with disabilities can be made sexually functional.

The onset of injury to the spinal cord, resulting in disability may be accompanied by feelings of worthlessness and irrational statements such as "I am undesirable", "My spouse will leave me" or "I will never

find anyone to love or to love me again". According to Leyson (1991: 122) functional limitations may lead the individual to back away from sexual intimacy. The self-programming into invalidism, makes a person with a disability distrust his own personhood and suspect other people's affection as pity.

The sexual challenge has to do with the full discovery that one is a loving, loveable, interacting human being, a participant rather than an onlooker. It is important for the person with a disability to believe in himself, to see himself as a loveable person who has something to offer in a relationship.

Mooney, Cole & Chilgren (1975: 2) maintain that if a person does not believe or think of himself as a sexual being then no one will. One's sexuality is one's own responsibility as much as are one's actions within society.

A step by step sex manual that guides paraplegics and quadriplegics men and women with practical information and suggestions that help them to enjoy mutually satisfying sexual experiences with their partners was provided by Mooney, Cole & Chilgren in 1975.

If the individual feels good about himself and is confident that he is desirable to his partner, he will be willing to experiment and discover what is satisfying to him and his partner.

Whatever is pleasurable and satisfying to the couple is acceptable as long as they mutually agree.

In the step by step manual by Mooney et al (1975), the authors cite the following areas as crucial to consider: communication, personal hygiene, arousal and intercourse.

1.1.1 COMMUNICATION

The role of communication in a sexual relationship is crucial to mutual satisfaction. For people with disability the need is even more pressing because they must communicate for any sexual activity to take place.

Language becomes the most powerful tool of communication. Personal meaning of certain terms need to be clarified to ensure that the interpretation is the same.

An essential part of expressing ones sexuality is knowing what turns one on and communicating that information to ones partner. Rabin (1980: 34) calls it discovering each other. He believes that for a person with a disability, it is even more crucial that present capabilities and present preferences be discovered and communicated.

Communicating preferences brings capabilities out in the open, reducing the fear of performance and inadequacy.

1.1.2 PERSONAL HYGIENE

Cleanliness is important to anyone's sexuality, but especially to people who have to wear catheters or devices to collect urine.

According to Mooney, Cole & Chilgren (1975: 7) the catheter does not always necessarily have to be removed, it can be bent and folded over along the shaft of the penis where it will be out of the way. The penis and catheter can be easily accommodated by the vagina.

Preparation for sexual activity is quite involved in people with disabilities, it demands forethought, education and discussion with the partner about the necessary mechanics, involving the emptying of the urine bag, regulation of water intake prior to sexual activity for those individuals who cannot control or predict urination and attending to bowel care.

Preparation can also help the partner with a disability to relax and to feel comfortable about his altered body appearance.

1.1.3 AROUSAL

By talking to each other about sexual topics, fantasies, or other activities about to be experienced, the mere verbalisation of the sensations or reactions can bring partners to such a level of arousal that they will be ready for physical contact.

For people with disabilities these conversations can be carried out while the partners are getting undressed, cleaning up or getting into position. Mooney et al (1975: 35) point out that talking and touching each other in a tender, sensuous way, while eating, drinking or just being close to each other in a comfortable spot is also enjoyable.

Stroking the partners breast, penis, vagina or giving each other a massage, caressing or kissing can be very stimulating. Male paraplegic, according to the manual, sometimes have a heightened sensitivity in their breasts, thus rubbing their breast can be exciting. The use of love oils can also be a turn on. Not only do they give one a pleasant smell and taste, but they also serve as a lubricant.

To an able-bodied individual the activities described above may be commonplace, but for the individual with a disability it is a necessary form of treatment that allows the partners to explore each others bodies, to discover and appreciate the erogenous zones and to communicate preferences because of the altered sexual functioning.

The sexual experience becomes more than penetration, it becomes an art with both partners participating fully. The central issue is that the partners have to use their imagination and experiment with anything as long as there is willingness and agreement on both sides.

1.1.4 INTERCOURSE

Spinal cord injury limits the positions that are possible for intercourse . Each persons limitations will depend on the level of the injury and his own abilities and inclinations.

As part of sexual rehabilitation treatment involves learning of alternate positions during intercourse. Mooney, Cole & Chilgren (1975: 60) point out that paraplegic males, with practice, can learn to have intercourse in the top position. If his arms are strong, he can achieve a great deal of friction and motion between the penis and vagina by doing push ups from the top position, using his arms for balance.

Another option is that of the woman assuming a superior position on top.

She will have more freedom for pelvic movement and the man can have his hands free for rubbing or stroking other parts of his partners body.

The side by side position is also recommended either face to face or front to back with the penetration of the vagina from the rear. The wheel chair can also be used, with the woman sitting on the man's lap with her back to him.

The actual position taken will, of course, depend on the sexual behaviour in which the couple engages, and on what type of contact they desire.

1.2 ORAL GENITAL AND MANUAL STIMULATION

A commonly used means of sexual expression for the spinal cord injured person is the use of the mouth to excite and give pleasure to his partner.

Mooney, Cole & Chilgren (1975: 73) maintain that in oral genital sex more pleasure is derived because the tongue and lips are not impaired by the injury and are more sensitive to touch and temperature than any other part of the body.

Oral genital sexual activity can be done mutually by two partners who position themselves in a way that make each partners genitals easily accessible to the other's mouth.

The degree of pleasure that couples experience in oral-genital sex differs a great deal, depending on their own preference.

Some men are not comfortable with cunnilingus just as some women are not comfortable about fellacio. Each person's choice will depend

on past personal experiences, cultural and religious traditions and personal values. The partners need to discuss the various methods to obtain sexual gratification. All activities undertaken must be mutually agreed upon. Each individual's social learning will profoundly influence which sex acts are considered to be acceptable and which are unacceptable.

1.3 MECHANICAL SEX AIDS

The sexuality of the man with spinal cord injury will be influenced by the onset of the disability. Sexual dysfunction involving erectile and ejaculatory functions, are treated by using intercourse-assistive devices.

There are multiple types of stimulators cited by various authors Leyson (1991: 241) Nordquist (1975: 52) Heslinga, Schellen & Verkuyl (1974: 49) and Mooney et al (1975: 61).

If a woman's partner is a paraplegic and cannot achieve an erection, he can still satisfy her by stimulation of the clitoris with the fingers, mouth or a massage apparatus.

If the option of penile-vaginal penetration is preferred then a penis stiffener or dildo can be used. Mooney, Cole & Chilgren (1975: 61) describe a dildo as an artificial penis usually made of semi-hard rubber, which can be strapped on above the penis or held in the hand. Other devices which can be used for stimulation are battery powered vibrators to give the partner the sensation of penetration and

penile-vaginal stimulation.

Trieschmann cited in Leyson (1991: 241) cautions that the main issue is love between two people, and sex acts are just one way of expressing that love. She emphasises that a good sexual rehabilitation program helps the partners to establish a communication style that allows for the sexual expression of love and sex acts become just one feature of this communication pattern.

The advancement of the use of mechanical aids as a form of treatment, seemed to be mainly in western countries such as Holland, Sweden, England and the United states of America. South African literature was not available on the subject , most probably because the field of sexuality and disability is still at an infant stage in this country.

1.4 SURGICAL MANAGEMENT OF IMPOTENCE

The male sexual response can be catergorised into libido, stimulation, erection, orgasm and ejaculation.

Impotence is defined as the inability to obtain an erection of sufficient firmness or having a sufficiently straight penile shaft to achieve vaginal penetration.

According to Sha'ked (1981: 167) despite advances in the field of neurophysiology, the precise mechanism of penile tumescence (swelling) remains unknown. The treatment of organic impotence, i.e.

impotence caused by disease or injury, which affects approximately ten percent of those men complaining of impotence, remains a surgical procedure.

Amelat and Dubin (1982: 62) report that a review of studies on men with spinal cord injury show that erections that are satisfactory for coitus are achieved by less than twenty five percent of injured men.

The surgical method currently used to deal with impotence utilises the placement of silicone rubber rod which may be either solid or inflatable, of appropriate diameter and size into the corporal body of the penis. The concept of creating a rigid rod within the penis, to allow intercourse, is a derivation of the existence of the penis os or baculum, a bone found in the penis of many lower mammals, particularly among the carnivores (Sha'ked 1981: 167).

Melman cited in Sha'ked (1981: 170) points out that the facts should be carefully explained to the patient, then he can choose either of the two designs of semi-rigid rods or inflatable penile prostheses.

The silicone rods are made of rubber. They are available in lengths from 12 - 23 centimetres and diameter from 0.9 - 1.3 centimetres. The operative technique involves a penile incision and inserting the rods filling the corpus. Melman in Sha'ked (1981: 173) points out that it is important that the patient understand that the rods are designed to accommodate the available internal volume of the corpora and that the penis cannot be made larger than it was before the onset of impotence. Healing after surgery is usually complete within four to six weeks.

The inflatable penile prosthesis is composed of inflatable silicone cylinders of appropriate size which are inserted into each corpus cavernosum through a lower abdominal incision. Each cylinder is connected to a pump which is placed in one scrotum and is, in turn, connected to a liquid filled reservoir placed beneath the abdominal muscle. When the person desires erection, the bulb pump is squeezed and fluid is forced into the cylinder chambers. When a flacid penis is wanted a deflation valve is pressed and the fluid returns to the reservoir.

The choice of prosthesis and method of treatment is left to the individual. The decision of the person will be influenced by factors such as pre-injury experience, the personal meaning of sexuality, value system, health status, physical capabilities and self-image.

1.5 BEHAVIOURAL TREATMENT

Though sexuality may not be the most important issue facing the spinal cord injured person, it is a significant aspect because it may affect the persons identity. It is therefore imperative that this area be addressed, if the person is to function optimally following spinal cord injury.

Eisenberg in Leyson (1991: 84) points out that the spinal cord injured person, has many other concerns that may occupy his attention such as financial difficulties, incontinence etc. Thus it makes identification of the correct time for raising sexuality issues difficult. Eisenberg warns, however, that spinal cord injured persons,

like others, are usually not direct in their requests for information and their expressions of concern about sexuality.

Rehabilitation staff should also be aware of the fact that alternative approaches to the achievement of sexual satisfaction for the patient may conflict with attitudes, religious beliefs and cultural values learned before injury. In order to plan a treatment program for the person with the spinal cord injury, the sexual functioning of the person (and his partner) must be carefully evaluated.

Griffith and Trieschmann in Sha'ked (1981: 121) emphasise that in the evaluation of a sexual problem in a person with a spinal cord injury, one must consider pre-injury function, present function and future expectations. Three areas are identified.

- A life history which includes the estimation of self-image and social skills before the onset of the spinal cord injury.
- A sexual history should include attitudes towards various kinds of sex acts, sex roles for male and female, likes and dislikes, previous sexual experience and value system. Cultural, ethnic, and religious sanctions and prohibitions should be elicited.
- Physical assessment - the present physical, psychological, social and vocational status will help to define the degree of change that the disability entails. The physical assessment should include various forms of mobility and self-care activities.

- A medical history should focus on associated conditions (cardiac disease, hypertension, pulmonary disease) and drugs which might interfere with sexual functioning should be obtained.

Leyson (1991: 84), Sha'ked (1981: 120) and Rabin (1980: 3) stress the importance of involving the sexual partner. In the event that the patient was sexually involved with the partner and the partner is still involved with the patient, it is imperative to evaluate the partner in terms of social history, self-perception, sexual likes and dislikes and the impact of the disability on the relationship. How the partner perceives the person with the disability and whether that perception changes the quality of the relationship must be determined.

The aim of the evaluation is to define the range of sexual behaviours which were in the couples repertoire before the injury, the number of sexual behaviours which are still possible after the injury, the impact of the disability on the relationship and their flexibility and willingness to try new approaches to sexual satisfaction.

Behavioural training in all the parameters of sexuality may assist the injured person and his partner to expand their repertoire of behaviours for their mutual satisfaction.

Behaviour change is a long process thus a thorough evaluation of the injured person and his partner is of paramount importance. A combination of several approaches may be the treatment of choice for a particular disabled person and his partner.

Annon and Robinson in Sha'ked (1981: 104) describe two conceptually different approaches to treatment: direct and indirect. In the direct approach, the presenting problem is usually accepted as the target for some form of intervention and is generally dealt with in a direct fashion. In the indirect approach, the presenting problem is usually seen as a symptom of the real or underlying problem.

In the indirect approach, the symptom is bypassed and the target is first to alter certain assumed intrapsychic systems which will result in the symptoms being resolved. Annon and Robinson in Sha'ked (1981: 104) term indirect approaches as psychodynamic and cites as examples such systems of therapy as the Psychoanalytic, Client-Centred and Gestalt view-points.

Annon and Robinson in Sha'ked (1981: 105) postulate that researchers in the field of sexuality have carefully reasoned theoretical explanations, with accumulated empirical support, of how sexual behaviours may be acquired and treated through methods and procedures based on general psychological learning principles (direct behavioural approach.).

The basic assumption underlying this approach is that maladaptive behaviours are acquired or learned and are subject to normal laws of learning. Learning is defined in a broad sense as a relatively permanent change in behaviour that is acquired as a result of practice.

There are numerous therapeutic procedures based upon the learning theory and derived from the methods of experimental psychology such as, systematic desensitisation, behaviour rehearsal, guided imaging, covert and overt reinforcement, and assertiveness training (Annon and Robinson in Sha'ked 1981: 108).

The important fact to keep in mind is that the therapist must determine what procedure works most effectively with which client under what circumstances. The therapeutic framework must be tailored to the goals of the individual person.

