

**TETRAPLEGIA: THE PSYCHOSOCIAL PROBLEMS  
ENCOUNTERED BY BLACK PATIENTS ONCE  
DISCHARGED FROM THE HOSPITAL.**

**BY**

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## DECLARATION

I declare that this is my original work, and all the sources used have been acknowledged and referenced according to the requirements of the university.

Signed by : \_\_\_\_\_

Date : \_\_\_\_\_

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**DEDICATED TO MY SUPERVISOR**

**DR JOHANNA SEKUDU**

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## **SUMMARY**

### **TETRAPLEGIA: THE PSYCHOSOCIAL PROBLEMS ENCOUNTERED BY BLACK PATIENTS ONCE DISCHARGED FROM THE HOSPITAL**

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The purpose of this study was to explore the psychosocial problems encountered by Black patients with tetraplegia once discharged from the hospital. Phenomenology as a research strategy was used with the aim of understanding the worldview of patients.

The medical aspects of spinal cord injury were discussed, firstly with emphasis placed on the incidence of spinal cord injury, causes of spinal cord injury, different levels of tetraplegia and the management of patients with tetraplegia.

The psychosocial problems encountered by black patients with tetraplegia once discharged from the hospital were discussed. The emphasis was placed on the patients'

emotional reaction to the injury, adjustment towards the injury and the guidelines for social work intervention with regard to the patient with tetraplegia.

Ten respondents participated in the study after they were selected by using availability sampling and the study revealed the following.

Tetraplegia results in a variety of psychosocial problems for both the patient and his/her family, which are:

Negative marital relationships and desertion by the healthier spouse. Disturbed family relationships. Negative self-esteem and lack of self-confidence due to physical limitations. Poor quality of life, stigmatization by the community and inaccessibility in as far as public transport is concerned.

Tetraplegia triggers psychological, social and financial problems. It is therefore concluded that social work intervention in the initial phase of the injury will ensure that the patients' psychosocial problems are explored and attended to, to prepare the patients for the difficult life thereafter.

## KEY CONCEPTS

Black	:	Swart
Caregiver	:	Versorger
Family	:	Gesin
Intervention	:	Intervensie
Lesion	:	Letsel
Multidisciplinary team:		Multi-disiplinere span
Paraplegia	:	Paraplegie
Rehabilitation	:	Rehabilitasie
Social worker	:	Maatskaplike werker
Spinal cord injury:		Spinale koord besering
Spine	:	Spina
Support	:	Ondersteun
Tetraplegia	:	Tetraplegie



## CHAPTER 1

### GENERAL INTRODUCTION

#### 1.1 INTRODUCTION

This is a study about the psychosocial problems encountered by black patients with tetraplegia, once discharged from the hospital. This study was undertaken at Dr George Mukhari Hospital, which was formerly known as Ga –Rankuwa Hospital in the Gauteng Province.

According to Bromley (1998:17), tetraplegia is a condition, which reduces an individual's enjoyment of normal health and activity to a state of complete immobility and dependence upon others. Bromley (1998:1) further indicates that the person is precipitated into an unknown and unreal world full of fears and problems. He/she has to deal with pain and incapacity, cope with stresses of hospitalisation, sustain relationships with family and friends, and to prepare for an unknown future.

To facilitate understanding of tetraplegia as a condition that is triggered by spinal cord injury the nature and functioning of the spinal cord will be explained briefly.

According to Adams (1992:14), the spinal cord is a discrete cylindrical mass of nerves contained within the spinal canal. It forms part of a very important body system called the nervous system. The nervous system is responsible for every bodily function as it sends and interprets the body's messages. The nervous system is divided into two major parts namely: the central nervous system and the peripheral nervous system. The central nervous system consists of the brain, optic nerves and the spinal cord (Adams, 1992:15).



All other nerves in the body are part of the peripheral system. Adams (1992:15) indicates that the peripheral nervous system originates primarily from the spinal cord and conducts electrical impulses to and from the rest of the body.

Thus, the spinal cord transmits messages to and from the brain. Adams (1992:17) points out that sensory nerves carry out sensations or things that people feel.

Somers (2001:65) stated that when the spinal cord is injured the processes involved in transmitting messages through the body are fundamentally disrupted. Messages from the area below the level of the injury can no longer be felt, as the brain is no longer in a position to communicate with other body parts beneath the level of the injury regarding the muscular activity. Therefore, all kinds of nerve input, sensory, motor and autonomic functions to and from the area below the spinal cord injury will be affected. Injury to the spinal cord results in paralysis (either tetraplegia or paraplegia) that is often irreversible and stressful to the affected person (Somers, 2001:66).

According to Steven, Bergman and Formal (1997:35), tetraplegia is an impairment or loss of both motor and sensory functions in the upper and lower extremities, trunk and pelvic organs. Tetralpegia occurs as a result of damage to the nervous tissue contained in the cervical spine. Steven *et al* (1997:37) further explain that damage to the nervous tissue contained in the thoracic, lumber or sacral regions of the spinal cord results in paraplegia.





Paraplegia is defined as loss of motor and sensory functions in the trunk, lower extremities and pelvic organs. Adams (1992:101) mentioned that with paraplegia both motor and sensory functions in the upper extremities are normal. Where as with tetraplegia, both motor and sensory functions in the upper and lower extremities are affected. The person with tetraplegia cannot distinguish pain or any other thing and therefore he/she is exposed to danger.

Adams (1992:102) further classified patients with tetraplegia according to the level of the lesion sustained such as C1-C7. For the purpose of this study it is important to briefly understand how the life of a person with tetraplegia is affected. Adams (1992:226) stated that the person's life, especially breathing, is compromised. The patient's breathing depends on mechanical respiration.

Patients with tetraplegia do not have control of the upper and lower extremities such as the use of hands and legs. This is due to the lack of coordination that occurs as a result of spinal cord injury. Adams (1992:229) stated that these patients can however, control their head and neck due to the availability of cervical flexors, extensors, sternocleidomastoid and trapezius. In the light of the above, patients with tetraplegia need special training in the use of respiratory equipment, use of wheel chairs and the procedures used to regulate bladder and bowel, which will be discussed in detail in the following chapter.

The above also demonstrates that patients with tetraplegia face a variety of problems. They cannot be independent in all functional activities because of the loss of the upper and lower extremities. They need full time attendant care and require help with activities of daily living, such as dressing, transferring in and out of the wheel chair, bowel and urine regulation, to name but a few. In the researcher's opinion, this is a

frustrating experience as patients  have to depend on the assistance provided by other people.

This study investigated the psychosocial problems encountered by patients with tetraplegia, once discharged from the hospital for appropriate social work intervention. According to the researcher, it is important to understand patients' problems at home so that the service provided for them could be responsive to their needs. The findings of this study will benefit both the patients with tetraplegia and their families because their problems will be understood and be addressed properly.

The researcher furthermore consulted with the following people who are experts in the treatment of spinal cord injury patients to obtain their input and professional opinions.

Lukhele (2002) is a specialist and has vast knowledge and experience in the treatment of spinal cord injured patients. He has been treating spinal cord injury patients since the unit was established in 1992 at Dr George Mukhari Hospital. He understands the difficulties spinal cord injured patients encounter and believes that the results of the study will improve their treatment.

Neuphen (2002) is an expert in the professional care of spinal cord injury patients. She is concerned about the readmission of patients with tetraplegia within a short period of time after they have been discharged from the hospital. She suspected that there could be problems at home that interfere with their adjustment. She felt that this study would bring these problems to the fore for appropriate service delivery.



Mogotsi (2002) who has been a social worker in the spinal unit since its establishment at Dr George Mukhari Hospital in 1992, and also encouraged the researcher to undertake this study, in order to investigate possible problems encountered by the patients at their homes, which may be responsible for readmission at the hospital, for the purpose of providing appropriate social work intervention.

## **1.2 PROBLEM FORMULATION**

According to Hult (1996:2), the research process involves the first awareness in the researchers that a problem exists that needs systematic inquiry. Researchers formulate the problem and begin to explore it. This is done by stating the problem in researchable format and by defining its distinctive characteristics.

Fouché (1998:51) holds a similar view; according to her, problem formulation involves the process of searching for a researchable topic or theme that must be stated in words verbally or in written form. Fouché (1998:52) further explains that topics or problems for research can be identified from day to day activities or in work situations. In the researcher's opinion problem formulation involves identification of a problem that needs to be investigated and provide answers.

At Dr George Mukhari Hospital, it takes an average period of six months to rehabilitate a patient with tetraplegia. Factors such as his/her level of insight, motivation, support from significant others, finance and acceptance by the community are taken into consideration when handling him/her. If all these factors are successfully handled, it is then assumed that the patient is ready to be placed back into the community.



From January to December 2001, the spinal unit admitted 30 patients with tetraplegia. Out of the 30 patients who were discharged, ten of them were readmitted and most of them were in a bad state as they developed pressure sores and a variety of conditions. The researcher became concerned and wanted to explore the real problems experienced by these patients at home that led to their readmission, so that the intervention strategies could be geared towards addressing the patients' problems.

As already indicated earlier on, tetraplegia is a condition that turns the person's life upside down. It poses several physical demands to the affected person and his/her family. Such demands involve inability to use both upper and lower extremities, and inability to control and regulate both urine and bowel systems. In addition, the person experiences change in terms of relationships in the family, work and the community. All these challenges require proper adjustment from the patient with tetraplegia in order to find meaning in life. Therefore, it is the role of the social worker and other team members to assist the patient to make the necessary adjustments.

For the purpose of this study the identified problem is' **“readmission of patients with tetraplegia at Dr George Mukhari Hospital spinal unit within a short period of time after they were discharged from the hospital.”** This suggests that there are problems that interfere with their adjustment, which are to be investigated and addressed.



### **1.3 PURPOSE AND OBJECTIVES OF THE STUDY**

#### **1.3.1 Purpose of the Study**

According to Fouché (2002:107), the purpose of a study is an abstract conception of the end towards which effort or ambition is directed. Neuman (2000:27) defines the purpose of social research in terms of what the researcher is trying to accomplish, which may be to explore a new topic, describe a phenomenon or explain why something occurs. In the researcher's opinion the purpose of research can be seen as a dream or an end towards which all efforts are directed.

The current study is an exploratory study whose purpose is to explore the psychosocial problems encountered by black patients with tetraplegia once they have been discharged from the hospital.

#### **1.3.2 Objectives of the Study**

De Vos (2000:107) defines an objective as steps one has to take one by one within a certain time span in order to attain the dream or goal.



The three objectives for this study are:

<ul><li>

To explore the psychosocial problems encountered by patients with tetraplegia.</li>

<li>To provide a broad theoretical framework on tetraplegia as a condition and social work intervention regarding patients with tetraplegia.</li>

<li>To provide recommendations for improved social work intervention regarding patients with tetraplegia.</li>

#### **1.4 RESEARCH QUESTION**

In this study no hypothesis was formulated to answer questions, as this was an exploratory study. Hence the researcher formulated a research question as the focus of the study. According to Creswell (1994:70) research questions are the general hallmark that distinguishes qualitative research from quantitative research. Creswell (1994:72) further mentioned that research questions are the focus of the study and they should be posed in terms of general issues so as not to limit the inquiry. This view is supported by Marshall and Rossman (1995:26) who argued that research questions should be general to permit exploration, but focused enough to delimit the study. These authors also mentioned that research questions can be theoretical ones; They maybe focused on a particular population or class of individuals.



The research question formulated for this study is as follows:

**What are the psychosocial problems encountered by patients with tetraplegia at their homes, which make it difficult for them to adjust after they have been discharged from the hospital?**

## **1.5 RESEARCH APPROACH**

Schurink (1998:17) describes a qualitative research approach as a multi- perspective approach to social interaction, aimed at describing, and making sense of this interaction in terms of the meaning people attached to it.

Creswell (1998:17) has a similar definition and defines the qualitative research approach as multi-modal in focus, which involves an interpretative and naturalistic approach to its subjects of matter. The qualitative approach studies things in their natural settings. Grinnell (1993:103) concurs with Creswell's definition of the qualitative approach, which is the study of people in their natural settings as they go about their daily living. Grinnell (1993:105) goes further to explain that the approach tries to understand how people live, talk and behave.

The researcher believes that a qualitative researcher should be human-oriented, try to understand people's worldviews from their standpoint. In this study, the qualitative research approach was used to explore and elicit information about the psychosocial problems encountered by black patients with tetraplegia from their perspective.



## **1.6 TYPE OF RESEARCH**

Applied research was used to study the psychosocial problems of patients with tetraplegia, once discharged from hospital. This type of research was found to be appropriate to this study because it is aimed at improving social work service delivery regarding patients with tetraplegia.

According to Fouché and De Vos (1998:69), applied research yields findings that can be linked and utilised in practical situations. Applied research aims to improve or bring change to the clients or subjects. Grinnell (1993:35) holds a similar view and defines applied research as research with findings that can benefit a particular type of client. Huysamen (1994:35) defines applied research as a way of solving problems in clinical education, forensic psychology or social work.

The researcher sees applied research as the type of research that brings immediate change to the situation of the client through utilisation of its findings.

## **1.7 RESEARCH DESIGN AND METHODOLOGY**

As this was a qualitative research, the researcher utilised the research strategy to guide her in the execution of the study. According to Fouché (2002:271), research strategy refers to the option available to the qualitative researcher to study certain phenomena according to certain formulas suitable to their specific research goal. Fouché (2002:274) also mentioned that qualitative researchers unlike quantitative researchers always develop their own designs as they go along using one or more of the available strategies or tools as an aid or guidelines.





In the researcher's opinion, a research strategy is merely a guideline to assist the researcher with proper planning of the research project in order to avoid disappointment and confusion. Hence, it is an important factor to consider when one endeavors to undertake research.

In this study, phenomenology as a research strategy was used to study the psychosocial problems encountered by black patients with tetraplegia, once they have been discharged from hospital.