1.6 GROUP SEXUAL COUNSELLING

In sexual training activities, it is imperative that the therapist should be sensitive to the true desires of the couple and not impose upon them the requirement that they must have a complete sexual relationship.

Eisenberg in Sha'ked (1991: 134) postulate that problems associated with altered sexual functioning which accompany a variety of physical impairments offer the rehabilitation counsellor a unique opportunity to utilise a group format to deal with this highly specific and concrete issue.

Participation in group sexual counselling must be voluntary. The therapist must understand that not all persons would be comfortable in discussing their sexual dysfunctions in a group setting.

Yalom (1970) in Sha'ked (1981: 135) divides the curative factors in group therapy into five categories: imparting information; interpersonal learning; universality; development of socialising techniques and imitative behaviour.

- **Imparting information**

A group setting provides a forum to impart information efficiently. A considerable amount of information concerning the anatomy and physiology of sexual functioning and the manner in which disability disrupts physiological processes must be provided to deal with sexual issues. Although individual differences exist, much of the information can be most economically presented in a group setting, thereby reducing the time commitment for both therapist and group members. Presentation of didactic instruction in a group setting helps provide structure and often functions as an initial binding force.

- **Interpersonal learning**

Therapy groups bring individuals with a variety of experiences, sexual as well as social. Group discussions bring out similarities and differences in experiences and in coping mechanisms. The group setting lends a unique opportunity to use the varied insights and experiences of persons with disabilities themselves as a source of support, hope and expertise.

Eisenberg in Sha'ked (1981: 136) point out that through sexual counselling conducted in group settings patients gain a more objective perspective on their interpersonal behaviour and learn

how their modes of interacting with others may be affecting their ability to form relationships.

- **Universality**

People entering therapy often believe they are unique in their problem situation. They believe that they alone have a frightening problem. Many people with disabilities express the conviction that they can be understood only by someone who is in a similar situation.

In a group setting the feeling of uniqueness is often dispelled because the members confront and disclose similar concerns and the members confront their disability together and initiate attempts to find solutions in overcoming problems created by the disability.

- **Development of socialising techniques**

The group sessions provide an opportunity to develop and nurture new socialising skills. Group members are afforded an opportunity to learn each others' impressions of their social habits that have been undermining their social relationships, the group may represent the first opportunity for accurate interpersonal feedback. The insights that are developed can be instrumental in the initial phase of therapeutic change.

- **Imitative behaviour**

Shaked (1981: 137) cites Bandura (1969) who has long claimed that social learning cannot be adequately explained on the basis of direct reinforcement. Bandura has successfully demonstrated that

imitation is an effective therapeutic force. In group therapy, it is not uncommon for a patient to benefit from sharing experiences with another who has resolved a similar problem. Group therapy can be used as a means by which sexual counselling and education for the disabled can be provided. The group can become an important support system to the individual.

1.7 INDIVIDUAL THERAPY

Sexuality is one of the most important components in the establishment of a positive self-concept and self-worth. Farrow (1990: 251) points out that clinical evidence has demonstrated that the sexual adjustment of persons with spinal cord injuries is greatly improved when they are given information concerning their sexual capabilities.

Annon and Robinson in Sha'ked (1981: 112) describe a model developed by Annon in 1975. The model termed PLISSIT provides for four levels of approach and each letter or a pair of letters designates a suggested method for handling presenting sexual concerns.

- P - Permission
- L, I - Limited information
- S, S - Specific suggestion
- I, T - Intensive therapy

- **Permission**

Frequently clients just want an interested professional to act as a sounding board for checking out their concerns. Sometimes all that people want to know is that they are not perverted, deviated or abnormal in raising sexual concerns. Mostly, they would like to find this out from someone with a professional background or from someone who is in a position of authority to know.

A person with a spinal cord injury may use this platform to verbalise his concerns about the sexual dysfunction resulting from the injury. He may find solace in the clinician's response that he is not alone or his concern is not unusual and that many other injured persons share his concerns.

A male paraplegic who prefers his partner on top during intercourse (perhaps to minimise the physical discomfort) may be worried that his preference might reflect something negative about his masculinity. Reassurance from a professional that it is all right to continue engaging in that position may alleviate the client's concerns.

Permission giving may allow the injured person to verbalise his concerns without feeling guilt. The first level of PLISSIT model provides the individual with a platform to talk about his sexual concerns and the right to be a sexual human being despite the limitations introduced by the onset of the injury.

The first level becomes particularly valuable to those individuals who prior to injury spoke of their sexual concerns. If the first level

of the PLISSIT model is not sufficient to address the client's concerns, and the clinician has the time, knowledge and skills, then he can move to the next level of treatment.

- **Limited information**

In contrast to permission giving, limited information provides the client with specific factual information directly relevant to his particular sexual concern.

Annon and Robinson in Sha'ked (1981: 114) stress that providing information helps to dispel sexual myths. The limited information is directly relevant to the clients concern. The information given will also depend on the clinicians style, breadth of knowledge and comfort with his/her own sexuality.

The limitation in this level of approach will be set by the clinicians knowledge, theoretical orientation and value system as well as the clients willingness to change attitude and behaviour.

- **Specific suggestion**

Before the clinicians can give specific suggestion to a client, they must obtain specific information about the client and his unique set of circumstances.

Obtaining the sexual history of the current sexual problem, which includes, the description of the current problem, its onset and the clients concept of the cause and maintenance of the problem, is a prerequisite before moving to the third level of the PLISSIT model.

For example, if the client is concerned about his inability to maintain an erect penis during intercourse, the clinician should obtain the history. It is important to know when the problem was first experienced. The client must give a clear description of what happens during intercourse and must share his own opinion as to what he attributes as the cause of the failure to maintain an erection. Of importance is for the client to state what he expects, and what his goals of the treatment are.

In contrast to the first two levels of PLISSIT treatment which generally do not require clients to take any active steps to change their behaviour, unless they choose to do so. Specific suggestions are direct efforts to help clients change their behaviour in order to reach their stated goals. Treatment at this level is done within a brief therapy framework, thus it is problem-limited leading to the next and final level.

- **Intensive therapy**

The intensive therapy may come after the first three levels have been tried. The PLISSIT is not a model or approach that needs to be followed all the way. It can be offered in stages depending on the needs of the clients and on how clients react to the first levels. Clinicians can adapt their use of the P-LI-SS-IT model to their particular setting, the amount of time they have available to them and to their particular level of competence.

The advantage of the PLISSIT model is that it can be used in a variety of settings and adapted to whatever client time is available.

Each level requires specific knowledge training and skills on the part of the clinician. It allows the care-giver to gear the approach to their own level of competence. Most of all the model provides a framework for discriminating between those problems which require brief therapy and those which require intensive therapy. The model does not bombard the client with too much information, it however, addresses his concerns and needs in stages enabling him to absorb and giving him time to consider alternate behaviour.

SUMMARY

While there are various treatment techniques, literature reviewed reiterated the need to know the individual and his specific situation before selecting a treatment approach.

Today rehabilitation professionals recognise that physical disability does not eliminate sexual feelings and that people with spinal cord injury continue to be sexual beings.

A large variety of treatment techniques have been integrated into the rehabilitation programs for spinal cord injured persons. Literature review has revealed that sexuality and disability has been increasingly receiving attention in countries such as Sweden, England, Israel Holland and North America, however, there is paucity of such programs in South Africa.

The attitude of the injured person toward his own sexuality is one of the most important factors determining the success of treatment, sexual expression is shared with another person, however the responsibility and the decision to be and remain sexual is the individuals. Each persons choice will be influenced by past

experiences, cultural and religious traditions and personal values as well as the personal meaning of sexuality.

CHAPTER 5

RESEARCH METHODOLOGY

INTRODUCTION

The purpose of this chapter is to outline the factors that had to be taken into consideration in selecting a method of data collection. To accomplish this a discussion of the research instrument, gathering, recording and analysis of data and the description of the sample will follow.

The subject being studied, sexuality, is a very private and sensitive area; a topic that is still regarded as a taboo amongst many people in our society. In spinal cord injured persons, the discussion of the issue is complicated by the presence of injury-related sexual dysfunction.

The paraplegic in-patient population included in this research constituted a minority group and it was therefore important that the instrument used did not discriminate on an educational basis, thereby restricting the available sample. Statistics obtained from the Central Statistics Bureau in Pretoria revealed that in 1994, 47 percent of the South African population was illiterate.

The hospital as the research setting proved to be favourable because of the easy access to the sample of spinal cord injured in-patients on the rehabilitation program.

It is significant to mention at this stage that the researcher, a female, conducted the study utilising an all male sample, of ten African spinal cord injured persons, with a diagnosis of paraplegia.

1. SELECTION OF THE RESEARCH INSTRUMENT

Interviewing was selected as a method of data collection because of its naturalness and it allows control of the environment, in the sense that the respondent is not assisted by other people in answering the questions.

An interview provides the privacy essential in the discussion of sexuality, a sensitive and personal aspect of an individual's life.

1.1 INTERVIEWING

Interviewing permitted spontaneity and observation and yielded unanticipated information.

- Interviews ensure that all questions are answered and provide an opportunity to clarify misunderstandings. Rubin and Babbie (1989: 268) point out that in a questionnaire some questions may remain unanswered due to perhaps lack of reading and language skills or not understanding the question. The presence of an interviewer allows for clarification.
- The setting of two people involved in a discussion resembles an everyday experience in conversation. The respondents say what comes to their mind at that given time thus spontaneity is achieved.

Grinnell (1988: 268) points out that interviews allow for more flexibility because the interviewer can use probing questions to obtain greater in-depth in the response. The interviewer has the freedom to change the ordering of the question and to study the characteristics of the individual to help the direction of the questions.

- The great advantage of an interview is the access to unanticipated information. The respondent can impart information that he may never have put in writing, information that can be valuable to the study. The interview eliminates the influence of other people on the respondent.
- Observation of non-verbal responses provide additional meaning to verbal communication. The interviewer is in a position to observe the non-verbal responses and to probe for clarification. The respondent has an advantage of observing the interviewer's reactions to his response, thus he may be encouraged to explore his feelings, experiences and behaviours further.
- In qualitative research where the main objective is to gain insight into and understand the subjective experiences of the respondent, the interview method is the only best suited method that can be used.

1.2 THE INTERVIEW SCHEDULE

The interview schedule comprises of three sections, A, B and C.

- Section A covers demographic data. The aspects included are age, language, marital status, accommodation, educational level, occupation and income bracket.
- Section B concentrates on the history of the injury and includes the following areas: the onset of the injury, the cause of the injury, the nature of the lesion and the impact of injury on the bladder and bowel programs
- Section C covers the relationship history. Areas included in this section are life before the injury and sexual involvement prior to injury.

The interview schedule was used by the interviewer as a guide.

1.3 SEMI-STRUCTURED INTERVIEW

The aim of the study was to gather information and learn as much as possible of the subjective world of the spinal cord injured male with paraplegia. The semi-structured interview allowed unanticipated answers to be used to explore the subject being studied further.

Sexual dysfunction is complex and its intimate nature makes it a difficult subject to discuss. The semi-structured interview seemed to be an ideal tool to break the ice and to introduce the topic.

Once the topic was introduced and after rapport was established, the discussions became more flexible. New themes emerged and the respondents had the freedom to introduce issues that were pertinent to them. The respondents were able to describe the impact of the injury on their sexuality in their own words.

2. GATHERING OF DATA

The respondents were individually informed of the nature and purpose of the research. Special attention was taken to put them at ease and to explain how their contributions would be valuable to other spinal cord injured persons and to the rehabilitation team.

The subjects were given assurance that anonymity would be maintained by not using any identifiable data in the reports and that all information gathered would be treated with the strictest confidence.

2.1 RESEARCH INSTRUMENT

The Interview Schedule was used to collect the data. To gather information on section A, covering the demographic data and section B outlining the injury details, the sister-in-charge in the spinal unit, the patient file and the respondents were used as the sources of information. Section C was used as a guide for the in-depth interviews.

2.2 THE INTERVIEWS

Great pains were taken to schedule the interviews, ensuring that the respondents were not scheduled for any other activity in the rehabilitation program.

Most interviews were conducted during weekends because the respondents were not scheduled for any other activities. The researcher was also off duty, thus there were no time constraints and no interruptions. The premises were quiet as most departments do not operate during weekends and those who do, utilise a skeleton staff.

The interviews were conducted over a period of five months. The length of the interviews varied, however they were seldom less than 45 minutes in duration. An average of six hours was spent with each respondent. An average of eight interviews were conducted with each person.

The researcher had to accommodate unscheduled breaks during the interviews, to allow the respondents to attend to their muscle spasms or incidents of excessive sweating due to temperature irregularities and leg pains that would erupt without warning. These interruptions enabled the researcher to observe some of the complications brought by the onset of spinal cord injury.

The repeated face to face encounters between the researcher and the respondents helped to build rapport. As the number of the encounters increased the respondents became more relaxed and shared very personal details about their disability and its impact on their sexuality.

The close relationship that developed over the months between the researcher and the respondents encouraged the latter to explore their feelings and experiences further and to share highly emotive issues. This behaviour plunged the researcher into an unanticipated role. During the emotional scenes the researcher became a researcher-therapist. Schurink, de Jongh van Arkel & Roos (1992: 23) describe this role as 'the simultaneous working in the mind of two incompatible wishes', which means that the researcher was compelled by the nature of the study to occasionally assume the role of the therapist. The researcher learned through experience that such a role is unavoidable in qualitative research. She learned to identify such situations and to deal with them by actively focusing on the behaviour pattern and its meaning and applying therapeutic intervention. Thus the researcher decided to assume the role of therapist as the need arose because of the sensitive nature of the research topic.

Of interest to note was the observation that the research subjects were keen on the interviews. Of the ten respondents no one ever arrived late or missed an appointment throughout the study. They were willing to participate and wanted to talk about the implications of the disability on their lives and in particular on their sexuality. The gender of the researcher did not seem to be a deterrent. In an unpublished community project (Sishuba: 1990) with the rehabilitation staff at Kalafong hospital, the female staff felt that sexual counselling would be hindered if it was done by females on male patients.

2.3 RECORDING OF DATA

The information gathered from the nursing staff, the respondents and the patient's files on demographic data and injury details was recorded on the interview schedule in sections A and B.

Permission to use the tape recorder was obtained during recruitment. The interviews were recorded on tape as far as possible to allow the researcher to listen attentively. The tapes were studied and pertinent sections were transcribed.

Field notes were compiled of observations made during the interviews. The notes were compiled after each interview and were used to recapture the observations, experiences and patterns that emerged during the interview.

The field notes were used in conjunction with the transcripts from the tapes in data analysis.

3. DESCRIPTION OF THE SAMPLE

The subjects in the study consisted of ten African males with paraplegia, all residents of the Republic of South Africa. All subjects were considered to be free of obvious medical or psychological complaints.

All subjects were in their initial hospitalisation period after the onset of the injury. They were at the initial phase of the rehabilitation program and ready to face the world in their disabled state.

The following tables will provide the demographic data of the respondents included in the study.

TABLE 5.1**AGE DISTRIBUTION OF THE SUBJECTS AT THE ONSET OF THE INJURY**

AGE	NUMBER OF SUBJECTS
15 - 19	1
20 - 24	-
25 - 29	4
30 - 34	2
35 - 39	1
40 - 44	2
TOTAL	10

The respondents ages ranged between nineteen and forty two years, suggesting confirmation of findings by Dewis (1989: 389) and Goddard (1988: 240) that spinal cord injury often affects young adults during the most productive years of their lives; when critical developmental tasks are being met.

The physical restrictions, impaired body limbs, loss of independence and the variety of stressors that accompany the onset of injury affects their lives negatively. Their career paths are disrupted, the self-image and the gender-identity suffers affecting sexuality. The loss of independence decreases their self-esteem.

TABLE 5.2**HOME LANGUAGE**

LANGUAGE	NUMBER OF SUBJECTS
Nguni	3
Sotho	4
Tsonga	3
TOTAL	10

The respondents came from three ethnic groups, Tsonga, Sotho and Nguni. Though the respondents registered the above languages as home languages they were also fluent in other African languages.

Communication was not an obstacle because the researcher was conversant with their home languages which included Zulu, Sotho and Tsonga.

TABLE 5.3**MARITAL STATUS AT THE ONSET OF THE INJURY**

MARITAL STATUS	NUMBER OF RESPONDENTS
Single	4
Married	6
TOTAL	10

All respondents had partners at the onset of the injury. Six were married and lived with their spouses. Of the six married respondents one had two wives and another had a steady mistress. Of the four single respondents two lived with their partners.

It is therefore clear that the impact of the injury on sexuality and on the individuals life will not only be a concern of the injured person but also for the partners. The partners in the relationship will have to make adjustments and changes to accommodate the disability.

TABLE 5.4**ACCOMMODATION AT THE ONSET OF THE INJURY**

ACCOMMODATION	NUMBER OF RESPONDENTS
Own home	2
Rented house	1
Rented room	2
Living with parents	4
Living with family	1
TOTAL	10

All ten research participants lived in homes. Two owned their houses, one lived in a rented house, two in rented rooms, and five shared accommodation with their families.

One comes to the conclusion that irrespective of the living arrangements at the time of the injury, all respondents might be faced with accessibility issues.

Financial security might be another area of concern. With the possible reduction of the income, concerns about the ability to maintain a home may escalate.

TABLE 5.5**LEVEL OF EDUCATION AT THE TIME OF THE INJURY**

EDUCATION	NUMBER OF RESPONDENTS
Standard 2	1
Standard 4	1
Standard 5	2
Standard 8	2
Standard 10	4
TOTAL	10

Of the ten respondents three were students, two full-time pupils at high school level and one part-time student at tertiary level. The other four had attained levels below standard eight.

The injury raised concerns about the interruption of current studies and future studies towards a higher level of education.

The limitation of mobility and inaccessible physical environment may hamper opportunities for employment.

TABLE 5.6**EMPLOYMENT STATUS**

NATURE OF EMPLOYMENT	NUMBER OF RESPONDENTS
Clerical	1
Sales	1
Welding	1
Delivery	1
Factory	1
Mine labourer	1
Bank teller	1
Petrol attendant	1
Student	2
TOTAL	10

Spinal cord injury threatens the individuals well-being at a number of levels. The imposed physical restrictions affect mobility and accessibility to the employment market.

The possibility of the inability to return to the employment held prior to injury was high. Without employment, the financial security would decrease, increasing dependence and loss of economic power and status.

All respondents except for the two students enjoyed financial independence prior to the injury. Re-entry into the work force becomes an issue of concern.

TABLE 5.7**DURATION OF HOSPITALISATION AT THE TIME OF THE STUDY**

DURATION OF HOSPITALISATION	NUMBER OF RESPONDENTS
10 weeks	1
11 weeks	1
12 weeks	4
13 weeks	2
14 weeks	1
15 weeks	1
TOTAL	10

At the time of the study the respondents had just completed a period of medical treatment and qualified to begin with the rehabilitation program which include mobility training and daily living activities.

The hospitalisation period varies according to the level of the injury and response to medical treatment as well as progress in the rehabilitation program. At the time of the study the duration of hospitalisation ranged between ten and fifteen weeks.

It is of significance to note that at the time of the study the respondents had just received information of the full extent of their injury. They were facing the reality of the impact of the injury for the first time and they continue to be in an environment surrounded by people in similar conditions and health care-givers who are familiar with their situation. They have not been exposed to the community they will eventually return to.

TABLE 5.8**CAUSE OF THE INJURY**

CAUSE	NUMBER OF RESPONDENTS
Motor vehicle accident	6
Gunshot	3
Stab wounds	1
TOTAL	10

Six out of the ten injuries in the study resulted from motor vehicle accident followed by gunshot and penetrating wounds. The figures lend support to the findings by Trieschmann (1980: 15) that in the United States of America most frequent causes of injury are motor vehicle accidents followed by penetrating wounds and gunshots, sports and falls. A survey of two spinal cord injury centres in South Africa by the researcher revealed that in the spinal unit in the Western Cape province the most frequent causes of injury was motor vehicle accidents followed by penetrating wounds, gunshot, fall and sports. However, in the Gauteng province as a whole, gunshot wounds were the most frequent causes followed by motor vehicle accidents, penetrating wounds, falls and sports. The survey included statistics from 1991 - 1995.

As indicated earlier spinal cord injured persons are predominantly male, quite young and active with a history of productive educational and vocational endeavours.

TABLE 5.9**LEVEL OF INJURY AND NATURE OF LESION**

DETAILS OF INJURY	NUMBER OF RESPONDENTS
LEVEL OF INJURY	
T1 - T12	4
L1 - L5	5
S1 - S5	1
TOTAL	10
NATURE OF LESION	
Complete	3
Incomplete	7
TOTAL	10

The capabilities of sexual response in spinal cord injured males vary depending on the level of the injury and on the completeness of the lesion.

The respondents sustained injuries resulting in paralysis of the lower extremities. According to Sha'ked (1981: 71) the incidence of erections is greater in persons with incomplete vs complete lesions and upper neuron lesions vs lower motor neuron lesions. Although all the respondents have paralysis of the lower limbs, they will experience altered sexual functioning in accordance with the level of the injury and the completeness of the lesion.

TABLE 5.10**MANAGEMENT OF BLADDER AND BOWEL PROGRAMME**

MANAGEMENT PROGRAM	NUMBER OF RESPONDENTS
BLADDER	
Dependent	10
Independent	-
TOTAL	10
BOWEL	
Dependent	10
Independent	-
TOTAL	10

The loss of control over the bladder and bowel functioning had a dramatic impact on the life of the individuals. The post-injury incontinence became a source of embarrassment; it had a negative impact on the self-esteem and on sexuality.

The respondents were young adults who had active lives. The loss of normal bladder and bowel control would have an impact on the social, psychological, vocational and sexual components of their lives.

TABLE 5.11**SEXUAL HISTORY AT THE ONSET OF THE INJURY**

HISTORY	NUMBER OF RESPONDENTS
Involvement in a steady sexual relationship	10
Sexually active pre-injury	10
TOTAL	10

All respondents had a steady sexual partner and were sexually active at the onset of the injury. The altered sexual functioning would also affect their able-bodied sexual partners. Acceptance of the disability would be a crucial factor in the participants adjustment to life as a person with a disability.

SUMMARY

What remained pronounced in this chapter was that the repeated face to face contacts between the researcher and the respondents facilitated the building of rapport. The mutual trust that was developed between the researcher and the respondents helped the latter to share their feelings, experiences and aspirations. The researcher was enabled to address critical issues pertaining to the respondents sexual dysfunction with more sensitivity, care and confidence.

The respondents willingness to talk about the world they had just entered as people with disabilities, indicated a need to verbalise feelings. The research method used was an appropriate platform to gain insight and understanding into the subjective world of the male paraplegic during the initial period of hospitalisation.

CHAPTER 6

EMPIRICAL RESEARCH FINDINGS

INTRODUCTION

The aim of the study was to gain insight and to understand what it means to be a spinal cord injured male (paraplegic). Therefore in presenting the data, the in-depth description of how the newly-injured male perceives his world during the rehabilitation period will be provided.

The themes that emerged during discussions were divided into subheadings and presented in a narrative form. Data analysis revealed the following themes: achievements during life before the injury, the onset of injury, mourning the loss of independence, life as a person with a disability and future aspirations.

1. THE SAMPLE

1.1 DEMOGRAPHIC CHARACTERISTICS OF THE RESPONDENTS

1.1.1 AGE

15 - 19	1
20 - 24	-
25 - 29	4
30 - 34	2
35 - 39	1
40 - 45	2

1.1.2 LANGUAGE

Sotho	3
Tsonga	4
Nguni	3

1.1.3 MARITAL STATUS

Single	4
Married	6

1.1.4 ACCOMMODATION PRIOR TO ACCIDENT

Own home	2
Rented house	1
Rented room	2
Living with parents	4
Living with family	1

1.1.5 EDUCATION LEVEL

Less than Std 8	4
Standard 8	2
Standard 10	4

1.1.6 OCCUPATION

Skilled labourer	3
Unskilled labourer	5
Students	2

1.1.7 INCOME LEVEL

Less than R5 000 per anum	3
R6 000 - R10 999	2
R11 000 - R15 999	2
R16 000 - R20 999	2
R21 000 - R25 999	1

DISCUSSION

Ten males with a diagnosis of paraplegia participated in the study. Their ages ranged from nineteen to 42 years with seven within the ages of nineteen and 35 and the remaining three between 36 and 42 years. Six were married and four single. Of the six married men, two owned their own homes, three lived with their parents and one lived in a rented house.

The onset of the injury brought forward numerous concerns. The participants were all employed prior to the injury and had financial security. With the paralysis of their lower limbs their re-entry into their respective work situation was questionable.

The reduction of income would have an impact on their lifestyles, their economic power and on the lives of their dependants. The injury also threatened their status as breadwinners and their independence.

The ages of the respondents range from nineteen to 42 years, a period during young adulthood when critical developmental tasks are being confronted and during the most productive years. The limitations introduced by the onset of the injury can have far-reaching effects on their ability to function in society.

1.2 INJURY HISTORY

Details pertaining to the injury.

1.2.1 DURATION OF INJURY AT THE TIME OF STUDY

10 - 11 weeks	2
12 - 13 weeks	6
14 - 15 weeks	2

1.2.2 CAUSE OF THE INJURY

Motor vehicle accident	6
Stab wound	1
Gunshot wound	3

1.2.3 LEVEL OF INJURY

T1 - T12	4
L1 - L5	5
S1 - S5	1

1.2.4 NATURE OF LESION

Complete lower motor lesion	3
Incomplete lower motor lesion	7

1.2.5 ASSISTANCE WITH BLADDER PROGRAM

Yes	10
No	0

1.2.6 ASSISTANCE WITH BOWEL PROGRAM

Yes	10
No	0

DISCUSSION

The respondents were newly injured. They participated in the research during their initial hospitalisation period. The duration of hospitalisation ranged from 10 weeks to 15 weeks during which time they received medical treatment. At the time of the study, they had just started with the rehabilitation program, involving activities of daily living and mobility training.

Of the six respondents injured in motor vehicle accidents, one was injured in a bus accident, three in taxis and two in a private car. Of the three gunshot wound injuries, one was a victim of the taxi violence, one was accidentally shot by a friend and one was shot in a dispute involving a woman. The respondent who sustained injuries from a stab wound was attacked by unknown assailants.

All respondents sustained injuries that resulted in paralysis of the lower limbs. In three cases the sensory and motor loss was total below the level of the lesion and in the remaining cases certain amounts of motor and sensory function remained intact below the level of the injury. All respondents required assistance with the bowel and bladder programs.

The implications on sexuality are far-reaching. The injury resulted in paralysis thus affecting the respondents appearance and sexuality. The loss of control of the bladder and bowel becomes a cause for concern. Whereas toileting was a private matter before the injury, it now has become a public matter because of the catheter and urine bag and the need for assistance. The injuries bring sexual concerns centering on several important questions, such as the ability to satisfy a partner, being desirable to others and the ability to be sexually satisfied.