According to Fouché (2002:274), phenomenology is an approach that is concerned with reality constituting interpretive practices. This approach examines how human beings construct and give meaning to their actions in concrete social situations. Creswell (1998:142) is of the same opinion and according to him the phenomenological approach aims to understand and interpret the meaning that subjects give to their everyday lives. Creswell regards a phenomenological study as a study that describes the meaning that an experience of a phenomenon, topic or concept has for various individuals. The researcher utilising this approach reduces the experiences to a central meaning and the product of the research is a description of the essence of the experience being studied. Creswell (1998:147) further mentioned that in order to accomplish this, the researcher should be able to enter the subjects' world, or life setting, and place him/herself in the subjects' shoes.



Phenomenology as a research strategy was found to be suitable in this study as it is used to understand the worldview of subjects.

### **1.7.1 Data Collection**

The research took place at the spinal unit at Dr George Mukhari Hospital during October 2004 to April 2005. In-depth interview as a method of data collection was used to elicit information about the psychosocial problems encountered by black patients with tetraplegia. According to Grinnell (1993:116), in-depth interview is a process of gathering data from respondents about their lives, personal encounters, oral histories, biographies and life histories. This view is also supported by Schurink (1998:300) for whom the purpose of in-depth interview is to enter the world of those under study to make theories, conclusions and definitions from the standpoint of those being studied. Tape recording was used with the permission of respondents to ensure that all information was captured.

In-depth interview was relevant to this study because it enabled the researcher to obtain in-depth information about the problems patients with tetraplegia encounter at home after they have been discharged from hospital.

### **1.7.2 Data Analysis**

According to Marshall and Rossman (1994:109), data analysis is the process of bringing order, structure and meaning to the mass of collected data. Data analysis should consider organisation, development of themes, categories, patterns, testing and report writing.



De Vos (2002:342) agrees in the sense that a data analysis involves organising the data into manageable units, creating categories, themes or dimensions of information. The researcher should then present what was found either in text, tabular or figure form.

In this study, data were analysed and interpreted through themes extracted from the interviews, these were categorised and then interpreted. The problems encountered by the respondents were also presented verbatim to emphasise what they go through. The findings of the study are presented in words in chapter four of this research report.

## **1.8 PILOT STUDY**

According to Strydom (1994:50), a pilot study refers to the process whereby the research design for a prospective study is tested. The purpose of a pilot study is to investigate the feasibility of the planned project and to bring possible deficiencies to the fore. The pilot study is a review of the main investigation.

Bless and Higson-Smith (1995:50) define programme on a small sample taken from the community for whom the programme is planned. It allows the researcher to identify any problems with the methods or materials and to investigate the accuracy and appropriateness of the measuring instrument. The researcher considers a pilot study as important in assisting determining the feasibility of the envisaged study.

In this study, the researcher used in-depth interview as an instrument for data collection. Two patients were interviewed to establish if this was the appropriate data collection tool for this study. The two patients were not included in the sample of the actual study.



### **1.8.1 Feasibility of the study**

The research was feasible in that it was conducted at Dr George Mukhari hospital where the researcher is employed. Thus, no traveling costs were incurred.

As an employee at Dr George Mukhari hospital, the researcher conducted the interviews during her working hours, hence no additional time was required to conduct the interviews. The researcher furthermore did not have problems in contacting respondents, as they were always available on clinic days at the hospital. Permission to conduct this study was granted by the Hospital's superintendent and the copy thereof is attached as Appendix A of this report.

## **1.9 RESEARCH POPULATION, SAMPLE AND SAMPLING PROCEDURES**

### **1.9.1 Research population**

According to Bailey (1994; 83), population refers to the sum of all units of analysis. Bless and Higson- Smith (1995:87) defines the population as the set of elements that the research focuses upon and to which the results obtained by the sample should be generalized. Strydom and De Vos (1998:190) define the population as all potential subjects who possess the attribute in which the researcher is interested.

In this study, the population consisted of all the patients with tetraplegia who attended the spinal cord clinic at Dr George Mukhari Hospital on Thursdays.



## **1.9.2 Sample**

According to Bless and Higson-Smith (1995:87), a sample is a subset of the whole population, which is actually investigated by the researcher. Bailey (1994:83) is of the same opinion and defines a sample as a subset or portion of the entire population.

In this study the researcher is going to use non-probability sampling specifically availability sampling to select respondents for the study.

Availability sampling is the process of taking all cases on hand until the sample reaches the desired size (Bless and Higson-Smith, 1995:95) According to Bless and Higson-Smith (1995:95), non-probability sampling refers to the case where the probability of including each element of the population in a sample is not known. The researcher interviewed all black patients with tetraplegia who were available at the spinal clinic of Dr George Mukhari Hospital between May 2004 and April 2005, until the desired sample of ten patients was reached.

## **1.10 ETHICAL ISSUES**

According to Strydom (1998:24), ethics is a set of moral principles, which offers rules and behavioral expectations about the correct conduct towards experimental subjects and respondents. Neuman (1997:143) is of the same opinion and according to him ethics defines what moral research procedure should follow.

Ethics defines what is or not legitimate to do.

Kvale (1996:110) defines ethics as the guidelines of conducting a social research.



The researcher understands ethics as guiding researchers when conducting social research to remember that they are dealing with people and not objects. Researchers should respect and protect subjects from any harm that might arise as a result of exposure to the study. In this study, the researcher observed the following ethical guidelines.

### **1.10.1 Informed Consent**

Informed consent means giving of accurate and complete information about the investigation to respondents so that they can fully comprehend the investigation and be able to make an informed decision to participate in the study (Strydom, 1998:25).

Informed consent to participate in this study was obtained from respondents through giving them information about the aim and objectives of the study before they gave consent to participate or not to participate. The respondents were requested to complete the consent forms that were co-signed by the researcher.

### **1.10.2 Voluntary Participation**

According to Bless and Higson-Smith (1995:24), voluntary participation implies that respondents have the right to either participate or not. Neuman (1997:25) argues that voluntary participation means that respondents are never to be forced or coerced to take part in the study.

Respondents were made aware that participation is voluntary and hence they were free to choose to participate or not to participate. Those who were interested in participating were made aware that should they feel to withdraw from the study at any point should be free to do so without fear of being reprimanded.



### **1.10.3 Confidentiality, Violation of Privacy and Anonymity**

Strydom (1998:26) explains “confidentiality” as the handling of information in a confidential manner, whereas “privacy” is explained as the individual’s right to decide when, where, to whom and to what extent his/her attitudes and behaviour will be revealed.

According to Neuman (1997:27), “confidentiality” means that the information may have names attached to it but the researcher will hold this in confidence or keep it secret from the public, whereas “privacy” means that private data identifying the subjects will not be reported, and “anonymity” means that the subjects will remain anonymous and nameless.

These aspects were observed through assuring respondents that the information obtained from them was going to be treated with confidentiality. They were also assured that the data obtained from them would only be used for the stated purpose of the research. The researcher also reassured them not to be afraid to disclose important information, as their identifying particulars were altogether omitted from the study.

### **1.10.4 Release or Publication of Research Findings**

Strydom (1998:28) mentioned that findings of the study must be introduced to the reading public in written format. The researcher should compile a report as accurately and objectively as possible to make sure that the report is clear and contains all the information necessary for readers to understand. The respondents were informed that the findings would be published with the aim of improving service delivery.



### **1.10.5 Harm to Respondents**

Strydom (1998:27) mentioned that harm to respondents in the social sciences would be mainly of an emotional nature. He goes on to explain that the responsibility lies upon the researcher to protect respondents against any form of discomfort that may emerge.

Respondents were protected from any harm arising from exposure to the study by informing them not to answer or disclose any information, which might cause emotional pain to them. In cases where harm occurred regarding the sensitivity of the topic, restoration was provided after data collection phase was completed. Respondents were referred to the social worker who is working in the spinal cord unit to provide further counseling, and arrangements to that effect were already in place..

## **1.11 DEFINITIONS OF KEY CONCEPTS**

Definition of the following key concepts is provided to facilitate understanding of the content of this chapter.

### **1.11.1 Tetraplegia**

According to Somers (2001:7), tetraplegia refers to impairment or loss of motor and sensory function in the upper and lower extremities, trunk and pelvic organs.

Bromley (1999:3) is of the same opinion and according to her defines tetraplegia as to loss of both motor and sensory functions in the cervical segments of the spinal cord due to damage of neural elements within the spinal cord.





From the above definitions, tetraplegia could be defined as loss of functional ability of both upper and lower limbs due to spinal cord injury.

### **1.11.2 Spinal Cord**

Somers (2001:7) defines spinal cord as that part of the central nervous system encased within the vertebral foramen, formed by vertebral bodies and arches. The Concise Oxford Dictionary (1995:597) also defines spinal cord as the portion of the central nervous system enclosed in the vertebral column consisting of the nerve cells and bundles of the nerves connecting all parts of the body with the brain.

Spinal cord could be said to be a link between the brain and the body and it conveys both motor and sensory messages from the brain to the body. Hence damage to the spinal cord results in impairment of motor and sensory functions.

### **1.11.3 Spine**

Concise Oxford Dictionary (1999:532) defines spine as a series of vertebrae extending from the sacral of the back enclosing the spinal cord and providing support to the backbone, the thorax and the abdomen.

Somers (2001:7) defines spine as a vertebrae column, which consists of 33 vertebrae separated by fibrocartilaginous discs and enclosing the spinal cord.



The researcher sees spine as a soldier protecting the spinal cord from accidents and fractures.

#### **1.11.4 Psychosocial Problem**

According to the New Dictionary of Social Work (1995:50), the term psychosocial problem refers to multiple and complex transactions pertaining to the social functioning of individuals or to the social and organisational functioning of larger social systems which are affected by, among others, personality disorders or mental illnesses, inadequate role performance and life transitions involving developmental changes, crises as well as communication and relationship difficulties.

According to Carbonatto (1996:35) the term psychosocial refers to the psychological aspects (mental, emotional and behavioural), and the social aspects to the social functioning and relationships between individuals, their families and the community system within which they function.

Within the context of this study, psychosocial meant the person's experience, i.e. mental, emotional and the social aspects that he/she encounters at home after discharge.

#### **1.11.5 Black**

According to the Concise Oxford Dictionary (1999:140) the term black refers to a human group having dark coloured skin especially of African or Australian aboriginal ancestry.



Barnhard (1996:201) sees the term black to refer to a person belonging to any of the black races of Africa characterised by brown or black skin, coarse, woolly hair, and a broad flat nose.

For the researcher, black refers to a certain group of people who are having dark coloured skin.

#### **1.12 PROBLEMS AND LIMITATIONS OF THE STUDY**

The problems that were encountered during this study and the limitations are as follows.

- ❖ The researcher experienced problems during the data-gathering phase, as most of the respondents did not attend the clinic as expected.
- ❖ Most of them died at home and hence data collection was slow. The researcher took a long time to get the desired sample of ten people.
- ❖ In addition little information was found from social work literature and as a result the bulk of scant literature used was taken from the medical profession.
- ❖ Because the study focused on a small sample, the results could not be generalised.



## **1.13 CONTENTS OF THE RESEARCH REPORT**

### **Chapter One**

General introduction consisted of the rationale for the study, the research methodology as well as the limitations of the study.

### **Chapter Two**

This chapter consists of a tetraplegia as a condition and problems experienced due to this condition.

### **Chapter Three**

Social work intervention regarding patients with tetraplegia is presented in this chapter.

### **Chapter Four**

The empirical findings of the study are presented in this chapter.

### **Chapter Five**

Provides summary, conclusion and recommendations.

The following chapter addresses the medical aspects of tetraplegia.





## CHAPTER 2

### TETRAPLEGIA

#### 2.1 INTRODUCTION

Spinal cord injury, especially tetraplegia, is a serious condition that requires the patient to follow a very strict and inconveniencing medical regime. It is a condition, which if not properly managed, could lead to death (Bromley, 1999: 11).

According to Stiens, Bergman and Formal (1997: 48), spinal cord injury is an uncommon condition that has a significant impact on the injured person as it affects his/her functional, medical as well as the economical well-being. The dependence on the support and care provided by family members, spouses and caregivers, adherence to strict medical regime, an increase in financial obligations, and the decrease in physical and social functioning result in feelings of depression, anxiety worthlessness and hostility.

Stiens *et al.* (1997: 48) further state that all these negative factors call for a dedicated team that is equipped to deal with the psychosocial, the medical as well as the economical challenges facing the patient and his/her family.

In the researcher's opinion, spinal cord injury is a traumatic experience to both the patient and family members. In order to be able to handle or assist the patient and family members in facing their traumatic situation, it is important that team members should have thorough knowledge and understanding of how the spinal cord functions, and the negative impact spinal cord injury has on the patient and his/her family.

In this chapter the following aspects will be discussed, namely: the anatomy of the spine and spinal cord, levels of spinal cord injury and treatment of the patient with special reference to the patient with tetraplegia.



## 2.2 DEFINITION OF MEDICAL CONCEPTS

To facilitate understanding of the content of this chapter the definition of the following concepts is very important:

- ❑ Accessory: This is the eleventh cranial nerve that arises from two roots: namely the cranial and spinal cord (Ballieres Nurses' Dictionary, 2002:240).
- ❑ Catheter: A tube for insertion into narrow opening so that fluids may be introduced or removed (Oxford Dictionary, 2001: 152).
- ❑ Caudal: It is a taillike structure ending at the lower part of the body (Oxford Dictionary, 2001:39).
- ❑ Coccygeal region: The lowermost element of the backbone (Oxford Dictionary of Nurses, 1998:289).
- ❑ Cystoscopy: Examination of the bladder by means of an instrument (Oxford Dictionary of Nurses, 1998:521).
- ❑ Diaphragm: This dome-shaped muscle separates the thoracic and abdominal cavities (Black's Medical Dictionary, 1999: 351).
- ❑ Expiration: This refers to the act of breathing air out from the lungs through the mouth and nose (Advanced Learners' Dictionary, 2000:89).