1.3 RELATIONSHIP HISTORY

1.3.1 DETAILS PERTAINING TO SEXUAL RELATIONSHIP WITH SPOUSE OR PARTNER

1.3.1.1 An ongoing steady relationship with someone prior to the injury

Yes	10
No	0

1.3.1.2 Sexually active with a steady partner prior to injury

Yes	10
No	0

DISCUSSION

All respondents reported having had a relationship with a partner or spouse prior to the injury. One of the six married participants had two wives. Another married respondent had a wife and a mistress. Two of the single respondents had two girlfriends each and were sexually involved with both of them prior to the injury. One of the single young men had a steady partner before the injury and acquired a new one during hospitalisation.

All ten respondents reported that they were sexually active with their spouses or partners prior to the injury.

The sexuality of the individual with spinal cord injury will be influenced by the onset of the disability. The physical disability challenges one's definition of self, and this altered definition will be confirmed by the reaction of loved ones. The injured persons greatest concern during this period is the effect of the physical changes on their relationships with particular emphasis on acceptance by the spouse or partner.

2. LIFE BEFORE INJURY

Ten respondents participated in in-depth interviews over a period of five months. To ensure anonymity a code name was assigned to each participant. Table 6.4 below will illustrate the coding system.

TABLE 2

CODE NAMES AND RELEVANT DETAILS

CODE	AGE	MARITAL STATUS	CAUSE OF INJURY	PERIOD OF HOSPITALISATION	OCCUPATION
R1	33	Married	Gunshot	12 weeks	Clerk
R2	26	Single	MVA*	14 weeks	Student
R3	25	Single	MVA*	12 weeks	Salesman
R4	41	Married	MVA*	13 weeks	Petrol attendant
R5	42	Married	MVA*	15 weeks	Delivery man
R6	25	Single	Gunshot	12 weeks	Welder
R7	19	Single	Gunshot	10 weeks	Student
R8	33	Married	MVA*	12 weeks	Factory worker
R9	36	Married	Stab wound	13 weeks	Mine labourer
R10	27	Married	MVA*	11 weeks	Bank teller

* MVA = Motor vehicle accident

All respondents spoke about their pre-injury life with enthusiasm and painted an explicit picture of a full and active life.

The subjects described their world before injury vividly, giving details of their career, social lives, support systems and their relationship with their sexual partners. Cole in Rabin (1980: iii) states that an exercise in memory and fantasy helps the able-bodied person to better understand what it may be like to have a physical disability. The researcher is of the opinion that the respondents had an urgent need to help the researcher to visualise their lives before the injury in order to make her understand their plight as people with disabilities.

2.1 CAREER

The respondents reported achievements in their work environment. R1 for instance reported job satisfaction and prided himself for his mastery of computers. R10 related with enthusiasm his progress in the banking business, his promotions had been remarkable and he saw himself climbing up the ladder in a short period. R6 reported that the company he worked for retrenched a number of employees including himself, however, because of his skill and expertise as a welder he was reinstated within six months. R5 gave an account of his popularity and reliability at his work place because of his dedication and positive work ethic. His strength (physical) made him to be in demand when heavy items were delivered. R7 spoke of his outstanding work as a standard 10 student, in standard nine he received an award in mathematics and in standard 10, he already had received recognition and was tutoring other students.

Most of the respondents gave accounts of their valuable contributions at work and at school. The researcher gathered from the information shared, that they were missed and that the injury was a setback in their career paths.

2.2 SOCIAL LIFE

The accounts of the social life were full of passion and longing. All respondents reported active social circles. The activities they participated in, and the friends they socialised with were remembered

fondly. The pictures were painted so vividly that the researcher could actually form a mental picture.

R9 lost in his thoughts, exclaimed: "You should have seen me running for the silver medal in the marathon, crowds cheering me on, the last lap visible, my body aching, sweat running down my entire body, I could smell victory!" He had been participating in the marathon for the past ten years, he has two bronze medals and one silver. He was a celebrity.

R6 reported his fame in discos throughout Gauteng. He was the lead dancer. He proudly reported his mastery of the modern dance. He added "I was the life of every party, if I left, the party ended. My friends would beg me to stay on". Pleased with himself, he smiled broadly and used his hands and head to demonstrate his dance moves.

R1 reported his active involvement in the committee responsible for fund-raising in his congregation. He was the treasurer.

R2 gave an account of his escapades with his friends over weekends. They travelled to any point where there was a party. To them a good time meant an all night session with music, liquor and women.

R8 a soccer fanatic never missed a game. A soccer player for his local club and at his employment, he and his friends travelled throughout the country to watch the game.

For R4, an immigrant, his leisure time was spent with friends from his native country. They formed a social club to assist each other with problems and to maintain some of their cultural activities.

R5 travelled a lot because of his work. He came home during weekends. Though he spent some time with a few friends occasionally, he devoted most of his time to his family and relatives.

It is apparent that leisure and social activities with friends or with family received attention in the pre-injury period.

2.3 SUPPORT SYSTEM

Family members including parents, brothers, sisters, cousins, uncles and aunts and other members of the extended family emerged as the strongest support system, followed by friends, colleagues and church members.

It was of interest to note that eight of the ten respondents identified their partners or spouses as pillars of their support system. The observation will be dealt with at a later stage.

2.4 SEXUAL PARTNERS

All ten respondents reported active sexual lives. As mentioned previously, six were married and four single. Of interest is that none of them reported having experienced sexual problems prior to injury. On the contrary they had satisfying active sexual encounters with their sexual partners.

For instance, R4 spoke of his sexual abilities and bragged about how no woman could resist him. He has two wives who are very possessive and content about their sex lives. He displayed self-confidence boasting that he could have any woman he wanted.

R2 had many sexual partners and prided himself on 'scoring' wherever he went. He emphasised though that he would not have sexual intercourse without using a condom. He had a steady girlfriend in his hometown but had several others in other cities.

R1 spoke very tenderly about his wife, he declared his devotion and love for her and related their times together affectionately. He described his wife as a very loving and caring person and he also described their life together with emotion. He felt he was fortunate to have such a fulfilling love relationship.

Similarly R7 counted himself a lucky man, he had a loving relationship and a satisfying sexual relationship with his wife. He added proudly that in their five years of marriage he had never been unfaithful and he trusted his wife completely.

R9, a mine labourer was forced to be away from his family because his place of employment was far. He came home once a month, thus he had a girlfriend with whom he was intimate. He believed that he respected his wife, he was discreet and took all precautions to ensure that his wife did not find out. This issue will be referred to in subsequent sections.

SUMMARY

The respondents reported active and satisfying sex lives. The concentration seemed to be on the sexual acts for most of the respondents, rather than on the multidimensional nature of sexuality.

Literature review has revealed that adulthood from approximately ages twenty to 40 is a time to make important decision and choices in ones life. Erickson in Masters, Johnson and Kolodny (1986: 159) states that the central task of the young adult is the capacity for intimacy.

The respondents recreated their lives before injury in a vivid manner. The researcher could not fail to observe how much that life was valued, what roles were played and the ability to form relationships especially intimate romantic relationships.

3. THE ONSET OF THE INJURY

Sixty percent of the respondents sustained their injuries in motor vehicle accidents, 30 percent from gunshot wounds and ten percent from a stab wound. All ten respondents sustained paralysis in the lower extremities, paraplegia.

R1 gave a sad account of events leading to his injury. He was travelling by taxi to a funeral, an unknown gunman opened fire, killing the driver and injuring several passengers. He was bitter, he felt he was a victim of taxi violence. He lamented that he is a peaceful man who did not deserve the suffering he was experiencing.

R2 was a victim of a prank. He was occupying the backseat in a car driven by his best friend. They had been drinking and the car was travelling at high speed. The driver suddenly announced that everyone must fasten his seatbelt as he was about to overturn the car. The driver lost control and R2 was thrown out and sustained injuries that left him paralysed.

Filled with anger and bitterness R5 blamed the reckless bus driver for changing his life overnight. Similarly R6 blamed his girlfriend who reported him to the civic committee after he had assaulted her. An argument ensued between him and the civic committee leader. A few days later the supporters and sympathisers in his camp attacked the supporters of the civic group. In retaliation he was gunned down at his home while asleep. He puts the blame squarely on the shoulders of his girlfriend.

R9 was assaulted and shot by a group organised by a woman he had jilted after a long affair. The woman was apparently no longer satisfied by being a mistress and the respondent decided to end the relationship. The group left him for dead.

After reprimanding and warning a gun-wielding friend to take the weapon seriously and stop pointing it at people, R7 was hit by a bullet after the friend pointed the gun at him. He still cannot believe that the accident happened. His friend, 17 years old, had taken his uncles gun without permission and was showing off when he shot his best friend leaving him paralysed.

R8 reported that he and his friends were celebrating the victory of their favourite soccer team when the taxi in which they were passengers overturned. He was thrown out and sustained injuries on the spinal cord. R3 and R4 were also victims of taxi accidents.

All respondents reported that during the trauma period at the intensive care unit they did not realise the extent of their injuries. They thought recovery would bring movement and sensation to the lower limbs.

They never anticipated the long hospitalisation, the feeling of helplessness and the total dependence during that period. Some report that they did not believe the diagnosis, they thought a mistake was made. Some were overcome with fear and sadness. There were also feelings of anger and blame as well as guilt. The reality of their situations had not dawned on them at that stage.

4. LIFE AS A PERSON WITH A DISABILITY

Individuals with spinal cord injury must make extremely difficult adjustments in their lives. Becoming a spinal cord injured person has a profound effect on the persons various life tasks.

4.1 MOURNING THE LOSS OF INDEPENDENCE

Mobility is the most visible loss that the respondents had to deal with. There was a general feeling that fate had dealt them a blow. Being confined to a wheelchair was perceived as the most limiting aspect of the injury.

R9 lamented about his present circumstances. As an underground mineworker and a marathon runner the injury put his life to a halt. He

reported that in the early days after he learned about his paralysis, he contemplated suicide, he cried out in frustration “what good am I without my legs, my life might as well have ended. I am the bread winner, what is going to happen to my wife and children?”

Similarly R6 felt that life in a wheelchair was a death sentence. He wished his assailants had killed him rather than to face a life of doom at age 25. “Look at me.” he said sadly, tears glistening in his eyes, “these legs are dead, they are heavy, you cannot lift them, I feel nothing down there, nothing, is that life? I have to be on this thing, pointing at the wheelchair for the rest of my life.”

The respondents felt the wheelchair was a big obstacle because it was going to affect accessibility in their places of employment. R5 sadly explained that he was the bread winner, his work provided security for his family. He felt that as a delivery man he needed his legs. Now that his legs were gone, his financial security and independence would be greatly affected.

The restricted mobility seem to have a negative effect on their careers, social life, self-image, family life and their relationship with their spouses or partners.

4.2 LOSS OF CONTROL

The predominant theme was control of both physical and emotional environment. All subjects seemed distressed by the fact that they no longer had control of their movements, they had to consider the physical barriers (architectural) and societal barriers of non-acceptance of the disabled by the non-disabled community at large.

Their concern about their limited mobility seemed to be dwarfed by the intense emotions that accompanied the loss of control over their bladder and bowel programs. The loss in this area brought feelings of shame, humiliation and embarrassment. One respondent gave a vivid account of his experiences.

"You cannot control your bladder and bowels. Your toileting is no longer a private matter. There is a tube leading from your urethra down your leg to a bag filled with yellow urine. Your bowels may move any time. You feel nothing, you can only tell by the smell and by observing people moving away in disgust, at that point you just want to disappear from the face of the earth."

Another respondent shared his feelings. "You are worse than an infant, in simple language it means you are an adult who wets and soils himself, God! that is humiliating. Do people really understand that you have no control over your program? Or do they just think you are disgusting?"

One lamented, his voice shaking, "At my age I need a diaper, an adult with a diaper on. Tell me who is going to change me and wash the

soiled clothes? An infant is better because he can be toilet-trained, I have to go through this for the rest of my life. For God's sake, I am 25 years old!"

All subjects found the area of bladder and bowel control devastating. They viewed toileting as a private aspect of their lives, however, their newly acquired disabilities robbed them of their control over this very private aspect. There was a general feeling that this aspect had a close relation to sexuality. We will return to this discussion at a later stage.

Another area of concern that emerged was the occasional but uncontrollable spasms in the legs which draws them together at the thighs, flexing the knees and hips.

Sometimes they are mild but at times, so intense that a person can be thrown out of his chair. The spasms are perceived as another area where control is lost and negative attention is drawn.

It should be noted that the study was conducted during the initial hospitalisation thus the subjects were still in a protected environment, the hospital, with trained medical personnel, patients in similar situations and physical surroundings geared to accommodate people with physical disabilities. Their concerns were limited to what was perceived within this environment, there may be different issues once they return to their homes in their communities of origin.

4.3 BODY IMAGE

The respondents perceived their bodies as different because of the injury. They felt they were less attractive than they were prior to the injury.

There was a general feeling that others will judge them according to how they look. One respondent described his perception that his body had a different appearance, where roundness and fullness were present, hollowness and bony prominences were appearing, i.e. signs of atrophy and wasting.

There was a perception that society tend to speak to people with disabilities as if they were children.

One respondent voiced the observation as follows: "They talk down at you instead of to you." Another respondent echoed the same concern: "I am a tall man, 6 feet, people used to look up to address me, now they have to look down."

Stubbins (1977: 453) position was supported wherein he described the self as three basic elements: the imagination of one's appearance to the other person, the other persons' appraisal of that appearance and some kind of self value, feelings such as pride and shame. The respondents seemed quite concerned about normalcy and other people's opinion and attitudes towards their changed body appearance.

4.4 RELATIONSHIPS

Of paramount importance during this initial stage of hospitalisation was the attention paid to the respondents by their partner, family, friends and significant others. There seems to be a concern regarding the changes that could be anticipated upon resumption of life at home and in the community.

4.4.1 FAMILY

Much as the family was still seen as the strongest support system, the respondents felt there would be aspects that change in the relationship. The areas wherein change was anticipated were: roles, lifestyle, decision making, discipline, status and sexual relations.

4.4.2 ROLES

Most of the respondents were the breadwinners and heads of the household. There was a general feeling that because of the anticipated reduced earning power this role would change. The ability to sustain employment and have financial security was seen as a determining factor as to the role one would play.

The other factor that would affect roles was identified as the lack of mobility. Whereas previously tasks that needed physical power were assigned to the man in the house, post injury, such a

person with a disability would not be considered.

4.4.3 LIFESTYLE

All respondents voiced concern about the anticipated change in their lifestyles. The reduced income, if employment cannot be maintained, was seen as the major obstacle. The family would have to re-organise priorities and give up some of the activities enjoyed prior to injury. The greatest fear seemed to be the inability to provide for the family.

4.4.4 DECISION MAKING

The other aspect that emerged in relation to the family was that as a disabled person one could not participate in decision making. The respondents felt that a person who is a contributing member of the family could participate in decision making.

There was a feeling that if you cannot carry out the actions decided upon, then you cannot be involved in the process.

What was troubling to most respondents was that as a dependent member, a perceived burden, a person with a disability may not be able to make decisions about his own life. That is part of the loss of control they mourned.

4.4.5 DISCIPLINE

As heads of the various households the men were in a position of power. They could exercise discipline over the family.

The respondents anticipated that family members would perceive them as powerless now that they were confined to a wheelchair and had lost their independence.

Out of the eight respondents who headed households only two felt confident that their families would respect their input. It was of interest to note that both were from rural settings and still upheld traditional values.

4.4.6 STATUS

There seemed to be an anticipated loss of status. This was linked to the loss of earning power and the belief that society devalues people with disabilities.

One respondent voiced his fear: "This disability will make my enemies happy. I have always viewed myself as progressing, I built my own house and provided well for my family. Now that I am disabled, they will laugh and say I am nothing."

There seems to be a general perception that society looks down upon people with disabilities. Thus the respondents felt that the loss of independence went hand in hand with reduced status in

one's community.

5. SEXUALITY

A major theme that emerged was the issue of sexuality and the resumption of sexual activity.

Disabling conditions inevitably impact upon sexuality. Rieve (1989: 265) points out that feelings of self-worth and attractiveness are threatened at a time when the need for intimacy and belonging is greatest thus causing a sense of loneliness and isolation. Disability removes the person from accustomed personal, social and sexual interaction.

5.1 IMPACT ON SEXUALITY

The manifestations of disability such as paralysis, sensory changes, alterations in the control of bladder and bowel functions, immobility and altered appearance, were of particular concern to the respondents and gave rise to questions about self-image, attractiveness to others and performance of sex acts.

5.2 IMPACT OF THE INJURY

5.2.1 ERECTION

The respondents voiced great concern about the observations they had made pertaining to erections. All ten respondents found the issue of erections of paramount importance.

Eight of the respondents reported having experienced reflexogenic erections of which five could not maintain the erections for long. Two respondents had lost all the ability to have an erection.

The revelation was devastating to the two respondents. R7 cried out helplessly, lamenting: "I am finished, I am no longer a man. My wife is 28 years old, she needs sex. We had planned our life so well, we had a good sex life. The hospital has got to help us. What will I tell her?"

There was a general feeling of fear, fear of the unknown. Questions arose pertaining to the permanence of the condition, the reaction of the spouses and partners and treatment to correct the condition. Erections seemed to be fundamental to a satisfying sexual interaction.

At this stage of the rehabilitation process, the respondents, because of the fact that they had not resumed sexual activity, were unaware of the effects on ejaculation. According to Sha'ked (1981: 70) ejaculation is a more vulnerable component

of sexual function than erection. The incident of ejaculation is greater in persons with incomplete lesions and with lower cord lesions.

Although the reflexogenic erections were a source of embarrassment because they occurred anytime, for instance during bed baths, the respondents seemed grateful that they have erections at all.

5.2.2 BOWEL AND BLADDER CONTROL

The loss of bladder and bowel control dampened the prospects of sexual activity as one respondent pointed out: "If my wife is to change my catheter and clean me after I have soiled myself, I then resume the position of an infant. How can I then turn around and feel sexually attracted to her or she to me?"

The respondents anticipated that the inability to control their bladder and bowel program posed a potential obstacle and barrier to resumption of sexual activity and to intimacy.

5.2.3 REJECTION BY SPOUSE OR PARTNER

All ten respondents gave accounts of the fears they had, one of their most pervasive fears was that the spouse or sexual partner may reject them because they cannot function satisfactorily.

Their fears were even great because at the time of the study their partners and spouses were not aware of the effects of the injury on sexual functioning.

Ninety percent of the married respondents felt there was a need to include the spouses in the rehabilitation program especially regarding sexual functioning information and counselling. Of the single respondents only twenty five percent wanted their partners to be involved.

Seventy five percent of the single respondents were pessimistic as they felt there was a strong possibility of rejection by their partners because there was no permanent commitment. They also anticipated difficulty in finding new partners.

One respondent in his fear of rejection vowed that his girlfriend will not have the luxury of rejecting him emphasising that: "She is responsible for my disability, she must remain with me. If she tried to leave me then I swear , she will also end up in a wheelchair."

The response of the partners and spouses seemed to be of paramount importance. All respondents had cited their spouses and partners as the pillars of their support systems. It is of interest to note that rejection by spouse or partner would be most devastating.

5.2.4 RESUMPTION OF SEXUAL ACTIVITY

All respondents expressed anxiety and apprehensions in their anticipation of the resumption of sexual activity.

They expressed a need to receive guidance pertaining to the approach they can take in their first sexual experience after injury. Eisenbergs position as cited in Leyson (1991: 83) was supported, wherein he maintained that the first sexual experiences after injury appears to be the most psychologically uncomfortable.

Data showed that all the respondents believed that the man must be the sexual aggressor.

The realisation that their sexual abilities were altered and that they may need physical assistance to initiate and perform sexual acts, induced fear of their female partners reactions.

Eight of the respondents reported being the aggressors at all times in their sexual relationships. They strongly believed that it was the responsibility of the man to give pleasure to a woman.

Typical responses to such attitudes were as follows. R1 explained in desperation that if only he could succeed the first time and bring his wife to such heights that she can remember what they had together, then he will have convinced her to remain in the relationship. R9 explained his strategy with excitement: "A fully erect penis is very essential, the good part

of my losing sensation in the penis is that I can hold onto my erection and remain in my wife's vagina longer so she can enjoy it as long as she wants."

R3 boasted that he was well endowed and that his erection is back to pre-injury stage: "I will give it to her once or twice, I will make sure she cries out, then I will be happy and confident that I can still please her."

R3, R2 and R6 felt that if their partners cannot derive pleasure and satisfaction because of the altered sexual abilities, then there would be no hope for commitment in the relationship.

R5 who has lost all the ability to have an erection emphasised that he will not even try: "What good will it do, why arouse her and raise her hopes, I cannot get an erection, there is nothing I can do about it. Perhaps it is my fate. I can never enjoy sex again." He seemed resigned to an asexual life. It is of interest to note that at age 42, his sexual life before injury was rather on a slow pace. He reported having had sex with his wife once in two or three months.

Though he was resigned to an asexual life, he insisted that his wife should be brought in for counselling and for information about his altered sexual capabilities.

The majority of the respondents, ninety percent, reported that after understanding the extent of the injury they had queries in their minds about their sexuality. They were concerned about

their desirability, their ability to satisfy their partners and their own satisfaction.

Typical responses of their concerns indicated the importance of sexuality to them. R8 gave an account of how he lost his appetite, had insomnia as he anticipated his wife's reaction to his state and newly acquired disability.

"This thing was eating me up. I stared in space for hours on end just trying to think of ways to cope. I could not imagine life without my girlfriend." reported R6.

R1: "That is one thing that almost drove me crazy. I asked myself a hundred times, will my wife still want me?"

R2: "Let us face it, no woman would settle for a cripple. How does she go to social occasions with a man in a wheelchair."

R7: "As I lay in that bed week after week feeling nothing below my waist, I wondered will I ever enjoy sex, when I can't even feel that my bladder is full."

R9: "I sit alone sometimes adding and subtracting. My very part of the body that distinguishes me as a man is dead. Will my wife still see me as a man. What good will sex be if I cannot feel the sensations I felt before."

From the above descriptions we can realise that the issue of sexuality has been one of the upper most concerns early in the

period of hospitalisation. Appearance and desirability as well as attractiveness to the opposite sex members was an issue. Performance and the ability to satisfy partners was a concern. Personal satisfaction seemed to follow satisfaction of the partner. The latter is in keeping with Rieve (1989: 266) findings that a review of 15 popular marriage manuals found that the authors placed great performance demands on the male. This stereotype places great pressure on the disabled man. The respondents greatest concern was their ability to satisfy their partners.

5.2.5 ATTITUDE TOWARDS ALTERNATIVE SEXUAL PRACTICES

Spinal cord injuries affect sexual functioning, with the nature and degree of the effects depending upon the level and completeness of the lesion. There may be problems with finding a comfortable and satisfactory position for intercourse, with spasms or incontinence and with achieving and maintaining erection. Physical sensation can also be affected.

Spinal cord injury alters the sexual abilities of the person. There are possibilities and options that are available for a satisfactory sex life.

Data analysis revealed that all respondents regarded genital contact, the insertion of an erect penis into the vagina and

ejaculation inside the vagina as essential and normal practice, and the ultimate goal of sexual activity. Failure to perform these sexual acts was regarded as occasion for great sadness and regret and as an indication of failure.

The responses showed that they were comparing their anticipated altered sexual abilities against the standard of normality which included certain acts as essential, particularly erection, penetration and ejaculation.

Ninety percent of the respondents felt very strongly about the need to resume sexual activity with their spouses. Seventy percent were willing to engage in alternative methods in order to satisfy their partners.

At the beginning of their rehabilitation program the respondents received information about alternative methods, including oral-genital activity, the woman assuming the superior position and mechanical aids such as artificial penises called dildos and vibrators. At the time of the study the respondents were aware of the options and various techniques available to people with physical disabilities.

The researcher found that there were definite differences pertaining to the type of acts the respondents were willing to try. Of the ten respondents, four were willing to engage in oral-genital activity. Of the four, one was open to the idea but the final decision would depend on his partners reaction because they had never engaged in this activity prior to the injury. R6 and

R7, two of the respondents willing to engage in oral-genital sex, reported having been involved in this activity prior to the injury. R5 felt it was a disgusting activity, unnatural and very unhygienic. R3 believed that oral-genital sex was morally wrong and unacceptable. It would be against his religious belief. Forty percent of the respondents found the activity unattractive.

The most widely used pre-injury position for intercourse was the missionary position. For six of the respondents, it was the only one ever used. Of the six, only three were willing to try alternate positions. Some of the respondents feared that if the woman assumed the superior position (on top) there may be further damage to the spinal column. Three respondents felt they would never subject themselves to a situation where a woman takes a dominant role, the superior position.

One respondent, R5, stated clearly: "The man must be on top. The reversed position would just emphasise my position of weakness, now that I have a disability." R3's response stressed his conviction that sex is a symbol of power: "I will never allow a woman on top, I am the man and I am in charge, her place is under me, no further discussion."

The responses showed that the pre-injury sexual practices were influenced by the respondents experiences, personal values, cultural and religious traditions. Their attitudes towards a variety of sexual options available to people with physical disabilities were similar to attitudes held before injury.

Mutual masturbation was welcomed by nine of the ten respondents. Six had engaged in the activity prior to injury. The respondents who were willing to engage in mutual masturbation felt, the activity would be an advantage because their hands are not paralysed, thus they would be able to ensure their partners derive pleasure.

Sex aids such as artificial penises, dildos and vibrators which are used to stimulate both males and females, were rejected outright. Eight of the respondents reported that they would never use mechanical aids. They viewed them as unnatural, inanimate and unacceptable. Typical responses were as follows:

R5: "I would rather lead a sexless life than use sex aids. My wife would be humiliated and it would be degrading to me to use a dead object on her, she would despise me."

R1: "My wife is very dear to me, I respect her, she is a decent woman. I would never put her through such torture."

R4: "What self-respecting man would stoop that low? I will not humiliate myself."

R9: "I will try my best to use my own penis.."

R8: "The whole scene would be too painful to watch. It would be like watching my wife having sex with another man. It would just emphasise my inability. I would feel inadequate."

R2, R6, R10 and R7 believed that mechanical aids are used in pornographic movies and by prostitutes. R6 added that even if he had an interest, he would not know where to obtain such devices. He admitted that he had never seen a sex aid.

It became apparent from the responses that the use of mechanical aids was viewed as unnatural. The respondents reported that using artificial penises or vibrators was distasteful and would be an indication of lack of self respect and for one's partner. One respondent felt very strongly that it was offensive and humiliating to realise that as a man you could be replaced by a "dead" object.

R5 objected strongly, he made an observation that in his culture, the Nguni tribe, if he had died in the accident, his wife would not resort to mechanical aids. His brother would marry his widow.

There was an outright rejection of the use of mechanical sex aids.

6. INTIMACY

A topic that emerged during the discussions pertaining to anticipated altered sexual activity was intimacy.

There was a concern among the respondents that the intimacy that was established prior to injury might be disturbed by the disability.