- Hyperventilation. This refers to breathing at an abnormally rapid rate at rest (Baillieres Nurses' Dictionary, 2000: 207).
- Hypoventilation: Breathing at an abnormally slow rate, this results in an increased amount of carbon dioxide in the blood (Oxford Dictionary of Nursing, 1998:58).
- Hypotention: A condition in which the arterial blood pressure is abnormally low. It occurs after excessive fluid loss (Black's Medical Dictionary, 1999:56).
- Intercostal muscle: Refers to the muscles that occupy the space between the ribs and are responsible for controlling some of the movement of the ribs (Baillieres Nurses' Dictionary, 2000: 77).
- Inspiration: It is the act of breathing air into the lungs through the mouth and nose (Oxford Advanced Learners' Dictionary, 2000: 105).
- Intravenous pelogram: Successions of x-rays films of the urinary tract following the injection into vein of an iodine containing substance. Intravenous pelogram tests kidney function and reveals the presence of stones in the kidneys or urethra and other abnormalities of the urinary tract (Black's Medical Dictionary, 1980:521).
- Suctioning: This is the use of reduced pressure to remove unwanted fluid or other material through a tube for disposal (Black's Medical Dictionary, 1980: 566).
- Supine position: Lying on the back or with the face upwards (Black's Medical Dictionary, 1980: 617).
- Spirometer: Instrument for measuring the volume of air inhaled and exhaled (Baillieres Nurses' Dictionary 2000: 237).





- Spinal cord: Somers (2001:7) defines spinal cord as that part of the central nervous system encased within the vertebral foramen, formed by vertebral bodies and arches.
- Spine: Concise Oxford Dictionary (1999:52) defines spine as series of vertebrae extending from the sacral of the back enclosing the spinal cord and providing support to the backbone, the thorax and the abdomen.
- Symphysis pubis: The joint between the pubic bones of the pelvis and the joint of the backbone, which are separated by intervertebral discs (Oxford Advanced Learners' Dictionary, 2000:156).
- Trachea: It is a windpipe or the part of air passage between the larynx and the main bronchi (Oxford Dictionary 2001: 158).
- Tetraplegia: According to Somers (2001:24) tetraplegia refers to impairment or loss of motor and sensory function in the upper and lower extremities, trunk and pelvic organs.
- Ventilator: A device to ensure a supply of fresh air (Baillieres Nurses' Dictionary, 2000:126).
- Ventilation: Passage of air in and out of the respiratory tract (Oxford Advanced Learners' Dictionary, 2000:156).
- Xiphoid process: The lower most section of the breastbone (Baillieres Nurses' Dictionary, 2000:230).

### **2.3 PREVALENCE OF THE DISABILITY**



According to the White Paper on Integrated National Disability Strategy (1997: 1), there is a serious lack of reliable information on the nature and prevalence of disability in South Africa. This is because disability is viewed within a health and welfare framework. This has resulted in severe isolation for people with disabilities and their families.

On the other hand, the social model of disability as outlined in the White Paper on Integrated National Disability Strategy (1997:2) calls for a change in both society and the physical environment where people with disabilities can play a participatory role.

In light of the above, it is the researcher's view that people with disabilities should be acknowledged, rehabilitated and assisted to take a full participatory role in society.

Due to inadequate information, the researcher found it difficult to collect the exact statistics on the prevalence of disability in SA. The only statistics available are from the year 2001. The following statistics were obtained from Statistics SA (Census 2001: 40) where people with physical disabilities were classified according to population group and gender (Table no 1)

**Table no 1: Physical disability according to race and gender**

Physical disability and gender	<b>Black</b>	<b>Coloured</b>	<b>Indian</b>	<b>White</b>	<b>Total</b>
Male	217496	30275	7140	26188	<b>281100</b>
Female	218707	23510	5654	28541	<b>276412</b>



The statistics for patients with tetraplegia at Dr George Mukhari Hospital for the period 2001-2002 is as follows: In the year 2001, 30 patients were seen and 50 patients were admitted in the year 2002.

Considering the complications and problems related to tetraplegia, 80 people with this condition are of concern and this calls for a comprehensive service for the patients and their families.

## **2.4 ANATOMY OF THE SPINAL CORD**

The spinal cord is a very delicate structure, which has important functions of transmitting and coordinating people's daily activities. In order to understand tetraplegia as a condition that occurs because of the injury to the spinal cord, it is therefore important to have knowledge of the structure of the spinal cord and the mechanism involved once the spinal cord is injured.

### **2.4.1 The structure of the spine**

According to Somers (2001: 105) and Boothe (1999: 5), the spine is made up of vertebral bodies and separated by intervertebral discs. A flexible column is situated in the middle line and forms part of the posterior trunk. The vertebral column is divided into cervical, thorax, lumber sacral and coccygeal regions. These authors further indicate that the spine is made up of seven cervical vertebrae (C1-C7); thorax (T1-T12); five lumber (L1-L5) vertebrae, five fuse sacral (S1-S4) and four fused coccygeal vertebrae. The cervical, thoracic and lumber are true movable vertebrae because they are not fused like the sacral and coccygeal vertebrae.

It is further argued by Somers (200:106) and Boothe (1999: 6) that a typical vertebra is made up of anterior portion, namely the vertebral body and posterior portion, which is the neural arch. Bromley (1999:16) indicated that the cervical vertebrae are the smallest of the movable vertebrae. They are



distinguished from the thoracic and lumbar vertebrae by the presence of a foramen that allows passage of the vertebral artery and accompanying plexus of the vertebral vein and sympathetic nerves.

It is further argued by Bromley (1999:18) and Somers (200:97) that the thoracic vertebrae start from T1 to T12 and they increase in size. They are different from other regions of the vertebrae because of the presence of demifacets on the lateral portions. Bromley (1999:20) goes further to explain that the lumbar vertebrae are larger and heavier than the thoracic region and the cervical region. They are also distinguished from these vertebrae by the presence of accessory and mammillary processes. The sacrum vertebrae are different from other vertebrae because of their triangular appearance, and the central portion is made up of the fused bodies of the sacral vertebrae.

It is further explained by Bromley (1999: 22) and Footner (1992: 233) that the spinal cord is made up of the junction of the vertebral body, the neural arch and the successive vertebral foramina. In the cervical and lumbar regions of the vertebral column, the spinal cord is large and triangular. In the thoracic region, where freedom of movement is limited, the spinal cord is small and rounded because no plexus are present at this area.

These authors further mentioned that the longitudinal ligament, the posterior longitudinal, the intervertebral disks, the musculature of the neck and trunk are the supporting structures to the spine. Furthermore the ligament flava, the supraspinal ligament, the ligamentum nuchae, the interspinal ligament and the intertransverse ligament provide stability to the spinal cord.

The anterior longitudinal ligament is defined as a strong broad band of fibres that extends from the axis to the sacrum along the anterior surfaces of the vertebral bodies (Bromley 1999:23). According to Footner (1992:240) and Bromley (1999: 24), the posterior longitudinal ligament extends from the axis to the sacrum thinning as it descends along the posterior surfaces of the vertebral bodies.



Bromley (1999:25) and Footner (1992:241) further state that the connection between the vertebral bodies is thus provided by the intervertebral disks. The circumference of intervertebral disks is made up of fibro cartilage, and the centre contains anterior mucoïd material in which collagen fibres are embedded. The intervertebral disks serve a primary function as articulate shock absorbers for the vertebral column.

It is evident from the information given above, that the spine is a very complicated structure, that plays a vital role in the functioning of our bodies. As human beings, our lives depend on the well being of the spine. This emphasises the importance of a healthy spine for a person to lead an independent life.

#### **2.4.2 The functioning of the spinal cord**

Black, Sipski and Straus (1998:240) explained the spinal cord as part of a very important body system, called the nervous system. The nervous system is responsible for every bodily function as it sends and interprets the body's messages. These authors mentioned that the nervous system is divided into two major parts, namely: the Central Nervous System and Peripheral Nervous system. The Central Nervous System consists of brain, optic nerves and the spinal cord. All other nerves in the body are part of the Peripheral Nervous system. The Peripheral Nervous system originates primarily in the spinal cord and conducts electrical impulses to and from the rest of the body. Thus, the spinal cord transmits messages to and from the brain (Black *et al*, 1998: 241).

Black *et al* (1998: 242) and Somers (2001: 65) also point out that when the spinal cord is injured, the processes involved in transmitting messages through the body are fundamentally disrupted. The brain can no longer feel messages from the areas below the level of the injury. All kinds of nerve input, sensory, motor and autonomic function to and from the area below the spinal cord lesion will be affected.



This view is supported by the Quadriplegic Association of Gauteng (2002: 10) that sees the spinal cord as an extension of the brain that carries messages to and from the brain. The spinal cord is made up of nerves that branch out of the spinal cord to various organs and muscles. The spinal cord is seen as working like a “telephone exchange”. Hence when the spinal cord is damaged no message can pass through the damaged area of the spinal cord to the other end. The brain is no longer in a position to communicate with other bodily parts beneath the level of the injury regarding the muscular activity.

From the above, one can see that the spinal cord is a very sensitive and delicate organ. Every single structure is built around it as it has a vital function in the sense that it enables people to interact with their environment and to survive. Therefore, injury to the spinal cord results in paralysis that is often irreversible and is stressful to the affected person.

The person having a spinal cord injury finds himself/herself in a helpless situation, as he/she has to deal with so many things at once, such as dealing with the trauma of becoming involved in an accident, coping with the environment (hospital) in which he/she finds him/herself and coping with the demands posed by the disability. This calls for effective social work intervention to capacitate both the patient and his/her family to come to terms with the disability and to deal with it in a meaningful manner, to ensure that there is life beyond disability.

## **2.5 CAUSES OF SPINAL CORD INJURY**

According to Hammel (1996:201), most spinal cord injuries occur because of direct or indirect trauma to the vertebral column. Most of these injuries involve either a single or limited number of vertebrae. In most cases of vertebral injury, the spinal column sustains damage to two or more levels that are separated by undamaged vertebrae.



Bromley (1999:23) shares a similar view and sees the spinal cord injury as a complex process that causes serious trauma to the person involved. It causes loss of motor, sensory and impairment of the autonomic nervous system thus, leading to disorganisation of almost every system of the body. Bromley (1996:24) further indicates that spinal cord injuries are not only caused by direct trauma to the vertebrae, but also that most injuries result from forces that cause violent motion of the head or the body. The magnitude and direction of the traumatic force determines the type and extent of the bony and ligamentous damage. Therefore Bromley (1999:25) mentioned that the degrees to which the vertebrae impinge upon the spinal cord determines the nature of the injury. The following factors have been found to be major causes of spinal cord injury.

□ **Sports activities**

According to Hammel (1996:17), amongst sports and recreational activities causing spinal cord injury, diving was found to be at the top of the list to a varying extent. Hammel (1996:18) further mentions that the most survivors of this accident are most likely to sustain quadriplegia rather than paraplegia. Other sporting activities associated with spinal cord injury as outlined by Hammel (1996:19) are: Football, rugby, boxing, horse riding, trampoline, tomogram, gymnastics and hay gliding. However, Hammel (1996:19) argued that in each activity the nature of the injury will be unique and the accompanying paralysis will differ according to the level of the lesion. Pentland, Walker, Minnes, Trembley, Brouwer and Gould (2002:374) agree. According to these authors some spinal cord injuries occur while playing soccer, wrestling, break dancing and horse riding.

Sport as a leisure activity has a certain influence on the occurrence of spinal cord injury. Careful consideration should therefore always be exercised before one considers participating in a particular sporting activity.



□ **Poverty**

Poverty such as overcrowding and unhealthy living conditions has been seen to be one of the contributory factors to spinal cord injury and disability in South Africa (White Paper on an Integrated National Disability Strategy, 1997:2).

The White Paper on an Integrated National Disability Strategy (1997:3) goes on to explain that poverty may present in various forms, such as lack of food deemed necessary for developing a person's physical, intellectual and emotional capacities, and inaccessibility to medical care. Poverty as a cause of disability calls for drastic intervention to eradicate its existence and therefore to eliminate disability.

□ **Violence and war**

Acts of violence, especially against women and children, land mines' injuries and psychosocial trauma also contributed towards spinal cord injury and hence disability (White Paper on an Integrated National Disability Strategy, 1997:201).

Other factors that are seen to caused spinal cord injuries as agreed upon by authors such as Somers (2001:13) and Hammel (1996:14) are: motor vehicle accidents, industrial and cultural accidents, unhealthy life style, such as the misuse of medication as well as the abuse of drugs and other substances. Environmental factors such as natural disasters, pollution of the physical environment, poison by toxic and other hazardous waste have also been found to be associated with the occurrences of spinal cord injuries. Spinal cord injury may furthermore be caused by stress and other psychosocial problems in a changing society (White Paper on an Integrated National Disability Strategy, 1997:9).





Somers (2001:14) indicated that males, especially younger ones sustain a larger number of spinal cord injuries. He further explains that the prevalence of such occurrences in males is simply due to the fact that they are prone to participate in high risk activities such as driving too fast, drunken driving and diving in unfamiliar water where stumps are hidden beneath the surface.

The researcher's observation is in line with the above-mentioned author, with respect to the prevalence of spinal cord injury in men and women. In the spinal unit where the researcher is working, men are admitted due to motor vehicle accidents, gunshots and involvement in sports activities. In comparison a lesser number of women are admitted due to factors such as illness, family violence and transport accidents.

## **2.6 PREVENTION**

According to disability policy (White Paper on an Integrated National Disability Strategy, 1997:4), the majority of spinal cord injuries can be prevented. The primary objective of the Policy is to try to prevent the diseases and accidents, which may cause impairments and disabilities. This can be done through the provision of the following: promotion of a healthy life style in the home, at school, in the work place and on the sports field; provision of protective measures, such as immunisation, protection against accidents and protection against occupational hazards; introduction of legislation and regulations that will reduce accidents at work and on the roads; and adaptation of the environment to prevent occupational and environmental accidents (White Paper on an Integrated National Disability, 1997:8).

This above view is supported by Somers (2001:20) who mentioned that spinal cord injury could be prevented through the introduction of educational programmes to teach people who like to take part in sports activities about the following: safer methods of diving in larger deeper areas of water, to avoid diving in lakes, rivers and oceans and introduction of improved rules and tactics when playing a particular sporting activity.



According to Stiens *et al.* (1997:65), spinal cord injury and disability can be prevented by the introduction of educational programmes at schools to encourage safe diving, seat belt use and safe driving techniques. The aim of these programmes should be to target school aged children to rectify maladjustment behaviour at an early age.

In the home behaviour that could lead to injury or disability can be minimised by removal of weapons from the home and teaching the community about the impact of violence, which would lead to spinal cord injury and therefore the disability.

According to the researcher, education is very important to make the society aware of the importance of adopting a healthy life style to prevent being exposed to accidents and trauma.

## **2.7 TYPES OF SPINAL CORD INJURY**

According to Whiteneck (1997:179), the level of the injury to the spinal cord will determine the degree to which both the motor and neurological functioning below the lesion will be affected.

Counsell, Abram and Gilbert (1997:36) argue that a complete spinal cord injury occurs if both sensory and motor functions are absent in the lowest sacral segment of the spinal cord (S1, S4). To test the sensory and motor function in the S4 and S5 the examiner inserts a finger in the anus of the patient. Absence of sensory function is witnessed by the patient's inability to feel the examiner's finger into the anus. A complete spinal cord injury effectively disconnects the brain from the body below the lesion, with disruption of the supraspinal control of the various systems situated below the lesion.

In contrast, an incomplete spinal cord injury occurs when some sensory and motor function is preserved below the level of the lesion (Counsell *et al.*, 1997: 37).



The researcher believes that knowledge of the difference between complete and incomplete spinal cord injury is very important because with an incomplete spinal cord injury the person can still feel some pain and thus can survive some dangerous acts. With complete spinal cord injury the person's motor and sensory functions are completely affected. He/she cannot distinguish pain or anything else and he/she is more exposed to danger. Therefore, knowledge of the type of lesion is very important to the social worker, because it will enable him/her to prepare counselling on what the patient has sustained in terms of the neurological level. This will facilitate the provision of appropriate social work intervention at the patient's level of understanding.

According to Whiteneck (1997:180), the level of injury can result in either tetraplegia or paraplegia. This author defined tetraplegia as impairment or loss of both motor and sensory function in the upper and lower extremities, trunk and pelvic organs. Tetraplegia occurs as a result of damage to the nervous tissue contained in the cervical spinal cord.

Whiteneck (1997:181) further explains that damage to the nervous tissue contained in the thoracic, lumbar, or sacral regions of the spinal cord results in paraplegia. Therefore paraplegia is defined as loss of motor or sensory function in the trunk, lower extremities and pelvic organs. With paraplegia motor and sensory functions are normal in the upper extremities.

Knowledge and understanding of the differences between tetraplegia and paraplegia is important because people having these conditions will not function at the same level. The patient with paraplegia is in a better position in terms of functional activities because his/her upper extremities are intact. He/she has a better chance to manoeuvre his/her environment unlike a patient with tetraplegia who cannot use either of his/her hands and legs. This warrants attention from a medical social worker who is supposed to offer counselling to the patient and his/her family. Following are examples of spinal cord injuries.



### **2.7.1 Types of incomplete spinal cord injury**

- **The central cord syndrome**

According to Bromley (1999:330), this type of the lesion occurs in the cervical region due to hypotension injury. The person with central cord syndrome experiences flaccid weakness of the arm, and spastic strong leg function. There is sacral sensory sparing of the bladder and bowel function. Neurological and functional improvement is good, though the functioning of the hands remain poor.

According to the researcher, a central cord syndrome could be defined as an incomplete spinal cord injury where the patient sustains weakness of the arms and legs but at the same time retains functioning of the bladder and bowel. In a way, this could be comforting to the patient in the sense that he/she still has control of his/her bowel and bladder functioning, hence boosting the ego, but it could also have negative emotions on the patients.

- **Brown sequard syndrome**

In the opinion of Footner (1992:245), this type of injury occurs as a result of stab wound. The patient with this type of injury will experience reduced or absence of motor power with relatively little pain and temperature sensation on the injured side. The uninjured side will have good power but sensation to pinprick and temperature is lost.



In simple terms the patient with brown sequard syndrome only experiences paralysis on the affected side of the injury. He/she is in a position to manoeuvre the environment through the functioning of the uninjured side.

- **Anterior cord syndrome**

Bromley (1999: 98) argued that this syndrome occurs because of direct trauma of the corticospinal and spinothalamic tract. The patient with anterior cord syndrome sustains the lesion that produces loss of motor and reduced sensitivity to pain and temperature.

In the researcher's opinion the patient with anterior cord syndrome will be prone to danger from the environment because of the inability to feel pain. This might lead to the patient's condition deteriorating because of environmental dangers.

- **Conus medullaris syndrome**

According to Bromley (1999: 334), this is another type of incomplete spinal cord injury that involves damage to the conus medullaris or the spinal nerves forming the caudal equina. The patient with this type of lesion will experience a reflexic bladder and bowel systems and loss of motor function to the legs with little sensation.

In the researcher's opinion patients with incomplete spinal cord injury, be it medullaris or anterior cord syndrome, stand a better chance to survive than patients with complete spinal cord injuries. Most of them are classified as patients with paraplegia with the control of the upper arms though the lower extremities are not functioning. Being able to use their hands they can manoeuvre the environment and thus can continue to live. What is needed is strong motivation and counselling from the medical social worker to capacitate them to use their remaining neurological functioning to their best abilities.



### 2.7.2 Complete spinal cord injury

As already indicated, the spine is made up of seven cervical (C1 – C7); twelve thoracic (T1-T12); five lumbar (L1-L5); and five sacral (S1- S5) vertebrae. In most cases injury to the cervical spine results in a complete lesion with the patient suffering from tetraplegia. This is due to the structure of the cervical spine that is more flexible, which makes it more vulnerable to trauma. The cervical spine also lacks mechanical stability, which is another factor that renders it prone to trauma (Somers, 2001:89).

According to the researcher, the cervical spine is the most fragile component of the spinal cord and thus people need to make sure that they are not involved in acts that will damage the cervical spine to avoid the disability.

Whiteneck, Tate and Chalifue (1999:1030), see the following as examples of complete spinal cord injury due to injury to the cervical spine.

#### ❖ C1-C4 Levels

It is indicated by Whiteneck, Tate, and Chalifue (1999:1030) and Footner (1992: 226) that C1 to C4 levels are complete tetraplegia where the patient's life especially breathing, is severely compromised. The patient's breathing depends on mechanical breathing respiration. Such patients do not have control of the upper extremities but they can control the head and neck due to the availability of the cervical flexors, extensors (muscle that causes the straightening of a limb or any other part of the body), sternocleidomastoid (long muscle in the neck that serves to rotate the neck and flex the head) and trapezius (triangular muscle covering the back of the neck and shoulder. Draws the head backwards to either side.)



Therefore the patient needs training in the use of special respiratory equipment, which will be discussed later in this chapter. Whitneck *et al.* (1999:1030) and Footner (1992:228) also mentioned that the patient with C1-C4 levels cannot be independent in all functional activities.

He/she requires full time attendance care and needs to be helped with activities of daily living, such as dressing, transferring and toilet care. However, Whitneck *et al.* (1999: 1033) and Adams (1992: 100) argued that with proper training the patient could be taught to drive a wheelchair with a tongue or chin and manipulate small objects with the mouth.

C1-C4 levels are associated with complete tetraplegia with the patient retaining only very limited functional abilities. Often this is very stressful to the patient and thus social work intervention should focus on to the patient's feelings and motivate him/her not to give up but to persevere, and try to have life after the injury. It is evident that it will never be an easy task but through supportive counselling, the patient could cope better.

#### ❖ C5 Levels

According to Adams (1992:102), patients at C5 functional level are dependent on other people in almost all activities of daily living. They cannot push their wheelchairs and require an electric wheelchair that can be controlled by mouth stick or chin. These patients also need a full time caregiver to help in activities of daily living.



C5 functional level places the patients in a very helpless situation because of the loss of functional abilities. This is a frustrating situation, which calls for thorough support and counselling from both the social worker and family members to assist them to come to terms with their disability. If proper counselling is not provided, most end up dying because of anxiety and stress.

#### ❖ C6 Levels

In the opinion of Adams (1992: 103) and Footner (1992:55) patients at this functional level unlike the C1-C5 are independent and this is due to the addition of wrist extensor muscle function. These patients can transfer from bed to the sitting position, they can dress themselves and manoeuvre their own wheelchairs. With the use of flexor hand splint, they can write and take care of their own personal hygiene. These patients are treated as incomplete tetraplegia because of some sparing neurological and motor function.

Patients at functional level C6 stand a better chance of surviving because of some sparing neurological and motor functional capabilities. They need motivation not to give up but to use the little functional capabilities left to cope with their condition.

#### ❖ C7 Levels

Adams (1992: 105) and Footner (1992:58) argue that patients at functional level C7 can do much better than the patients at functional level C6. They can control their shoulders, elbows with wrist and wrist extensors and flexors, but at the same time they lack finger flexors for grasping. They can manoeuvre themselves in bed to a sitting position, dress themselves, and transfer from bed to a wheelchair. Like patients at functional level C6, patients at functional level C7 are regarded as incomplete lesion with some sparing motor and neurological functioning.





In light of the above-mentioned characteristics of patients with tetraplegia, one can see that it is a condition, which limits the patient's enjoyment of a normal healthy life style. However, the researcher is of the opinion that though the level of injury decides what a person can do or not do, his/her mental commitment to make use of the remaining functional capabilities plays an important role. Tetraplegia is a stressor to everyone who might experience it. There is a need for patients to be informed about their conditions in order to improve their insight into the situation. The social worker can do this by educating them about their condition as well as providing them with support to be able to cope and to alleviate stress and frustrations.

## **2.8 MANAGEMENT OF PATIENTS WITH TETRAPLEGIA**

According to Whiteneck *et al* (1999:1034), the overall goal of the rehabilitation process is to achieve a transition from a medically unstable dependent and uneducated patient to one with sufficient medical stability, knowledge and independence. A dedicated team that is prepared to provide proper management of complications related to tetraplegia could achieve this. At the same time the team should not underestimate involvement of the patient in his/her rehabilitation process as well as teaching family members and caregivers about the patient's condition.

According to the researcher, involvement of both patient and his/her family in the rehabilitation process is important because at the time of discharge the patient will be well prepared to fit within his/her family. The family will also be well prepared to deal with the patient's condition, with all the accompanying challenges.

Gates, Campbell and George (2002:704) see the following as issues that must be addressed by a treatment team.



- **Respiratory care**

Gates *et al* (2002:705), mentioned that respiratory complications are a threat to many patients with tetraplegia and one of the leading causes of death. This occurs as a result of paralysis of the intercostal muscles or the diaphragm that may lead either to acute or chronic respiratory failure.

Therefore Gates *et al* (2002:708), argue that the primary goal of the rehabilitation process should be the promotion of optimal respiratory function as well as the prevention of complications that go with it. Respiration is a threat to patients with tetraplegia; therefore, great care and effort should be given to them to minimise the risks involved.

- **Mechanism of respiration**

According to Belciug (2001: 157) and Norris (1994: 225), respiratory functions occur according to two phases namely: inspiration and expiration. During normal breathing inspiration involves the contraction of the diaphragm and external intercostal muscles, which causes it to descend. As a result of this descent; the vertical diameter of the thoracic cavity increases causing a decrease in the intrathoracic pressure.

These authors further explain that the external intercostal muscles elevate the ribs during inspiration, their contraction causes an increase in the lateral thorax that create a negative pressure gradient in the thoracic cavity. This negative pressure gradient results in airflow into the lungs.

In the opinion of Beciug (2001:159), the diaphragm and external intercostal muscles are active muscle in normal inspiration. In a compromised respiration system, the patient is forced to use accessory muscles of inspiration to assist with ventilation. These muscles act to elevate the ribs.



According to Whiteneck *et al* (1999:1035), the use of accessory muscles in inspiration is a clear indicator that breathing is impaired. Hence the patient with high lesion tetraplegia experiences significant compromise of these activities. They experience paralysis of both intercostal muscles, i.e. the muscles that occupy the spaces between the ribs and are responsible for controlling some of the movement of the ribs and abdominal muscle. The paralysis will cause a decrease in both inspiration and expiratory outflow.

Somers (2001:330) cautioned that if there is abdominal muscle paralysis, the team should take care of the manner in which they position the patient, as this affects the distribution of the visceral content and the resting length of the diaphragm. Somers (2001:330) goes on to explain that the upright position puts a greater demand on the diaphragm as the down ward pull of gravity causes the diaphragm to be in a lower resting position. This results in patient's reduction in inspiration.

Respiratory complications are a great concern to patients with tetraplegia. There is therefore a need for them to be informed about these complications in order to improve their insight into the situation for them to co-operate with the treatment team.

Krause, Sternberg, Lottes and Maiden (1997:814) outlined some respiratory parameters that may be used to assist the treatment team to establish functional goals within the respiratory limitations of a patient with tetralpegia. These are:

- **Vital capacity**

According to Krause *et al* (1997:815), vital capacity refers to the amount of air that a patient can breathe out after a maximal inspiration effort. The normal vital capacity measures four to five litres, but in a person with tetraplegia vital capacity measurements are less than two litres. This is due to paralysis of the intercostals and abdominal muscles. In such a situation mechanical ventilation, which will be discussed later, is needed.