The caring, sharing, trust, commitment and acceptance developed pre-injury may be affected now that the person had acquired a disability.

There was a general feeling and fear that the injured person would go back home as a changed man in terms of his appearance, self-view, self-acceptance and abilities. Rejection of this new person was anticipated. The respondents feared that their needs as people with disabilities may not be understood by their spouses or partners and families.

The respondents voiced their concerns about the affection, passion, sexual sharing, mutual trust, acceptance and commitment which may be affected by the disability. Typical responses such as the following were noted:

R8: My greatest pride used to be the pleasure my wife derived when I ejaculated. I am now told all that could be gone. So now what will happen to her needs? Let us be realistic here, she may just decide to pack and go.

R9: This catheter will always be in the way, to get to me, the poor woman has to go through it. I see the fear in her eyes when she visits me.

She is so afraid I will hurt myself further. She is always cautioning me to be careful.

The respondents were concerned that intimacy in their new world as people with disabilities maybe rejected by their able-bodied spouses and partners. Their concerns seemed to border around physical and psychic intimacy.

In the physical intimacy they feared that the altered sexual functioning and the assistive devices such as the wheelchair and catheter would diminish the passion. On the psychic level they feared that their able-bodied partners may reject them and their new world as people with disability. The following were noted:

R5: "Let us face it, no woman would put up with emptying of urine bags, cleaning up soiled clothes, constant complaints about leg pains and then still

be expected to arouse this 'dead thing'." He referred to his erectile dysfunction. At the time of this study, he was experiencing problems, he had not had an erection since his injury.

R6: "Is my girlfriend going to understand when I say 'No sweetheart, we cannot have sex today because it is Thursday, the day for my bowel program'. Will she find me attractive when I have had an accidental fecal incontinence? At age 23 she can have any able-bodied man she wants. She needs passion and excitement not a burden."

R4: "I used to take one look at my wife or feel her body next to mine and be ready for sex. Now she has to work hard to keep me erect because I am not able to maintain an erection. She will just despise me. Sexual intercourse can no longer be spontaneous for us."

The respondents seemed to be in the process of redefining their intimacy as people with disabilities. Their relationships were formed when they were able-bodied and their perceptions of intimacy were formed when they had a different picture pertaining to the self. They now have to incorporate disability into the self. They are aware of and understand the technical part, it is the psychological impact that they are battling with.

SUMMARY

The respondents viewed life as a disabled person as a life filled with drastic changes and adjustments.

Their restricted mobility was perceived to affect all aspects in their lives, their independence and control over their lives, their self-image and relationships with their families and significant others.

Sexuality emerged as one of the major issues of concern. The respondents feared that their altered sexual abilities may lead to rejection. Feelings and perceptions of being less attractive and inadequate as a man, emerged from the interviews.

7. FUTURE ASPIRATIONS

7.1 HOPE

Hope seemed to provide the needed encouragement to continue with the interminable demands of rehabilitation.

None of the respondents who expressed hope for recovery seemed to be living in a world of unreality. They merely needed more time to consciously accept that which they already knew to be true.

The hope of walking again was expressed by most of the respondents. Restoration of body image seemed to be maximal

physical rehabilitation goals.

R9 who at the beginning of the interviews had reported his contemplation of suicide, subsequently shared his dreams: “I work hard at physiotherapy. I know that if I continue at this pace, I will walk again and will run the marathon again.”

R6 reported intently: “With determination, I know I can make it, I can walk again. By the time I start university, who knows, I may be using a walking frame.”

7.2 CAREER

Eighty percent of the respondents planned to negotiate with their employers to be assigned tasks that they could manage on a wheelchair. R5 intended to start his own business. As a delivery man he did not see his future in the company. He hoped that the compensation he would receive from his accident and his benefits would give him enough capital.

All the respondents felt they were still too young to stay at home and receive a monthly pension of R410-00. As bread winners they would not be able to make ends meet without employment.

Earlier all respondents had referred to financial independence as a source of status, power and high self-esteem. Maintaining financial independence would probably affect all other aspects of their lives positively.

7.3 RELATIONSHIPS

7.3.1 FAMILY

All the respondents expressed hope that the family will remain their strongest support system.

They perceived the family as a valuable resource in their rehabilitation and adjustment.

There was appreciation for the support and concern shown by family members during hospitalisation.

7.3.2 SPOUSE AND SEXUAL PARTNERS

As far as the partners and spouses were concerned there was a general feeling that acceptance and commitment by them would set the pace for successful adjustment.

There was a desperate plea for understanding of the plight of a person with a disability and an empathic view of the partners was sought.

7.4 SEXUALITY

The respondents expressed a need to be recognised as sexual beings.

There was a call for attitude change pertaining to the perceived tendency of society to devalue people with disabilities.

All respondents hoped that their sexual partners will accept them as people with disabilities. They had a special need for the partners to be receptive and have an empathic view to their altered sexual ability.

There was an expectation and a plea to the health care team to intervene by giving information educating and counselling the partners before sexual activity could resume.

7.5 RECONCILIATION

Most of the respondents hoped that confrontations and conflicts would be minimal.

Some expressed a wish that those they had hurt or offended in the past would not take the opportunity to retaliate.

R9 expected his wife to forgive him for his infidelity. He claimed that he had been discreet because he loved and respected his wife. He perceived the conflict he had with his former girlfriend unfortunate. The dispute led to his assault and injury.

Though R6's girlfriend was blamed for the injury, he wanted reconciliation because he felt she was the only woman who could understand him as she knows him well. Theirs is a five year old relationship.

There seemed to be a desperate need to bury the hatchet and to start on a clean slate.

7.6 ARCHITECTURAL AND SOCIETAL BARRIERS

All respondents cited physical barriers as a major stumbling block to accessibility. They expressed a wish that buildings could be made more accessible to people with physical disability. They viewed the barriers as an impediment that would affect their pursuing their careers and social lives.

Another perceived barrier was the society that is showing non-acceptance to people with disabilities. One respondent articulated his feelings clearly: "I was injured and I have a disability but I can still think. I have needs and feelings. When we sit outside our wards, people walk past us and talk as if we do not exist."

Most respondents expressed hope that attitudes towards people with disabilities in our society would change.

SUMMARY

The respondents reviewed their lives, reliving past experiences and examining present feelings.

The newly acquired disability was perceived to have a spiralling effect on a persons life.

The physical limitations and the altered abilities were seen to affect independence and control over one's life. The loss of financial independence was anticipated to have a negative effect on one's status, power, lifestyle and on relationships.

Sexuality emerged as one of the major issues of concern among the respondents. There was fear that the altered sexual abilities may lead to rejection by the spouses and partners.

There was a plea for change of attitude towards people with disabilities and acceptance to facilitate adjustment and resocialisation into the community.

CHAPTER 7

CONCLUSION AND RECOMMENDATIONS

INTRODUCTION

In this chapter the aim is to briefly summarize the conclusions under the following headings: dependence, relationships, sexuality, intimacy, the therapeutic nature of the study and implication of the findings. The final section will outline the recommendations.

- i) To provide a platform for the spinal cord injured male paraplegic to explore the implications of the injury on his sexuality.
- ii) To gain insight and to understand what it means to be a male paraplegic.

Sexuality emerged as one of the major issues of concern during the initial period of hospitalisation. Three broad areas were identified and perceived to have an impact on the whole issue of sexuality, namely, physical appearance, independence and relationships.

The study provided more than a platform for the respondents to explore their world as newly injured persons. It also gave them freedom and permission to view themselves as sexual beings.

1. CONCLUSION

1.1. DEPENDENCE

Spinal cord injury results in loss of mobility, loss of control of bowel and bladder programs and threatens financial independence. Loss of independence threatens the person with a disability's self-worth and self-esteem leaving him feeling inadequate.

- Financial security was perceived as the cornerstone of personal success. The disability introduced financial dependence resulting in loss of control over ones life, loss of economic power, status and authority. Failure to provide for ones family threatened masculinity, leaving the person with a feeling of inadequacy and a sense of failure.
- The loss of control over the bowel and bladder programs became a social embarrassment , impacting negatively on sexuality and sexual activities: toileting a private aspect of ones life became a public matter, an experience the respondents found humiliating, degrading and reducing sexual attraction and desirability.
- The functional limitations caused by impaired mobility, force the person with a disability to depend on others. This dependency restricts sexual intimacy because the injured person may feel that he is a burden and fail to see himself as a desirable sexual person. He may interpret attention from a member of the opposite sex as pity.

- During the initial stage of hospitalisation the fears of rejection are heightened because life outside the hospital is still theoretical. The respondents have not tried out all the issues mentioned during the interview. The unknown lifestyle changes and the anticipated rejection by their loved ones and by society is frightening. The world outside the protected environment of the hospital seem cruel and unkind to the person with a newly acquired disability.
- Loss of independence impacts upon sexuality. Sexuality being defined by the respondents as the self-image encompassing a sense of maleness, the learned behaviours associated with this status and the roles and patterns of functioning.

1.2 RELATIONSHIPS

The partners commitment to the relationship emerged as crucial than ever before. Love, caring, support and understanding within a relationship serves as a major impetus for continued sexual activity and can help the injured person with post-traumatic psycho-sexual adjustment, to recapture his sense of self-worth.

The post-injury reaffirmation of love by the partner for the man with a disability, can provide the context for the man to begin to love himself again.

The fear of rejection that results from the injured man's development of a negative self-image at the onset of the disability, can be reduced by the support and understanding of the spouse or partner.

The success of the relationship will be determined by the emotional maturity of each partner, their mutual love and respect, their ability to communicate their needs, feelings and experiences and the establishment of a deep commitment. The understanding and acceptance by the spouse or partner, of the post-injury shortcomings can foster self-acceptance by the injured partner.

The attitude and reaction of the able-bodied partner toward disability, plays an important role on the post-injury adjustment and on the broader definition of sexuality by the injured male. A solid relationship based on love, caring, sharing, trust, commitment and mutual acceptance is a foundation for a positive sexual adjustment after the onset of disability.

1.3 SEXUALITY

Sexuality is one of the three major areas of concern to the newly injured male paraplegic. The respondents were concerned about the physical appearance, financial security and sexuality. Of interest was to note that even at this early stage of the injury, there were concerns about desirability, ability to satisfy a partner and the ability to derive pleasure during sexual activities.

Even though performance (sex acts) was perceived to be crucial in a relationship, sexuality was defined in a broader sense. The definition included self-image, masculinity, attractiveness, roles as a male and desirability to the opposite sex.

The spinal cord injured persons attitudes, beliefs and values were formulated during his sexual development as an able-bodied person. It is against that background that he is evaluating himself as a person with a disability.

Physical appearance and attractiveness is measured against images and expressions used by able-bodied persons. Expressions and descriptions such as "tall, dark, slender and handsome" do not fit the description of a man sitting in a wheelchair.

Throughout the study the researcher came to a realisation that no amount of rehabilitation would retrieve the natural, God given, pleasure of orgasm. The spinal cord injured person has lost the most intricate and innate part of his being, and of his sexuality.

1.4 INTIMACY

Intimacy is generally marked by a mutual sense of acceptance, commitment, tenderness and trust. The injury seems to call for a revision of the definition. Redefinition is indicated because the injured person begins to have doubts about his acceptance by his partner. The love, trust, caring and commitment come under scrutiny.

The injured person's task to redefine intimacy is an overwhelming task. Their first task is to incorporate the disability into the self. This entails acceptance of the once rounded and full areas of the body now replaced by bony prominences, spasticity of the lower body that occurs frequently, the loss of bladder control that now empties through a tube

which travels down the legs to a plastic bag that fills with yellow urine, fecal incontinence that can occur without warning. The ability to stand and walk is lost and the environment is viewed from four feet above the ground. Conversation is carried on with erect people by tilting the head and looking up. Physically controlled erections cannot occur in spite of intense arousal and orgasm in the physical sense is lost.

The newly injured male paraplegic is confronted with a new world, a world that he is not certain can be easily absorbed by the society he must re-enter. The alteration of his body is so profound that he questions whether sexual expression is possible. As his sexuality comes under scrutiny his self-worth is affected. The second task in his redefinition is to communicate his new world to his spouse or partners and to gain empathy and understanding.

The third task or hurdle in his attempt to redefine intimacy is the lack of privacy. There are now outsiders who become involved, starting with the doctor who reveals the diagnosis and explains the limitations, the entire health-care team who assist him with coping mechanisms in his new world. His sexual functioning becomes public knowledge to complete strangers. private issues such as the ability to have an erection, to ejaculate, to experience a physical orgasm and to assume a particular position during intercourse become public knowledge to the rehabilitation team and subsequently to the partner or spouse.

The final task is to deal with the realisation that the public discussion of the new world of people with disabilities and the redefinition of the self and of intimacy takes care of the theoretical reality and the technical issues but does not solve the individual problem and the psychological

issue that accompany the post disability adjustment. The psycho-social ramifications are enormous. They newly injured male is haunted by sexual concerns such as his ability to satisfy his partner, his own sexual satisfaction and his desirability. He has to deal with three basic areas in his new world physical limitation, economic capability and sexual functioning. Even if he can succeed to redefine intimacy, he is haunted by the fear that his partner may reject the new definition. The altered sexual ability involving erectile, ejaculatory and fertility dysfunctions, makes it difficult for the male with a disability to remain being the traditional sexual initiator.

Leyson (1991: 122) observes that in the American culture, sex has been associated with orgasm and ejaculation, femaleness with attractiveness and maleness with an erect penis, the ability to play sports and to be a successful wage-earner. The ability (or perceived ability) to fulfil these stereotypical expectations strikes the spinal cord injured at the core of his identity and stability. This stereotype is also found in Nigeria. Nwuga (1982: 79) states that in the Nigerian culture the myth that men instinctively know how to satisfy woman is reinforced. They are therefore expected to play the dominant role. A change of roles as made necessary by the onset of disability may not be easy to achieve because of cultural attitudes.

The researcher is of the opinion that there may be similarities in the South African culture, where masculinity is equated with a good physique, success as a wage earner and the ability to satisfy the sexual needs of a female. These expectations put pressure on the spinal cord injured male. He maybe fearful of the females reaction to his altered sexual abilities and to his need for physical assistance to initiate and

perform sexual acts.

His redefinition of intimacy must include learning more verbal strategies if he wishes to maintain the role of initiator or he must be willing to accept a more dominant role for the female.

Spinal cord injury violates the well entrenched media fostered ideal of desirability. The lifeless limbs, incontinence, spasms and wheelchairs affect the persons self-confidence and erode self-esteem.

Though the spinal cord injured male has defined sexuality in a broad sense, the sex act and performance involving erection, penetration and ejaculation remain crucial. He still uses standards of normality set pre-injury as a measure.

The willingness to engage in other options of sexual expression such as mutual masturbation, oral-genital sex and the use of mechanical sex aids differs in each individual. The individuals personal past experiences, value system, religious and cultural tradition play an important role in determining his sexual adjustment post injury.

1.5 THERAPEUTIC NATURE OF THE STUDY

The research did not only provide the respondents with a platform for exploration, but also afforded them a therapeutic intervention by implication.

The researcher, a woman, gave the men an opportunity to brag about their prowess, their conquests and escapades prior to the injury. Reliving the past allowed them to take stock of their lives, their roles, achievement and contributions thus their self-worth. It was an opportunity to look at their lives yesterday, today and to face tomorrow.

Acceptance and willingness to listen to them as experts of their own lives, allowed them the freedom and gave them permission to share their world as people with a disability and to go into intimate details of what the injury and the disability meant to them.

The in-depth interviews created an opportunity to take sexuality out of the closet and to desensitise the respondents to talk about sex, in particular to talk about the altered sexual abilities and sexual dysfunctions.

The discussion, aimed at understanding the newly injured male from his perspective was therapeutic. Ventilation was allowed, helping them to deal with their feelings and experiences pertaining to disability and sexuality.

The opportunity created to discuss intimate details of their lives with a member of the opposite sex may have established a foundation for an open communication with the partner or spouse. The long hours spent with each individual, on the average 6¼ hours allowed close contact between the researcher and the respondents, establishing rapport and modelling a relationship based on trust, mutual respect and open and honest communication.

The researcher was the only research instrument utilised. The subjects were encouraged to freely express their thoughts and their innermost feelings about the impact of disability on their sexuality. The subjects viewed the researcher as interested enough in them and their activities to have maintained direct contact throughout a period of five months without resorting to other instruments such as questionnaires.

In all interactions in hospital, the respondents receive information and instructions from professionals, problems are identified and solutions are formulated by experts (the health care team). The study reversed the situation. The researcher did not come with prejudgement of the nature of the problem. The respondents were in charge for the first time since their hospitalisation, they had all the information and were eager to educate the researcher about their private world.

2. APPLICATION OF THE FINDINGS

- 2.1 The findings cannot be generalised to the entire male paraplegic population because the size of the sample was small and the first available appropriate subjects were included in the study.
- 2.2 The study was exploratory in that it aimed at capturing the private world of the spinal cord injured male paraplegic and his interpretation of his injury and the subsequent loss of function. The information and knowledge generated can be used to formulate hypotheses and test them.
- 2.3 The key themes drawn from the study can be used for future practice and research.
- 2.4 The respondents gave detailed descriptions of their experiences, needs and feelings as newly spinal cord injured people. The rehabilitation team will benefit because they can have a better understanding of the world of a male paraplegic during the initial hospitalisation period. The information and insight gained will enable the team to develop appropriate rehabilitation programs.

3. RECOMMENDATIONS

- 3.1 Sexuality counselling should be a high priority concern for the total rehabilitation of the newly injured person.

- 3.2 In designing a rehabilitation program, the issues from the perspectives of the injured persons must be taken into account.
- 3.3 The role of the partner or spouse needs to be emphasised in the sexual rehabilitation program.
- 3.4 Counsellors need to be aware of and respect the individuals personal moral codes, values, sexual preferences, religious and cultural traditions as well as acceptable sexual behaviours.
- 3.5 Follow-up services should be introduced, in order to monitor the emotional climate of the family with regard to the disability to ensure optimal adjustment.
- 3.6 Opportunities to verbalise issues of concern should be provided, to the person with a disability early in the rehabilitation period.
- 3.7 The knowledge and information generated in the study should be used to formulate hypotheses and tested in future research.

BIBLIOGRAPHY

Abraham K.S. 1981. The impact on marriages of adult-onset paraplegia. Paraplegia, 19 (4): 253-259.

Alexander C.J., Sipski M.L., Thomas W. & Findley W. 1993. Sexual activities, desire and satisfaction in males pre- and post- spinal cord injury. Archives of sexual behaviour, 22 (2): 217-228.

Alexiewich D. 1990. Evaluation of a videotape: orientation of patients to rehabilitation. SCI Nursing, 7 (2): 31-3.

Amelar R.D. & Dubin L. 1982. Sexual function and fertility in paraplegic males. Urology, 20 (1): 62-65.

Arkava M. & Lane T. 1983. Beginning social work research. Boston: Allyn & Bacon Inc.

Arkles S. 1987. The price of gold: Paraplegic injuries on the mines. South African Labour bulletin, 12 (2): 70-84.

Bertino L.S. 1989. Stress management with spinal cord injured clients. Rehabilitation-nursing, 14 (3): 127-129.

Biren J.E. & Deutchman D.E. 1991. Guiding autobiography groups for older adults: exploring the fabric of life. Baltimore, Maryland: The John Hopkins University Press.

Bloch R. & Basbaum M. 1986. Management of spinal cord injuries. Baltimore: Williams & Wilkins.

Bloom M. & Fischer J. 1982. Evaluating Practice: guidelines for the accountable professional. New Jersey: Prentice Hall Inc.

Bodenhamer E., Achterberg J., Kevorkian G., & Belanus A. & Cofer J. 1983. Staff patients perceptions of psycho-social concerns of spinal cord injured person. American Journal of physical medicine and rehabilitation, 62 (4): 182-193.

Bogdan R.C. & Bilken S.K. 1992. Qualitative research for education: an introduction to theory and method. Second edition. Boston: Allyn & Bacon.

Bozzacco V. 1993. Long-term psycho-social effects of spinal cord injury. Rehabilitation-nursing, 18 (2): 62-87.

Booth T. & Booth W. 1994. Parenting under pressure: mothers and fathers with learning difficulties. Buckingham, Great Britain: Open University Press.

Brockway J.A. & Steger J.C. 1981. Sexual attitude and information questionnaire: reliability and validity in a spinal cord injured population. Sexuality and disability, 4 (1): 49-60.

Bullard D.G. & Knight S.E. 1981. Sexuality and physical disability: personal perspectives. St. Louis: The C.V Mosby Company.

Capildeo R & Maxwell A. 1984. Progress in rehabilitation: paraplegia. London: Macmillan Press.

Chase B.W. & King K.F. 1990. Psychological adjustment of persons with spinal cord injury. International journal of rehabilitation research, 13 (4): 325-327.

Coates R. & Ferroni P.A. 1991. Sexual dysfunction and marital disharmony as a consequence of chronic lumbar spinal pain. Sexual and marital therapy, 6 (1): 65-69.

Cock J. 1988. Voices from the margin: environmental constraints experiences by spinal cord injured people in Soweto. South African journal of occupational therapy, 18 (2): 7-15.

Comarr A.E., Cressy J.M. & Letch M. 1983. Sleep dreams of sex among traumatic paraplegic and quadriplegics. Sexuality and disability, 6 (1): 25-29.

Cushman L.A. 1988. Sexual counselling in a rehabilitation program. Journal of rehabilitation, 54 (2): 65-69.

Crewe N.M. & Krause J.S. 1988. Marital relationship and spinal cord injury. Archives of physical medicine - rehabilitation, 69 (6): 435-438.

Dahlberg A. & Hovatta O. 1989. Anejaculation following spinal cord injury does not induce sperm-agglutinating antibodies. International journal of andrology, 12 (1): 17-21.

De Azvedo L. 1990. Rehabilitating paraplegics in the mining industry. Nursing R.S.A, 5 (11): 32-34.

de Jong G., Branch L.G. & Corcoran P. 1984. Independent living outcomes in spinal cord injury: multivariate analysis. Archives of physical medicine - rehabilitation, 65 (2): 66 - 73.

Dewis M.E. 1989. The meaning of body changes: spinal cord injured adolescents and young adults. Journal of advanced nursing, 14: 389-396.

Dijkers M. & Cushman L.A. 1990. Differences between rehabilitation disciplines in view of depression in spinal cord injury patients. Paraplegia, 28 (6): 380-291.

Dunn M. 1983. Sexual questions and comments on a spinal cord injury service. Sexuality and disability, 6 (3): 126-134.

Dunnum L. 1990. Life satisfaction and spinal cord injury: The patients perspective. Journal of neuroscience nursing, 22 (1): 43-47.

Elliot T.R., Witty E.T. & Herrick S. 1991. Negotiating reality after physical loss: hope, depression and disability. Journal of personality and social psychology, 61 (4): 608-613.

Eisenberg M.G. & Saltz C.C. 1991. Quality of life among ageing spinal cord injured persons: long term rehabilitation outcomes. Paraplegia, 29 (8): 514-520.

Eisenberg N. 1987. Contemporary topics in developmental psychology. New York: John Wiley & Sons Inc.

Farrow J. 1990. Sexuality counselling with clients who have spinal cord injuries. Rehabilitation counselling bulletin, 33 (3): 251-259.

Frank R., Elliot T.R. 1987. Life stress and psychologic adjustment following spinal cord injury. Archives of physical medicine-rehabilitation, 68 (6): 344-347.

Frank R. Elliot T.R. 1989. Spinal cord injury and health locus of control. Paraplegia, 27 (4): 250-256.

Goddard L.R. 1988. Sexuality and spinal cord injury. Journal of neuroscience nursing, 20 (4): 240-244.

Green B.C., Pratt C.C., Grigsby T.E. 1984. Self-concept among persons with long-term spinal cord injury. Archives of physical medicine - rehabilitation, 65 (12): 751-754

Genz S. 1990. Sexual ethics: a biblical perspective. Dallas: Word Publishing.

Grinnell R.M. 1981. Social work research and evaluation. Third edition. Hasca, Illinois: F.E. Peacock Publishing.

Hammell K.R.W. 1992. Psychological and sociological theories concerning adjustment to traumatic spinal cord injury: the implications for rehabilitation. Paraplegia, 30 (5): 317-326.

Haney M., Rabin B. 1984. Modifying attitudes toward disabled persons while re-socialising spinal cord injured patients. Archives of physical medicine - rehabilitation, 65 (12): 751-754.

Heslinga K., Schellen A.M.G. & Verkuyl A. 1974. Not made of stone: the sexual problems of handicapped people. Springfield: Charles C. Thomas - Publisher .

Holmes R.G. 1981. A comparative study of spinal cord injured males and females with regard to self-concept and sexuality. Unpublished MA dissertation, University of South Africa, Pretoria.

Holmes R.G. 1987. Quadriplegia factors critical to the involvement in intimate relationships. Unpublished doctoral thesis, University of South Africa, Pretoria

Holmes T.H. & David E. 1989. Life change, life events and illness. New York: Praeger Publishers.

Iwatsubo E., Tanaka M., Takahashi K. & Akatsu T. 1986. Non-inflatable penile prosthesis for the management of urinary incontinence and sexual disability of patients with spinal cord injury. Paraplegia, 24 (5): 307 - 310.

Jaworski T.M., Richards J.S. & Lloyd L.K. 1992. Retrospective review of sexual and marital satisfaction of spinal cord injury and diabetic males post penile injection or implant. Urology, 40 (2): 127-131.

Katz S. & Kravetz S. 1987. Rehabilitation status of spinal cord injured persons. International journal of rehabilitation-research, 10 (4): 428-430.

Kennedy S. & Over R. 1990. Psychological assessment of male sexual arousal following spinal cord injury. Archives of sexual behaviour, 19 (1): 15-27.

Kester B., Rothblum E., Lobato D. & Milhaus R.L. 1988. Spouse adjustment to spinal cord injury: long-term medical and psycho-social factors. Rehabilitation counselling bulletin, 32 (1): 4-21.

King N.J., Klein R.M. & Remenyi A.G. 1985. Sexual counselling with spinal cord injured persons. Australian family physician, 14 (1): 47-52.

Kiwerski J. 1982. Social and professional evaluation of para and tetraplegics. Paraplegia, 20 (2): 97-102.

Koehler M.L. 1989. Relationship between self-concept and successful rehabilitation. Rehabilitation Nursing 4 (1): 9-12.

Krathwahl D.R. 1988. How to prepare a research proposal. Third edition. Syracuse, New York: Syracuse University Press.

Leduc B.E., Roy D. & Paulin O. 1992. The use of physostigmine in men with spinal cord injury with ejaculatory dysfunction. Canadian Journal of Rehabilitation, 5 (4): 231-235.

Leyson J.F.J. 1991. Sexual rehabilitation of the spinal cord injured patient. Clifton, New Jersey: Human Press.

Linsenmeyer T.A. Evaluation and treatment of erectile dysfunction following spinal cord injury: A review. The journal of the American Paraplegia Society, 14 (2): 43-51.