Because of their condition, patients with tetraplegia experience difficulties with exhalation. This needs to be properly communicated to them so that they can understand and become actively involved in their treatment process.

- **Respiration**

According to Krause *et al* (1997:814), respiration is assessed when the patient is at rest and unaware that his/her breaths are being counted. In an intact respiratory system the respiratory rate decreases with observed signs of hypoventilation. Hyperventilation may cause feelings of faintness and numbness in the extremities. Hypoventilation, on the other hand can lead to drowsiness, irritability and restlessness.

Respiration is one of the complications that accompany tetralpegia. This needs to be communicated to the patient so that he/she can have insight into the situation.

- **Breathing patterns**

In the opinion of Somers (2001: 336) breathing patterns should be evaluated frequently to determine the quality and quantity of muscle contribution to inspiration. These should be observed while the patient is put to rest in different positions as gravity may affect the efficiency of the muscles, therefore causing a change in breathing patterns.



Breathing patterns of patients with tetraplegia are different from that of a respiratory system that is intact, and therefore it needs careful attention from the treatment team.

- **Cough force**

It is argued by Somers (2001:337) that cough force is evaluated to determine the patient's ability to clear secretions. In a patient with tetraplegia coughing is compromised as the abdominal muscle power necessary for cough is decreased. Somers (2001:338) classified cough as either functional, weak-functional and non-functional which will be briefly explained as follows:

- In a functional cough the patient is able to produce secretions by means of forceful cough.
- In a weak-functional cough the patient is able to clear secretions from the airway, but cannot expel the secretions unless assisted with coughing.
- In a non-functional cough the patient cannot inhale or exhale with any functional force, and cannot move secretions out of the major airways and hence requires assistance to clear secretions and cough.

- **Chest mobility**

According to Bromley (1999:203) a mobile chest wall is important for optimising aspiratory capacity and lung expansion. In a patient with tetraplegia there is paradoxical rib motion because of intercostal muscle paralysis. The chest wall does not go through its normal excursion during respiration. Eventually the chest wall loses its normal mobility, which leads to further impairment in respiration. Proper chest wall should be maintained to facilitate patient's breathing.



- **Posture**

Somers (2001:34) is of the opinion that poor posture affects the patient's respiratory capacity. The accessory muscles of respiration work more efficiently in expanding the wall when the patient is adequately supported.

The manner in which the patient is positioned plays a vital role in promoting his/her breathing. All these complications cause a great deal of concern to both the patients and their families. There is a need for them to be informed about these complications so that they can have insight into the situation and to become actively involved in the rehabilitation process. The medical social worker can play a vital role in providing the patients and their families with the necessary information or establishing whether they understand these complications.

## **2.9 INTERVENTION STRATEGIES GEARED TOWARDS ALLEVIATING RESPIRATORY PROBLEMS**

According to Bromley (1999:209), the respiratory treatment of patients with tetraplegia is divided into two components, namely: respiratory treatment of patients with tetraplegia who are not depending on mechanical ventilation and treatment of those patients who depend on mechanical ventilation for breathing. These two treatment strategies will be discussed briefly .



The treatment of patients who are not ventilator assisted will be discussed under five subheadings:

## **2.10 PATIENTS WITHOUT VENTILATOR ASSISTANCE**

### **✓ Chest physical therapy**

According to Bromley (1999: 211) and Hammel (1996:175), chest physical therapy involves the usage of manual techniques to clear chest and this includes vibration and percussion. The purpose is to dislodge and mobilise secretions into the bronchial tube. The secretions should then be suctioned. Appropriate chest physical therapy to assist patients with tetraplegia to clear secretions from the chest is important and should be done regularly.

### **✓ Assisted coughing techniques**

According to Bromley (1999:217), assisted coughing technique is the best method of ensuring bronchial cleansing and chest wall mobility. This is done when the patient is immobilised or is resting on the bed. The cough is facilitated by instructing caregivers to position or put the hand below the xiphoid process and to apply pressure into the abdomen of the patient with an inward and upward movement. The patient should be encouraged to exhale forcefully. Assisted coughing techniques are methods used to assist the patient to clear secretions and facilitate his/her breathing. The procedure should be well communicated to both the patient and his/her caregivers for its effectiveness.

### **✓ Breathing exercises**

In the opinion of Bromley (1999: 218) and Krause (1997:651) breathing exercise is the process of teaching the patient breathing exercises to ensure a balanced use of all available muscles and ventilation to all parts of the lungs. The breathing exercises begin with slow relaxed and



diaphragmatic breathing and progress to breathing with manual resistance applied over the diaphragm. The weight should be placed over the upper abdominal area while the patient is encouraged to maintain good diaphragmatic excursion. Spirometers are used to provide feedback of progress to the patient and to check the efficiency of the treatment programme.

Breathing exercises like other techniques used to assist the patient with breathing should be communicated to the patient so that he/she can understand that these are meant to assist him /her with breathing in order to survive. In doing this the patient's co-operation will be enhanced.

#### ✓ **Posture**

As already indicated, proper posture should be maintained to promote better breathing, to optimise chest excursion and to improve vital capacity. Bromley (1999: 219) and Krause (1997:652) mentioned that any abdominal posture hinders rib and diaphragm movement. In addition trunk support may be needed to provide postural alignment and stabilisation of the trunk.

Patients should always be motivated to maintain good posture even when resting, and this should be communicated since they may wonder why they should be put to rest in certain positions only. Even though this can be uncomfortable for the patient, he/she will co-operate if he/she understands why it is done. Proper communication will foster for effective service rendering. The social worker can be very influential in this regard to ensure that the patient is receiving a comprehensive service.

#### ✓ **Abdominal support**

According to Hammel (1996: 245), a corset or abdominal binders are used to support the abdominal content against the effect of gravity. Hammel (1996:245) goes further to mention that the corset allows the diaphragm to rest in a better position while the patient is sitting upright.





The corset or binder should be placed over the lower ribs and extend over the iliac crests bilaterally. The lower part of the corset should be tighter than the upper portion.

From the above the researcher deduced that though these patients depend on a number of factors for breathing, they still have a chance to survive. It would seem that the patients' understanding of his/her position would help in motivating him/her to co-operate. This would increase the patient's survival, as breathing is vital for survival.

## **2.11 VENTILATOR DEPENDENT PATIENT**

According to Whiteneck *et al.* (1999:91), ventilatory support is considered for patients with tetraplegia, who have sustained high spinal cord lesion from C1-C3 with paralysis of the diaphragm muscles. These patients require immediate resuscitation and life long ventilatory support. Mechanical ventilatory support is also needed when there is deterioration in respiratory systems from ascending oedema in a lower cervical spinal cord injury.

The following types of mechanical ventilatory support will be briefly discussed to facilitate understanding.

### **□ Suction**

Whiteneck *et al* (1999:90) defined suctioning as a method used to remove excess secretions from airways of a ventilator- dependent patient. The respiratory therapist uses a rubber catheter tube and a suction machine to remove the excess secretions from the airways. After suctioning the machine is washed with saline solution and is placed in a clean container.



Bromley (1999:220) mentioned that what is important in the respiratory care of the ventilator-dependent patient is clear communication between the treatment team, the patient and the caregivers about the proper use of suctioning technique.

Family members and caregivers should be made aware that suctioning is not only limited to the clinical or bedside environment. They should understand that suctioning could be done at any time irrespective of time and place. Caregivers should be instructed on how to suction the patient while he/she is at a party, picnic or even at church (Bromley, 1999:312).

In the researcher's opinion suctioning the patient at any time and place will assist the ventilator-dependent patient to feel in control of his/her life and also to boost his/her confidence to appear in public without fear of respiratory crisis. This could also improve his/her social interaction outside his/her families and reduce isolation.

#### □ **Nasotracheal intubations**

According to Stiens *et al* (1997:548), nasotracheal intubation is a procedure performed during the emergency situations or short-term intubation. The tube is inserted from the nose of the patient to the trachea.

Stiens *et al* (1997: 649) further pointed out that this procedure has a disadvantage, as patients do not tolerate it. Patients resist it because it induces vomiting, excessive saliva formation, and the patient cannot communicate while the tube is inserted. The advantages will always bypass the disadvantages because here we are dealing with a life threatening condition, if not properly handled it can claim the patient's life. The researcher is of the opinion that with proper communication the patient would ultimately understand and tolerate the procedure.



#### □ **Tracheotomy tubes**

According to Hammel (1996:378), a tracheotomy is a procedure, which is used when the patient requires permanent mechanical ventilation or long-term ventilator assistance. The tracheotomy tube is inserted to the patient during an operative procedure.

Hammel (1996:379) further explains that the procedure allows for monitoring of airflow and vital capacity and prevents aspiration in those patients who cannot swallow. However the main disadvantage of this procedure is that a patient cannot communicate when the cuff is activated.

In this regard Whiteneck (1997:370), suggests that in order to minimise the disadvantages, the cuff should be adjusted so that there is minimal amount of air leakage, and as soon as the patient is able to swallow, and his/her lungs are clear of secretions, the cuff should be deflated for short periods.

Whiteneck (1997:372) states that this is an unpleasant experience for the patient, as the secretions that have accumulated above the cuff will drain down the trachea into the lungs. Although the patient will cough a great deal soon he/she will learn to endure having the cuff down.

Bromley (1999:207) explained that when the patient can tolerate the cuff being down for longer period, the respiratory therapist should consider use of a reusable stainless steel trachea. The advantage of this procedure is that it is easier to clean, lasts longer and is cost effective. Another advantage is that patients are happy to have it because it allows them to communicate freely.



It is further argued by Bromley (1999:208) that for those patients who are not ready to use a cuffless trachea, a talking trachea maybe used. This uses an external air source that is controlled to pass air above the cuff so that it may go up the larynx. The disadvantage of this type of trachea is that it produces a different sounding voice, dries out mucus membranes and causes a sore throat.

Stiens *et al.* (1997:549) tend to differ with the above-mentioned authors. According to them tracheal suction is an invasive technique that carries many recognised complications, and if possible the use of this procedure should be kept to a minimum. Stiens *et al.* (1997:557) advocated for the use of functional electrical stimulation to assist respiratory function of patients with tetraplegia. The use of this procedure is seen to have reduced problems of respiratory dysfunction, such as postural hypotension and inability to cough.

From the above, one can see that there are no ideal methods, what works for one patient might not work for the other. What is important is that the team needs to make a thorough assessment of the patient's situation.

## **2.12 THE WEANING PROCESS**

According to Hammel (1996:373) the weaning process should be initiated as soon as the patient has achieved a vital capacity of 800cc, is free from infected secretions, water imbalances or other uncontrolled pulmonary and medical complications.

Hammel (1996:378) further explained that this process is often accompanied by anxiety since the patient is depending on a machine to sustain life. Hence weaning the patient from mechanical ventilation should be gradual where the patient should be given a chance to strengthen his/her existing respiratory muscles and to learn to breathe without external mechanical help.



In the researcher's opinion, weaning the patient from mechanical ventilation means preparing both the patient and his/her family thoroughly. Both the patient and the family need counselling from the medical social worker to assist them to deal with fear and anxiety related to the weaning process. They need to be assured that the patient is out of danger and at the same time the social worker should motivate them to practise what they have learned from the rehabilitation process.

## **2.13 UROLOGICAL MANAGEMENT**

According to Norris (1994:266) urological function is another area that is affected or altered in a patient with tetraplegia. This author further mentioned that in every individual the urinary system has three major functions, which are: the formation of urine, the storage of urine and the actual excretion of urine.

It is further argued by Norris (1994:2667) that nerves transmitting messages to and from the brain achieve bladder control. When the bladder is full and needs to be voided, a message is sent warning the person of the fullness of the bladder and at that point the person will feel a sensation of fullness and the need to urinate provided the time and place are convenient. If the place and time are not convenient, the brain will send the message through the spinal cord ordering the sphincter to tighten and the bladder to relax and in this way the person is able to delay urination until a more convenient time and place is achieved.

Norris (1994:279) mentioned that after the spinal cord injury, this co-ordination no longer exists. The patient will develop inability to void, experience urinary leakage and making accidents in public, which is often frustrating and always embarrassing. Hammel (1996: 380) mentioned that the goal of the rehabilitation is to assist the patient to develop a system that will enable him/her to empty the bladder at appropriate time and place. Proper bladder management is vital to the patients with tetraplegia to boost their self-confidence and self-esteem.



Urological management procedures will be briefly discussed as follows:

- **Evaluation of urinary function**

According to Hammel (1996: 382), urinary function is done through the following:

- Intravenous pelogram to check kidney function or whether or not any structural changes have occurred that could indicate kidney damage.
- Cystoscopy to check how well the bladder is voiding.
- Voiding cystourethrogram to check urinary functioning during voiding.

It is important to evaluate urinary functioning in a patient with tetraplegia to detect early complications and for proper management.

- **Bladder management**

According to Hanks, Rapport, Millis and Deshpande (1999:90) three approaches to bladder management used by spinal cord injury patients are the following:

- **Catheter free voiding**

Hanks *et al* (1999: 91) state that catheter free voiding is a procedure used to assist the patient to develop reflex voiding in which the bladder is able to contract and thus assist in the control of voiding. Hanks *et al* (1999: 93) further explained that though the bladder may manage to contract and void, the patient will not feel the sensation of fullness and the need to urinate, hence patients



and caregivers need to be educated about the various techniques used to empty the bladder, such as using fingers to tap bladder, stroking the thighs, pulling on pubic hairs or digitally stimulating the rectum.

Patients and caregivers need to be provided with adequate information on the use of catheter free voiding. Even though this could be viewed by the patient as threatening his/her privacy, it has to be done. Of importance is to have an open communication line, for the patient to understand. The social worker has to address the patient's emotions in this regard.

- **Intermittent catheterisation**

According to Kreuter, Sullivan and Siosteen (1996:541) and Somers (2001:106) intermittent catheterisation is a process in which a catheter is inserted into the bladder four to five times a day to empty the bladder. One of the goals of this procedure is to promote urine that is free from infections and to maintain the muscles of the bladder. Patients on intermittent catheterisation are restricted on intake of fluid in order to prevent regular retention of urine.

Thorough education on how to use intermittent catheterisation of both the patients and caregivers should be the focus of the rehabilitation team, as understanding will facilitate co-operation.

- **Indwelling catheters**

According to Somers (2001:107) and Kreuter *et al* (1996:542), indwelling catheters are used for those patients who cannot void without a catheter or to use intermittent catheterisation. To be sure of adequate urinary drainage an indwelling catheter is placed into the patient's bladder for a period of



three to four months. The catheter should be cleaned two times a day to eliminate places where bacteria can grow.

Kreuter *et al* (1996:547) further explained that there are two types of indwelling catheters that are used in high lesion tetraplegia, such as suprapubic catheter and urethral catheters. Suprapubic catheter is inserted directly into the bladder wall above the symphysis pubis. Urethral catheters are inserted into the bladder via abdominal incision.

It is important that patients and caregivers actively participate in the urological management of patients. The social worker can play a vital role of educating them about the various procedures used to improve understanding and management of their own urological functioning.

## **2.14 BOWEL MANAGEMENT**

According to Kennedy, Duff, Evans, & Beedie (2003:41) treatment of bowel dysfunction in patients with tetraplegia is administered according to the level of the lesion the patient has sustained.

Kennedy *et al.* (2003: 42) further explained that in the patient with upper motor neuron, using the defecation reflex stimulation, bowel regulation is done after checking the rectum for hard stool. The hard stool should be carefully removed by inserting a gloved lubricated finger into the rectum and moving it in circular motion to stimulate rectal emptying.

Special care should be considered to teach patients and caregivers about these procedure, as this is a sensitive and emotionally taxing act for the patients and caregivers.





According to Somers (2001:593), another method that is used to stimulate rectal emptying is that of placing patients on dulcolax suppository. This is done by inserting the suppository (i.e. the medicinal preparation in solid form), in the anus and placed against the wall of the rectum and after 10-15 minutes the stimulation is done to assist in moving the stool. The patient should then be placed on the toilet or commode chair to allow gravity to assist in eliminating the stool. Respect should always be communicated to the patient when regulating his/her bowel functioning.

According to Somers (2001:594) bowel management of patient with lower motor neuron is more difficult because the patient has lost defecation reflex. The patient with this type of lesion experiences bowel incontinence because of flaccid internal and external sphincter. The patient should therefore be placed on daily suppository programme. The suppository should be inserted against the bowel wall. This should be followed by rectal check. If any stool can be felt the individual is then transferred to a commode chair and he/she should be encouraged to push the stool out.

It is evident from the above information that bowel control is a dehumanising procedure. For most of the time patients depend on the assistance of family members, caregivers and spouse to perform most of the bowel routine for them. This may trigger uncomfortable feelings, embarrassment and may also destroy their self-esteem and confidence.

The researcher is of the opinion that the treatment team must acknowledge these feelings, and aspects of bowel routine should be explored with the patient. The patient should be encouraged to acknowledge that attendant care is done to optimise his/her independence and to promote his/her health.



## 2.15 CONCLUSION

Spinal cord injury is a traumatic experience for both the patient and his/her family, mainly because it was never anticipated.

There are many causes of spinal cord injury, but what is important is that most of them can be prevented and thus its prevalence can be reduced. Causes of spinal cord injury, such as accidents, sport injuries and family violence can be prevented through the introduction of road safety measures, adopting healthy life styles and following proper rules and procedures pertaining to sports.

Spinal cord injury in most cases is accompanied by a variety of complications due to the fact that the co-ordination that existed between the brain and the spinal cord no longer exists due to trauma. These complications make the chances of survival of a spinal cord injured patient uncertain.

The complications include problems related to breathing, inability to control or regulate urine, as well as inability to control or regulate one's bowel. Proper management of these complications is very important as it will promote the patient's health and enjoyment of life.

After thorough involvement in a rehabilitation programme, where the patient and his/her family have been educated on how to cope with the patient's condition, and it has been observed that they can cope, the patient can be prepared for discharge into the community.

The following chapter deals with the psychosocial problems encountered by patients once discharged from hospital.





## CHAPTER 3

### THE PSYCHOSOCIAL PROBLEMS ENCOUNTERED BY PATIENTS ONCE DISCHARGED FROM THE HOSPITAL

#### 3.1 INTRODUCTION

Spinal cord injury is a devastating and accidental crisis that produces a constellation of unanticipated physical, psychological and social consequences for the patient and his/her family. According to Stevens, Bergman and Formal (1997:72), these impairments are life changing through immediate experience and through the patient's perceptions of options for the future.

Spinal cord injury creates a crisis for both the patient and the family because it comes when it was never expected. It causes emotional turmoil in both the patient and the family as the patient suddenly finds him/herself paralysed with no sensation in the limbs and no control of bladder and bowel. Somers (2001:115) mentioned that life, as a person has known it, will be interrupted by months of hospitalisation and a lengthy period during which new techniques must be mastered as a necessity for survival and independent functioning.

Spinal cord injury brings with it some significant changes in the person's life, which demands proper adjustment if the person is to survive. This includes learning to accept and deal with a situation designed for and dominated by other people who might not be very accepting of the person with physical disability. The ability to produce economically is severely reduced. The social and family lives of people with tetraplegia are drastically affected (Somers,2001:116)

In addition the person's recreational activities she/he previously enjoyed as an able-bodied person are often available in altered forms, if not impossible. At the same time, the person with tetraplegia must learn to cope with emotions, and social difficulties as produced by the physical losses. He/she



must learn to accept the reality of friends who drift away and thus to seize opportunities to meet new people and to make new friends. He/she must learn to cope with the attitude of the public that may find it difficult to interact with him/her and yet at the same time he/she must try to put these people at ease and to make them forget about the presence of a wheel chair (Stevens *et al.*, 1997:76).

The above scenario clearly confirms that spinal cord injury has psychosocial problems for the patient and his/her family. Hence there is a need for social work intervention in this regard where the patient's psychosocial situation will be dealt with appropriately. In this chapter the following aspects will be discussed, namely: reaction to spinal cord injury; adjustment to spinal cord injury; and social work intervention with regard to patients with tetraplegia and their families.

### **3.2 IMPACT OF SPINAL CORD INJURY ON THE PATIENT**

According to Haythornwaite, Wegeners, Benrud-Larson, Fischer, Clark and Dillingham (2003: 572), spinal cord injury produces a constellation of unanticipated physical, psychological and social challenges to both the patient and his/her family. The primary challenge to the patient with tetraplegia is adjustment to a very sudden and massive change.

Hammel (1996: 28) agrees with these authors and argues further that at one moment the individual is involved with a job, family, recreation and many other sectors of life. The next moment he/she is involved in fighting for his/her life, experiencing pain, tolerating hospital procedures and must attempt to come to terms with the nature of his/her paralysis. Hammel (1996:30) goes on to explain that very few human beings are prepared for such a rapid change. It is further explained that a patient with spinal cord injury experiences incredible loss of control. The person with tetraplegia may need help to breathe, eat, talk, eliminate, bath, dress, move, cough and so on.



Hammel (1996:32) further mentioned that a normal person has control over his/her environment, make choices and experiences the outcome of these choices. However, the patient with tetraplegia is at the mercy of strangers, for a considerable period that is whilst in hospital.

Haythornwaite *et al.* (2003:580) concur with Hammel's view in the sense that other than finding themselves out of control of their lives or environments, patients with tetraplegia also find themselves facing a totally unknown environment. The total environment may include a strange rocking bed, a variety of endless tests and personnel who maybe asking the patient to do actions that may turn out to be impossible. In addition the patient may find him/herself experiencing a lot of pain as he/she is subjected to great deal of treatment, and at the same time he/she must deal with fear that has the power to destroy even the strongest person.

Other factors that have been found to have an impact on the psychological state of a person with spinal cord injury are the following: pain, medication, isolation and body image. Each of these will be discussed in turn.

### **3.2.1 Pain**

According to Dudgeon *et al* (1997:560), pain continues to be a major problem for individuals' following spinal cord injury. Ongoing pain has been shown to be associated with depression and affects the quality of life of patients with spinal cord injury. Individuals who were exposed to prolonged pain due to their injury reported to have reduced quality of life with associated psychological factors, such as depressed mood, anxiety and low acceptance of the injury (Dudgeon *et al*, 1997:56).

This calls for immediate medical intervention to control the pain and to reduce the occurrence of these problems. The researcher is of the opinion that better pain control will ease the patient's life and enable him/her to focus on the rehabilitation process.



### **3.2.2 Medication**

Somers (2001:210) mentioned that following spinal cord injury patients frequently take a lot of medication to help them with the problems related to pain and spasms and this may have adverse effects, such as sedation, confusion and fatigue and may affect their mental activity. They might not be in a position to make proper decisions, and under these conditions, team members should not pressurise them to take part in the rehabilitation process.

Team members, as experts, should be in a position to recognise when a person experiences the side effects of medication and to assist him/her properly. The medical team must also be sensitive towards what the patients are telling them regarding the side effects. This must not be seen as a way of getting attention.

### **3.2.3 Isolation**

Somers (2001:223) also found that isolation of patients following spinal cord injury in intensive care unit results in disturbances of thoughts and cognition and even perceptual changes. It is further stated that the period of isolation not only interrupts the rehabilitation progress but it also hampers the patients' level of adjustment to the injury (Somers, 2001:225).

Team members should carefully consider the patient's isolation period so that it does not have a negative impact on his/her progress to adjustment to the injury. Patients could benefit from supportive counselling during this period of isolation.



### 3.2.4 Body image

According to Somers (2001:224) and Bromley (1999:217), spinal cord injury may produce marked changes in body image and self-concept of patients with tetraplegia. For example, a patient who is using a halo brace may experience disrupted body image and distracted self-concept.

Also in this regard, Gill (1995:5) speaks of the four D's syndrome to illustrate the manner in which the patient who has undergone spinal cord injury will react to the new demanding situation. The four syndromes are dependency, depression, drug addiction and if married, divorce.

According to Gill (1995:4) a patient with spinal cord injury may be dependent on other people for most of the activities of daily living such as bathing, dressing, eating and toileting. This can have a negative impact on the person's sense of worth, self-esteem and self-efficacy. Gill (1995:5) further explained that many patients with such reduced level of independent functioning end up giving up rather than feeling obliged or depending on someone else. They may feel that receiving support places them at a disadvantage and this further reduces their level of self-esteem.

Depression is the second "D" that follows as a result of spinal cord injury. Depression is a necessary process for adjustment towards the disability. People with tetraplegia display period of low mood that will diminish over time. According to Gill (1995:7), the patient with tetraplegia is displaying such low mood because he/she is vulnerable to trauma, and this could lead to further isolation.

The third "D" syndrome outlined by Gill (1995:7) is adjustment of those individuals who abused drugs and alcohol prior to spinal cord injury. These individuals may have a higher risk of poor adjustment and of becoming dependent after the injury. People who fall into this category become dependent on prescriptions and they use drugs as a way of getting rid of the pain they might be





experiencing. Due to the period of hospitalisation these patients maybe absorbed in their own world of craving that could increase their isolation.

Divorce is the last “D” discussed by Gill (1995:8) in elaborating the impact of the injury on the patients and their families. Gill (1995:9) maintains that when people marry they commit themselves to each other but as soon as one of the partners becomes disabled this commitment is often challenged. The healthy partner becomes frustrated and starts to focus on his/her own needs. This stressful event may eventually lead to divorce.

All of the above call for immediate intervention from the social worker to assist these patients and their families in developing the necessary skills to adjust to their changed circumstances.

### **3.3 REACTION TO SPINAL CORD INJURY**

Several reactions to spinal cord injury will be discussed.

#### **3.3.1 Regression**

According to Pentland, Walker, Minnes, Trembly Brouwer, and Gould (2002:180), many patients with spinal cord injury react to the nature of their injury by means of regression. Pentland *et al.* (2002:181) defined regression as becoming more child- like dependent, losing control, losing reinforcement, becoming egocentric and becoming focused on more basic levels of needs. These authors further explain that regression can be directly observed in a patient who turns to focus more on his/her body, upcoming events, future events or when she/he can return home. However, these authors warn against the negative connotations that professionals place on regression. They mention that when regression occurs it should be seen as serving a useful and important function to enable the individual to adjust with the ability to tolerate to some extent, the overwhelming frustrations related to the loss of control, the unknown environment and the personal distress.



This view is supported by Barbeau, Fung, Leroux and Ladouleur (2002:137) who see regression in spinal cord injury as a phase in which there is a retreat from standards of adult independence, with more dependence on others and a more child-like level of weakness. Regression therefore enables the person to pull back and regroup so that he/she can then move towards adjustment as adaptively as possible.

Gates, Cambell and George (2002:34) tend to differ in the manner in which patients with tetraplegia will react to the nature of their disability. According to these authors, not all spinal cord injured patients will react in a similar manner despite issues to be faced and similar tasks and activities to be mastered.

These authors explain that every individual with spinal cord injury has a unique source of experience upon which to draw. Some patients may react to the newly demanding situation in a manner that seems best for them, while others might keep to themselves. Hence, it is important for professionals to become aware that there is no right way to go about adjusting to spinal cord injury. The roles of professionals should be to facilitate patients' progress rather than dictating it.

### **3.3.2 Depression**

Other common reactions to spinal cord injury observed are depression and denial.

According to Ladouleur, Barbeau and Mcfayden (2003:25) depression is seen as a normal consequence and plays an important role to adjustment to spinal cord injury. Depression is seen as internalised anger, sadness over loss, a result of biomechanical changes and learned helplessness. Hence Ladouleur *et al.* (2003:26) mentioned that patients with tetraplegia often show signs of depression such as being withdrawn, tearful and they have difficulty in sleeping and eating, though they continue to work hard in therapy and make reasonable progress.