Linton S.S. 1990. Sexual satisfaction in males following spinal cord injury as a function of locus of control. Rehabilitation Psychology, 25 (1): 19-27.

Mackelprang R.W. & Hepworth D.H. 1987. Ecological factors in rehabilitation of patients with severe spinal cord injuries. Social work in health care, 13 (1): 23-28.

Manganyi N.C. 1970. Body image in paraplegia. Unpublished doctoral thesis, University of South Africa, Pretoria.

Masters W.H., Johnson V.E. & Kolodny R.C. 1992. Masters & Johnson on sex and human loving. New York: Macmillan Publishers.

McGowan M.B. & Roth S. 1987. Family functioning and functional independence in spinal cord injury adjustment. Paraplegia, 25 (4): 357-365.

Miller S.B. 1987. Spinal cord injury: self-perceived sexual information and counselling needs during the acute rehabilitation and post-rehabilitation phases. Rehabilitation psychology, 33 (4): 221-226.

Miller S., Szasz G. & Anderson L. 1981. Sexual health care clinician in an acute spinal cord injury unit. Archives of physical medicine rehabilitation, 62 (7): 315-320.

Mooney T.O., Cole T.M., Chilgren R.A. 1975. Sexual options for paraplegics and quadriplegics. Boston: Little Brown Publishers.

Mouton J. & Marais H.C. 1990. Basic concepts in the methodology of the social sciences. Pretoria: Human Science Research Council.

Nordqvist I. 1971. Disabled persons relationships and sexuality. Bromma, Sweden: Swedish Central Committee for Rehabilitation.

Nordqvist I. 1975. Life together: the situation of the handicapped. Stockholm: The Swedish Central Committee for Rehabilitation.

Nordqvist I. 1986. Sexuality and disability a matter that concerns all of us. Stockholm: Liber Tryck AB.

Neumann R.J. 1979. The forgotten other: women partners of spinal cord injured men, a preliminary report. Sexuality and disability, 2 (4): 287-292.

Novak P.P. & Mitchell M.M. 1988 Professional involvement in sexuality counselling for patients with spinal cord injuries. The American Journal of Occupational Therapy, 42 (2): 105-112.

Nwuga V.C.B. 1981. Ability to cope with prejudice and role of the visibility factor among paraplegics and the emotionally disturbed. International journal of rehabilitation research, 4 (1): 17-22.

Nwuga V.C.B. 1982. Sexual adjustment among upper class Nigerian male paraplegics and tetraplegics. Journal of Tropical Medicine and Hygiene, 85 (2): 77-80.

Pachalski A. & Pachalska M.M. 1984. Programme of active education in the psycho-social integration of paraplegics. Paraplegia, 22 (4): 238-243.

Page R., Cheng H., Cohen P., Pate, Mathus B., Pryor D. & Ko J. 1987. The perceptions of spinal cord injured persons toward sex. Sexuality and Disability, 8 (2): 112-132.

Pearson V. & Klook A. 1989. Sexual behaviour following paraplegia: an exploratory study in Hong Kong. Disability, Handicap & Society, 4 (3): 285-295.

Phelps G., Brown M., Chen J. 1983. Sexual experience and plasma testosterone levels in male veterans after spinal cord injury. Archives of Physical Medicine and Rehabilitation. 64 (2): 47 - 52.

Pilsecker C. 1990. The first six months post-hospital for spinal cord injured veterans. American journal of physical medicine and rehabilitation, 69 (2): 91-95.

Power P.W., Dell Orto A.E. & Gibbons M.B. 1988. Family interventions throughout chronic illness and disability. New York: Springer Publishing Company.

Rabin B.J. 1980. The sensuous wheeler: Sexual adjustment for the spinal cord injured. San Francisco Multi Media Center.

Ray C. 1984. Coping with spinal cord injury. Paraplegia, 22 (4): 249-259.

Richards J.S., Lloyd K., James J. & Brown J. 1992. Treatment of erectile dysfunction secondary to spinal cord injury: sexual and psycho-social impact on couples. Rehabilitation and Disability, 42 (4): 205-213.

Rieve J.E. 1989. Sexuality and the adult with acquired physical disability. Nursing clinics of north America, 24 (1): 265-276.

Robbins K.H. 1985. Traumatic spinal cord injury and its impact upon sexuality. Journal of applied rehabilitation counselling, 16 (1): 24-31.

Roesler R., Bolton B. 1978. Psycho-social adjustment to disability. Baltimore: University Park Press.

Rucker B., Carpenter C., Szasz G. 1989. Survey of men with spinal cord injuries demonstrated interest in fertility enhancement. Canadian Journal of Rehabilitation, 3 (1): 37-41.

Russel C. 1992. The rocky road: paraplegic care in rural KwaZulu. Mining survey, 225-31.

Rubin A. & Babbie E. 1989. Research methods for social work. Belmont, California: A division of Wadsworth Inc.

Sawyer H.W., Allen H.A., Reisin B.L. 1983. Micro-counselling: a counsellor training format relating to sexual concerns of spinal cord injured women. Sexuality and Disability, 6 (1): 30-37.

Seftel A.D., Robert D., Oates R.D. & Krame R.J. 1991. Disturbed sexual function in patients with spinal cord disease. Neurologic clinics, 9 (3): 757-778.

Schuerman J.R. 1983. Research and evaluation in the human services. New York: The Free Press.

Schuler M. 1982. Sexual counselling for the spinal cord injured: a review of five programs. Journal of sex and marital therapy, 8 (3): 241-252.

Schutz R., Decker S. 1985. Long-term adjustment to physical disability: the role of social support, perceived control and self-blame. Journal of personality and social psychology, 48 (5): 1162-1172.

Schurink W.J. 1995. Criteria for evaluating qualitative studies. Pretoria: Human Science Research Council. Unpublished lecture presented during the HSRC's 1995 progress training program.

Schurink W.J., de Jongh van Arkel J.T. & Roos J.L. 1992. Methodological account of the execution of qualitative methods in the family murder study. Geneeskunde, 34 (8): 13-24.

Shaffir W.B. & Stebbins R.A. 1991. Experiencing fieldwork: an inside view of qualitative research. Newbury Park: Sage Publications.

Sha'ked A. 1981. Human sexuality and rehabilitation medicine: sexual functioning following spinal cord injury. Baltimore: Williams & Wilkins.

Simmons S., Steven E. & Ball E. 1984. Marital adjustment and self-actualisation in couples married before and after spinal cord injury. Journal of marriage and the family, 46 (4): 943-945.

Siosteen A., Lundqvist C, Blomstrand C., Sullivan L. & Sullivan M. 1990. The quality of life of three functional spinal cord injury subgroups in a Swedish community. Paraplegia, 28 (8): 476-488.

Sishuba J. 1991. Attitudes of spinal cord injured persons toward sexual options. Unpublished research study presented at the seventeenth World Congress - Rehabilitation International in Kenya in 1992.

Solomon J. 1982. Sex and the spinal cord injured patient. Journal of neurosurgical nursing, 14 (2): 125-127.

Solyom C., Solyom L. 1990. A treatment program for functional paraplegia/muchausen syndrome. Journal of behaviour therapy and experimental psychiatry, 21 (3): 225-230.

Somasundaram O, Balakrishnan S., Ravindaran A.S., Shanmugasundaram T.K. 1992. A psychological study of spinal cord injured patients involved in the Madras Paraplegia Project. Paraplegia, 30 (11): 799-802.

Sonksen J., Biering-Sorensen F. 1992. Fertility in men with spinal cord or cauda quina. Lesions seminars in Neurology, 12 (2): 106-114.

Stanton G.M. 1984. A needs assessment of significant others following the patients spinal cord injury. Journal of neurosurgical nursing, 16 (5): 253-256.

Steinglass P., Temple S., Lisman S. & Reiss D. 1982. Coping with spinal cord injury: the family perspective. General Hospital Psychiatry, 4 (4): 259-264.

Stien R. 1992. Sexual dysfunction in the spinal cord injured. Paraplegia, 30 (4): 54-57.

Specht R. & Craig G. 1982. Human development: a social work perspective. New Jersey: Prentice Hall, International Inc.

Stubbins J. 1977. Social and psychological aspects of disability: a handbook for practitioners. Baltimore: University Park Press.

Tenenbaum G., Gal-Or Y., Dekel S., Hovan N. 1987. Perceived dimensionality of attributions following success and failure by paraplegic males. Personality and Individual Differences, 8 (1): 121-124.

Tepper M. 1992. Sexual education in spinal cord injury. Rehabilitation: current trends and recommendations. Sexuality and disability, 10(1): 15-31.

Trieschmann R.B. 1980. Spinal cord injuries: psychological, social vocational adjustment. New York: Pergaman Press.

Urey J.R., Viar V. & Henggeler S.W. 1987. Prediction of marital adjustment among spinal cord injured persons. Rehabilitation Nursing, 12 (1): 26-30.

Vargo F.A. 1984. Adaptation to disability by the wives of spinal cord males: a phenomenological approach. Journal of applied rehabilitation counselling, 15 (1): 28-32.

Van den Bout J., N. Van Son-schoones N., Schipper J. & Groffen C. 1988. Attributional cognitions, coping behaviour, and self esteem in in-patients with severe spinal cord injuries. Journal of clinical psychology., 44 (1): 17-22.

Villeneuve M.J. 1989. Sexual function and fertility: the impact of spinal cord injury. CONA Journal, 11 (1): 12-17.

Weinberg J.S. 1982. Human sexuality and spinal cord injury. Nursing Clinics of North America, 17 (3): 407-419.

White E.J. 1986. Appraising the need for altered sexuality information. Rehabilitation Nursing, 11 (3): 6-9.

White M.J., Rintala D., Hart K., Young M.E. & Fuhrer M. 1992. Sexual activities, concerns and interests of men with spinal cord injury. American Journal of Physical Medicine and Rehabilitation, 71 (4): 225-231.

Yarkony G.M. 1990. Enhancement of sexual function and fertility in spinal cord injured males. American Journal of Physical Medicine and Rehabilitation, 69 (2): 81-87.

Yerxa E.J. & Locker S.B. 1990. Quality of time use by adults with spinal cord injuries. American Journal of Occupational Therapy, 44 (4): 318-326.

Zasler N.D. & Katz P.G. 1989. Synergist erection system in the management of impotence secondary to spinal cord injury. Archives of Physical Medicine and Rehabilitation, 70 (1): 712-716.

PERSONAL INTERVIEWS

Cameron I. Orthopaedic Surgeon, Conradie Hospital, Cape Town. 07 December 1992. Personal Interview, Cape Town.

Holmes R.G. Psychologist, Rand Mutual Hospital, Johannesburg. 30 October 1993. Personal interview, Vereeniging.

Manganyi C.N. Director General - Department of Education, Pretoria. 16 July 1995. Personal interview, Pretoria.

Maggy M. Director - Independent Living Centre, Cape Town. 07 December 1992. Personal interview, Cape Town.

Mzimba T. Member of Disabled People of South Africa, Pretoria. 17 September 1994. Personal interview, Atteridgeville.

Nordqvist I. Author and expert in the field of sexuality and disability, Sweden. 08 September 1992. Personal interview, Nairobi.

Schurink W. Pretoria, 15 June 1995. Personal interview, Pretoria.

Sudbury R. Pastor for Centre for Paraplegics, Zimbabwe. 10 September 1992. Personal interview, Nairobi.

APPENDIX 1**QUESTIONNAIRE****A. DEMOGRAPHIC DATA**

1. Age in years

40 - 45	()
35 - 39	()
30 - 34	()
26 - 29	()
20 - 25	()
15 - 19	()

2. Language

Nguni	()
Sotho	()
Tsonga	()
Venda	()
English	()
Afrikaans	()
Other (Specify)	()

3. Marital Status

Single	()
Married	()
Divorced	()
Widowed	()
Separated	()
Cohabiting	()

4. Accommodation

Own home	()
Rented house	()
Rented flat	()
Rented room	()
Living with parents	()
Living with family	()
Living with friends	()
Sharing house with others	()

5. Educational level

Less than Std 8	()
Std 8	()
Std 10	()
College Diploma	()
University Degree	()

6. Occupation

- Self-employed as a ... ()
- Skilled labourer as a ... ()
- Unskilled labourer as a ... ()
- Professional as a ... ()
- Unemployed ()

7. Into which of the following categories did your annual income fall?

- Less than R5 000 ()
- R 6 000 - R10 999 ()
- R11 000 - R15 999 ()
- R16 000 - R20 999 ()
- R21 000 - R25 999 ()
- R26 000 - R30 999 ()
- R31 000 - R35 000 ()
- R36 000 - R40 000 ()
- R40 000 and above ()

B. INJURY HISTORY

8. Onset of injury

- 10 - 12 weeks ()
- 13 - 14 weeks ()
- 15 - 16 weeks ()

9. Cause of injury

- Motor vehicle accident ()
- Fall ()
- Gunshot ()
- Penetrating wound ()
- Sport ()
- Other (Specify) ()

10. Level of injury

- C1 - C8 ()
- T1 - T12 ()
- L1 - L5 ()
- S1 - S5 ()

11. Nature of lesion

- Complete upper motor neuron ()
- Incomplete upper motor neuron ()
- Complete lower motor neuron ()
- Incomplete lower motor neuron ()

12. Do you require assistance with your bladder program?

- Yes ()
- No ()

13. Do you require assistance with your bowel program?

Yes ()

No ()

C. RELATIONSHIP HISTORY

14. Were you involved in a steady ongoing relationship with someone prior to the injury?

Yes ()

No ()

15. Were you sexually active with a steady partner prior to the injury?

Yes ()

No ()