According to Hammel (1996:152), the signs and symptoms of depression in various spinal cord injured patients represent a range of meaning, and once again, each individual is unique. For one person depression maybe perceived as a period of gaining strength to go on, for another it maybe sinking into failure and still for another patient depression may never occur or exist.

The above is supported by Counsel, Abram and Gilbert (1997:40), for whom depression is seen as a normal response to traumatic disability. If depression does not occur, this does not mean that the reality of the loss has not been recognised. It is postulated that sadness and grief are normal responses to life events that are painful, life threatening or disabling, but these should be differentiated from the clinical syndromes of depression.

Counsell *et al.* (1997: 43) further explained that grief is a complex emotional response and although people who grieve a loss may define themselves as being depressed, they usually experience a number of emotions such as anger, sadness, anxiety, despair and guilt rather than prolonged depressive mood.

Counsell *et al.* (1997: 44) observed that depression affected a few spinal cord injured patients within the first few months of the accident.

It therefore does not appear to be a universal phenomenon and even if it does occur, it does not appear to be as severe or prolonged as expected.

Therefore knowledge and understanding of the emotional reactions to spinal cord injury, especially the uniqueness of the individual, will facilitate the social worker's intervention. This will also be facilitated by the application of unique social work values and principles that emphasise the uniqueness of each client.



### 3.3.3 Denial

This is another factor displayed by spinal cord injured patients in adjusting to the nature of their injury and disability. According to Dudgeon, Massagi and Ross (1997:553), denial is the person's ignorance of either physical or emotional reality or suppression of both. Hence denial is considered a maladaptive attempt to protect oneself from distress. However, Dudgeon *et al* (1997:554) cautioned that like depression, denial could serve a positive function for some individuals. By dealing with what is tolerable at that moment, the individual can keep from being overwhelmed and can continue to function appropriately.

Yaggie, Niemi and Bueno (2002:802), saw denial in a different perspective. These authors argued that some professionals believe that immediately after the injury patients will react by refusing to accept their condition. Essentially, denial implies rejection or refusal and may be a more active process that is actually occurring in the early weeks following the injury. Yaggie *et al* (2002:803), mentioned that instead of treating or describing the patient who is not facing reality about his/her situation as being in denial, we should see denial as a direct confusion and disorientation due to the injury and its management. Rehabilitation should expand on the factors that may keep reality at bay, such as medication, severe pain, total immobilisation and enforced bed rest. This view is supported by Adams (1992:115), for whom reaction to spinal cord injury should not be examined in terms of the psychological reaction to the injury alone, but also to the procedures utilised to ensure survival of the patient during the acute treatment period.

Adams (1992:310), further explained that paralysis and the procedures used to immobilise the spine further restrict movement for many weeks. Patients with tetraplegia who have tongs in the head to immobilise the neck have less mobility than those with paraplegia.



Furthermore, these patients have a restricted visual field, looking at a ceiling or floor only. Medication to relax the person, to ease the pain and to control muscle spasms further reduces patient's mental activity.

Adams (1992:311), therefore stated that once the dulling effects of the early treatment procedures have passed, the individuals with spinal cord injury show eagerness to receive information on what had happened to them.

Whiteneck *et al.* (1999:804), distinguish between denial and hope used by many patients with spinal cord injury to adjust to their disability. Whiteneck *et al.* (1999:805), explained that many patients respond to the prognosis of the paralysis with an assertion of will and strength and most of them plan to prove the health professionals wrong in the sense that after having been discharged, they will be able to walk. Professionals should therefore treat such behaviour and statements as proof of maladaptive coping responses rather than evidence of hope and the powerful resources on which a person draws strength in time of adversity or frustrations.

Hence Whiteneck *et al.* (1999:807), explained that information about disability should be given in such a manner that it does not destroy the patients' hope that things will get better. These authors believe that hope need not interfere with the rehabilitation process but can provide a motive to the patients with tetraplegia to keep working despite the many frustrations facing them.

According to Hammel (1996:44), an individual's reaction to spinal cord injury is characterised by a process of denial, preventing an individual from facing the sudden changes in him/herself and the implications of this for the future. According to this author, the individual's reaction could be viewed as normal reaction to an abnormal situation. It is further argued that this reaction is characterised by a range of conflicting emotions, which may include numbness, disbelief, anger, fear, hope and despair.



Mathew, Ravichandran and Morsley (2001:644), view this period as that of emotional turmoil and disorganisation in which individuals may see their world as fragmented and uncertain. Mathew *et al* (2001:645), further explained that this type of psychological disturbance is a necessary process leading to readjustment and can therefore be described as appropriate. Hence, individuals' reaction to spinal cord injury may vary in degrees and it will differ according to age, level of the injury, social class, education and the pre-injury personality.

Denial as a defence mechanism is used by some patients to block the experience of the unpleasant event and to draw some strength to deal with their situation. The social worker needs to have insight regarding the reactions of these patients in order to provide an appropriate service.

### **3.4 IMPACT OF SPINAL CORD INJURY ON THE FAMILY**

According to Krause, Sternberg, Lottes and Maides (1994:646), spinal cord injury imposes multiple stresses not just for the patient but also for the family. These authors argued that the impact is far reaching as relationships and roles may be radically changed. Chronic health problems, feelings of frustration, isolation, resentment and guilt are reported to be experienced by family members (Krause *et al.*, 1997: 647).

It is further argued by Krause *et al.* (1997:647), that it is not only the perception of physical disability and distress in the patient with tetraplegia that creates emotional turmoil for family members, factors such as financial constraint as employment is adversely affected also puts pressure on family members.

Spinal cord injuries have also been found to have a negative impact on the marital relationship of couples. Krause *et al.* (1997:648), mentioned that many spouses reported to have a stronger fear of separation and a higher sense of dependency as a result of the injury. The healthy spouses



experience higher levels of depression, physical stress, emotional stress, and anger than the person with spinal cord injury.

This view is supported by Gill (1995:11), to whom spinal cord injury brings turmoil to the whole family. This may include the roles and responsibilities that the injured person performed as a member of that system. A marriage in which a give and take relationship existed may change to that of caregiver in which the abled spouse is forced to take the responsibility of providing care to the patient.

According to Gill (1995:12), another factor that is affected is the interpersonal relationships of a patient with tetraplegia. Gill (1995: 14), mentioned that friends who previously had common interests with the patient are now different. The person with tetraplegia may become apathetic and may not want to see friends because they are different from him/her.

This is a painful experience and the researcher is of the opinion that timeous interventions by the social worker could assist in reducing some of the impact of crisis and emotional turmoil experienced by both patients with tetraplegia and their families. Supportive counselling, which will be discussed later in this chapter, can be beneficial to the patients and their families.

### **3.5 ADJUSTMENT TO SPINAL CORD INJURY**

The process of adjustment to spinal cord injury is difficult, when taking all the factors into consideration. Several factors have been identified by different authors as playing a role in the process of adjustment. These are: motivation, perception of the injury, social support systems and spiritual support.



### 3.5.1 Motivation

According to Stiens *et al.* (1997:65), motivation is an important factor in the process of adjustment to spinal cord injury. These authors indicate that spinal cord injury is a dramatic state in which learned helplessness may occur. With the sudden onset of paralysis and the loss of control over life, certain individuals may be vulnerable, be helpless and may believe that there is nothing that they can do to improve their situation. Abbas and Trioli (1997:12), speak of a person's locus of control that may be defined as the expectations that one can control the rewards that the environment has to offer. These authors mentioned that those individuals who possess characteristics of internal locus of control believe that their behaviour will be rewarded if they work hard, whereas those with external locus of control believe in fate and luck. Therefore spinal cord injured patients who possess internal locus of control are more interested in gaining knowledge of their disease, work hard in the rehabilitation process, and engage in educational activities and employment than those with external locus of control because they perceive knowledge as important to control their lives.

Motivation as a determining factor towards successful adjustment towards spinal cord injury is supported by Hammel (1996:302), who defines motivation as an inherent drive that enables an individual to establish important goals and work hard towards achievement of these goals.

Hammel (1996:303), also speaks of internal locus of control to refer to those patients who have a belief that they will be rewarded by hard work, gaining knowledge, establishing and pursuing goals.

In contrast, those patients who have learned that other people have control over their lives will not pursue goals, nor control their self-worth and situations. They may not be motivated to learn self-care skills, nor see the possibilities for a meaningful and fulfilling life in the future (Hammel, 1996:70).





Hammel (1996:304) further explained that other people may be significantly influenced by the attitude of the rehabilitation team, family members and friends. Therefore if the significant others perceive the injury as a tragedy this will have an impact on the patient and upon his/her commitment to rehabilitation.

Bromley (1999:69), aligns himself with this view of motivation to explain how successfully a person will adjust to his/her injury. According to him, a person with internal locus of control belief system takes responsibility for life events, shows less depression, and shows more independent behaviour than those with external locus of control belief system. Patients' motivation therefore may be a function of their expectations, environmental demands and their perceived capabilities to affect the future.

According to the researcher, knowledge of the concept of internal and external locus of control is important for the social worker because it will enable him/her to assess the individual's perception and belief system and to offer appropriate intervention. What is important is that the social worker should assess the patients' level of insight in terms of their disabilities and to encourage them to develop internal locus of control to work hard towards adjustment to the disability. The social worker should be able to identify those patients who have developed learned helplessness and to instil hope to realise that they are able to improve their situation.

### **3.5.2 Perception of the injury**

This is another factor that influences a patient's ability to adjust to spinal cord injury. According to Somers (2001:245), adapting to spinal cord injury is a process that evolves over time. Somers further explained that adaptation takes place on three levels, namely the individual, the social and the environment. This author mentioned that certain personality traits play an important role in how effectively a person will cope with the injury. For instance Somers (2001:246), mentioned that a person with a history of alcohol and substance abuse or suicide attempts might not adjust well to the



injury. Therefore perceptions, preinjury level of functioning, a sense of control over one's life are variables to consider in determining how successful a patient with spinal cord injury will adjust.

### **3.5.3 Social support system**

According to Gill (1995:20), social support systems play a vital role in adjustment towards spinal cord injury. Gill (1995: 21), mentioned that during this period of emotional turmoil, a patient with tetraplegia might have lost coping skills and problem solving capacities on which to rely. Limited social support, a sense of hopelessness, low self-esteem, a fragmented family system and non-religious beliefs, are characteristics associated with poor coping. In addition Somers (2001:248), mentions that a person with solid social and emotional support systems and faith in a higher power will have greater trust that he\she will get through this traumatic event and to go on with life. The injured person will learn to accept that the injury has occurred and that although the circumstances cannot be reversed, they can be managed.

### **3.5.4 Spiritual support**

According to Stiens *et al.* (1997: 69), spiritual support of those who believe in a superior power can be a great source of comfort and peace to the patient and the family. Spiritual support can be provided by the assistance of the social worker through the hospital's spiritual services if they are available, pastors from the patient's local churches or other means as chosen by the injured person.

Other factors that have been seen to be associated with adjustment be it healthy or unhealthy are: age, gender, duration of the disability, educational level, employment status, access to transportation, financial status, assertiveness and problem solving capacities (Stiens *et al.*, 1997: 68).



All of the above suggest that the social worker must work hand in hand with patients and their families in deciding what is best for them. An effort must always be made to maintain a social network from which the patient could draw some strength to survive the trauma.

As has already been indicated, thorough assessment by the social worker will enable him/her to identify those patients who are helpless and to offer intervention accordingly. It is important for the social worker to understand that many factors are involved in the patient's situation after spinal cord injury. The social worker must utilise his/her time effectively to gather as much information as possible about the patient's situation so that effective intervention can be provided to both the patients and their families. Each person must be treated as an individual and those who struggle to adjust to the injury must be given time to make sense out of their traumatic situation. Empathy and acceptance of the patients as they undergo this emotional turmoil are important principles to be applied by the social worker in supporting patients with tetraplegia and their families.

### **3.6 SPINAL CORD INJURY AND SEXUALITY**

According to Stiens *et al.*(1997:65), sexuality is another area that is drastically affected by spinal cord injury. Stiens *et al.*(1997:66), mentioned that sexuality through limitations of movement and sensation can have a devastating impact on the sexual relationships of couples and this calls for professional assistance to help patients with tetraplegia develop new body image, identity and interpersonal relationships.

This view is supported by Bromley (1999:36), who agreed that spinal cord injury imposes marked changes on aspects of sexuality. Hence it is important that counselling be provided by the social worker to address issues of physical relationships and alternative sexual activities. It is therefore important for the social worker to instil hope in both the patient and the spouse to realise that their



situation can be changed. This can be achieved through providing information constantly to empower the couple and encourage them to be positive.

### **3.7 INTERVENTION THEORIES TOWARDS SPINAL CORD INJURY**

There are different intervention theories that could be adopted when dealing with patients with spinal cord injuries, and each of these will be briefly discussed next.

#### **3.7.1 The Medical Model**

According to Anderson, Biering-Sorenson, Galbo, Bangsbo, Wagner and Kjaer, (1997:1), in the first weeks after the onset of spinal cord injury, survival of the patient becomes the prime concern of the hospital personnel and the person becomes the passive recipient of treatment designed to fix his/her body, such as provision of skeletal traction, surgery, treatment of associated injuries, management of bladder and bowel control and prevention of skin problems. When the person has reached medical stability, the person is no longer sick but he/she is now physically disabled, and a rehabilitation programme will be outlined to teach him/her the activities of daily living and necessary techniques to adjust to the outside world. In the medical model, the person is treated as a passive recipient of treatment. He/she does not become the decision maker; the staff delivers treatment to him/her according to the schedule and the sequence designed by the staff. Anderson *et al.* (1997:5,) stated that adjustment of the person to his/her injury is the result of a give and take relationship between the patient and the medical staff.

According to Bromley (1999:85), the medical model is only relevant in the earliest acute care of someone who has sustained a spinal cord injury. At this stage the individual is not in a position to internalised knowledge and skills with respect to his/her disability, nor is he/she in a position to make informed choices concerning his/her treatment.



However, Bromley (1999:86), cautioned that when it comes to the rehabilitation process, this model is unlikely to be successful. He further explained that coping with spinal cord injury implies that the individual may have to make major adjustments in his/her life, must learn to be responsible for his/her own health status, learn new skills and learn to solve problems creatively. At this stage the person cannot afford to be the passive recipient of treatment and comply with the goals as set by other people. The medical model is therefore said to be unsuited to the management of a traumatic disability such as spinal cord injury.

With respect to the acute stage, the same view is supported by Putzek, Richard, Bret, Hicken and Devivo (2002:58), who speak of the sickness role to refer to the process in which the patient is excused from exercising his/her obligations and responsibilities and who is dependent on the staff as long as he/she does everything to recover, such as seeking and following medical advice. This role includes the process of negotiation between the individual, his/her family and the medical staff and if they agree, the treatment can begin or offered to the patient.

The researcher agrees that the medical model is only applicable in the early phase of the injury, because at this stage the patient needs medical stability to survive. However, as the process unfolds, other efficient treatment therapies that respect the individuality of the person should be introduced.

In introducing these therapies, special caution should be given to the appropriateness regarding time and preparation of the patient.

### **3.7.2 The Learning Approach**

In contrast to the medical model is the learning approach to rehabilitation. According to Bromley (1999:101), rehabilitation is seen as a process of teaching the person to live with the disability in his/her own environment. According to this model the person is the active participant in his/her treatment. The rehabilitation programme is designed by staff in consultation with the patient to meet



his/her individual needs and goals. The needs will be determined by an assessment of the person's personality style, desire, preferences, and the environment to which he/she will return.

According to Mathew *et al.* (2001:648), adjustment to the injury is a function between the personality factors, organic factors and environmental factors. The personality factors will include habits, locus of control, methods of coping with stress, rewards, self-image and creativity. Organic factors will include the level of the injury, age, medical complications, strength and endurance. Environmental factors will include issues such as finances, access to medical attention, recreational and educational opportunities, architectural barriers as well as transportation.

Galvin and Godfrey (2001:645), offer a similar view of the learning approach where the spinal cord injured person is an active person, who rejects the passivity of the sick role and assumes responsibilities for his/her own care.

The individual in the learning approach seeks explanations, asks questions, state his/her preferences and expects his/her opinion to be heard. As a result of this active behaviour, the patient with tetraplegia is more satisfied with his/her treatment.

The learning approach emphasises teaching the patients with tetraplegia to acquire problem solving skills, analyse the situation, plan, execute the plan and to apply the learned skills and techniques to maintain health and physical capabilities and to interact with and engage in the physical and social environment. The learning approach therefore outlines some important learning skills that a person with tetraplegia must face in seeking independence within the parameters of his/her disability (Galvin & Gdfrey2001: 647). These are:

- Bladder and bowel management;
- Pressure sore prevention and spasticity;
- In the social area, the learning will be acquisition of social skills, sexuality, sports and leisure and activities of daily living.



- In the environmental area the learning needs will be acquisition of knowledge about resources, and environmental aids and equipment, community resources, financial management, employment and housing.

The learning approach emphasises the active involvement of the patients in learning as much information as possible about their disability. A patient who is knowledgeable about his/her condition is likely to work hard to bring change to his/her situation.

### **3.7.3 The Social Model of Disability**

This model explains how adjustment to disability could be made possible.

According to the White Paper on Integrated National Disability Strategy (1997:2), disability as a human right and developmental issues should lead to recognition and acknowledgement of people with disabilities as equal citizens who should therefore enjoy equal rights and responsibilities.

According to this model, the needs of every individual are equally important and all needs should be made priority for planning.

The White Paper on Integrated National Disability Strategy (1997:3), further explains that the collective disadvantage of people with disabilities, especially those with tetraplegia, is due to a complex form of institutional discrimination.

This is fundamental to the way society thinks about the circumstances of patients with tetraplegia. The discriminations they face are socially created phenomena and have little to do with their impairments. This model calls for immediate removal of barriers to equal participation and the elimination of discrimination based on disability.

The social model of disability has also outlined some inputs that can be used to facilitate independence and inclusion in society's activities of people with tetraplegia.



Rehabilitation has been seen as a powerful tool that can be used to empower and teach patients with tetraplegia to use their potential to participate fully in society. Rehabilitation is described as a way of helping them to become fully participating members of society, with access to benefits enjoyed by other members of society. This implies that patients with tetraplegia should have access to benefits enjoyed by other members of society, such as education and training, job opportunities and community development programmes (White Paper on Integrated National Disability Strategy, 1997:12).

It could thus be said that patients with tetraplegia should be fully rehabilitated to become active members of society.

#### **3.7.4 The Ecological Model**

According to Belciug (2001:157), adjustment to spinal cord injury is based upon the equilibrium between the individual and the environment. The ecological model view human development and functioning, including health and disability, as the outcome of a continuous exchange between the individual, the social environment and the physical environment and the cultural setting. When the exchange between the person and the environment goes well a state of adjustment or person environment fit is said to exist. This will include the individual's rights, needs, goals and the capabilities and qualities of the environment to meet these needs. Therefore, this model explains that people's genetic potential for health and social functioning is released, whereas the environment retains or increases their capacity to support health development and adjustment functioning.

The personality factors include physical, cognitive and sensory perceptual capacities and language facility. Personal factors also include the life experiences and the particular life stage of the individual (Belciug, 2001:159).





According to this model people use an almost limitless variety of physiological, cognitive, emotional, social and cultural processes to adjust towards disability. Adjustment may include active changes in the self to meet environmental demands such as those imposed by the disability (Belciug, 200:158).

This view is supported by Hepworth and Larson (1993:75), who see disability as not focusing exclusively on ailments or impairments. According to these authors, disability also relates to society. What is significant can be revealed only by the understanding of ecological framework in which the person with disability exists, by the interactions through which society engages disability, by the attitudes others hold and by the architecture, means of transportation and social organization as constructed by people. According to Hepworth and Larson (1993: 75) the extent of the disability is reciprocally determined by the transactions between people and their environments rather than residing exclusively within the individual.

In conclusion one can see that goodness of fit between the needs of people with physical limitations and the corresponding environmental resources to meet these needs such as adequate rehabilitation programmes, physical accommodation, education, employment opportunities and enough social support systems minimizes disability. This implies that the social worker must be attuned to the needed environmental resources to facilitate successful adjustment.

The researcher has provided various views on adjustment to spinal cord injury and disability. The aim was to facilitate understanding of different perceptions towards disability and to demonstrate that there is no right or wrong way of approaching it. For the purpose of this study the researcher has used the ecosystem model to demonstrate how the social worker can intervene in facilitating adjustment to spinal cord injury. The reason is that this model places emphasis on adjustment that should take place both within the person, the environment, society, and cultural factors. Understanding of the interactions of these systems will enable the social worker to influence change in both the individual and the various systems to adjustment to spinal cord injury.



## **3.8 SOCIAL WORK INTERVENTION**

When rendering social work intervention it becomes very important to look at the various phases that a person with spinal cord injury goes through.

### **3.8.1 Social work intervention in the acute phase of the illness**

This is the period during which the patient is overwhelmed by what has happened. This phase will be discussed with respect to the following aspects: Crisis intervention, relaxation techniques, mobilisation of support system, mobilising community resources and supportive counselling.

#### **3.8.1.1 Crisis Intervention**

According to Gill (1999:72), spinal cord injury is a devastating event that has not only physical but also social and psychological ramifications for both the injured person and the family. Such alteration comes unexpectedly; the person did not anticipate that being involved in an accident could bring about such a great change in his/her life and thus create emotional turmoil for him/her.

As has been indicated, a crisis is an upset in a steady state that poses an obstacle to the fulfilment of important life goals and the individual cannot overcome the crisis by using the usual method of problem solving. A crisis is stressful, disruptive and usually affects the psychological, physical and social functioning of the individual experiencing it (Gill, 1999:73).

Spinal cord injury is something that was not anticipated, it is overwhelming to the individual as his/her coping skills are affected. Here crisis intervention as a method of helping people to deal with their emotional turmoil would be useful. According to Hepworth and Larson (1993:88), crisis intervention is time limited, focuses on problems of living rather than psychotherapy, it deals with



the here and now and the social worker assumes an active and directive role and gives advice to a greater extent. The aim is to assist the person experiencing the crisis to restore and return to the pre-crisis equilibrium.

According to Bromley (1999:97), immediately after the injury and during the time the diagnosis is disclosed, individuals react with shock and even denial. The social worker can relieve emotional distress experienced by the individual by responding empathetically.

He/she can facilitate adjustment by encouraging the patient with tetraplegia to ventilate pent up emotions and by reassuring him/her that these emotions are a natural reaction to an extremely distressing situation. What is important is that the social worker should simply be there for the patient especially when the bad news is broken.

Haythorhwaite *et al.* (2003:522), mentioned that a patient who finds him/herself in a crisis may be overwhelmed by grief, confusion, and anxiety to an extent that he/she may not have absorbed and incorporated what was said. It is important for the social worker to realise that discussions and explanations are not always understood or remembered by the patient who has just received the news that he/she will be confined to a wheelchair for the rest of his/her life. Intervention should therefore focus on advocating for the patient and to promote and strengthen the communication between the patient and the medical staff. The social worker can promote the communication between the patient and staff by alerting the staff about the patient's needs for simple explanations, which should be delivered in a humane way. To facilitate understanding of his/her condition the social worker should reinterpret in lay man's terms what the medical staff said.

According to Hepworth and Larson (1993:90), the patient's perception of his/her medical treatment can also be promoted by the social worker through information giving, by simply giving explanations about the use of medical equipment, such as the use of tracheotomy, to disband unfolded fears and to reduce anxiety.



Crisis intervention calls for the social worker to take a lead and become active in assisting the patient with tetraplegia to deal with the trauma, but at the same time, he/she should not underestimate involvement of the patient throughout the process to prepare him/her for the learning that is to take place.

### **3.8.1.2 Relaxation Techniques**

According to Hepworth and Larson (1993:93), relaxation techniques are a form of intervention to assist people to reduce anxiety and to keep emotions within manageable units. As already indicated, patients with tetraplegia cannot move their arms, legs and most of the techniques deployed by this method will not be applicable, especially in the acute phase when most patients still experience weakness of the muscles.

Therefore, it is important for the social worker to assess the patient's condition thoroughly before application of these techniques. But the use of some of these techniques, such as closing of eyes tightly, clenching jaws and pressing of lips to release tension can be helpful to the patient with tetraplegia (Hepworth & Larson, 1993:39).

Relaxation techniques can be used to a minimum to assist the patient with tetralpegia to release the stress and tension related to the trauma.



### **3.8.1.3 Mobilisation of Support System**

According to Noreau and Fougeyrollas (2001:170), support systems play a vital role in helping a person adjust and cope with spinal cord injury. The support systems can be family and friends, health care professionals and spiritual leaders. During the acute and rehabilitation phases, the primary support of family and friends provides comfort, encouragement, hope and inspiration to the patient with tetraplegia. Hence, these authors mentioned that social support has been found to be related positively to desirable outcomes following spinal cord injury.

Gill (1997:103), argued that during the crisis situation, social work intervention entails meeting with family upon their arrival at the hospital. The social worker needs to reassure them that the medical team will meet with them to report on the person's condition as soon as possible. In the interim, the social worker also acts as a liaison between the staff and the family providing needed information to both. According to Gill (1997:105), one of the tasks of the social worker is to address immediate questions and concerns and to provide continuous information on the patient's status.

According to Hammel (1996:330), one of the tasks of the social worker is to make sure that the family sees the injured person as soon as possible. He/she can facilitate this by advocating on their behalf to bring it to the attention of the team that this will help to stabilise the family, through knowing that their loved one is still alive. The team also needs to realise that seeing their loved one as soon as possible will reduce the family's anxiety and provide the family with an opportunity to express words of affection and encouragement and to emphasise the reality of the situation.

Hammel (1996: 332), also mentioned that before the family visits the patient for the first time, some preparations need to be done by the social worker such as orientating them about the unit, preparing them for what they will see and what to expect.



In the researcher's opinion, a crucial time arises when the family and friends meet the patient for the first time after the injury. The best approach to be adopted by the social worker is simply to be there and to be prepared to handle whatever emotions that could arise.

According to Hepworth and Larson (1993:450), some families may react to the disability of their significant other with much anger and hostility and therefore it is the task of the social worker to be there and assess these feelings and intervene appropriately.

Hepworth and Larson (1993:455), further mentioned that some may be overwhelmed by the grief, confusion, anxiety and even cry. It is important for the social worker to realise that these people are expressing their grief and that simple gestures such as offering a box of tissues, or a cold cloth might be helpful to them. By doing so, the social worker demonstrates a non-judgmental and caring attitude.

Another important factor that must be observed by the social worker when interacting with their loved one is prevention of any inappropriate or utterances of inappropriate responses by family members that might give the patient false hope about his/her condition. However, the social worker must interpret these responses as a form of calling for help from her/him as a professional. The social worker must realise that as much as the patient is undergoing emotional turmoil, the family too might be experiencing the same feelings such as denial of what their loved one is undergoing. Hence, it is important for the social worker to allow the family to express these feelings in an appropriate manner.

Another important aspect that requires social work intervention is mobilisation of situational support where the social worker can explore with the family its source of support when problems were experienced in the past to provide immediate support. This can involve contacting the pastor of their church if they are religious people, or members of extended families.



#### **3.8.1.4 Mobilisation of Community Resource**

As already indicated by Gill (1997:109), spinal cord injury is a condition that requires long-term hospitalisation and adjustment. Some families are not living within the catchment area of a hospital and constant interaction with the patient in assisting with decision-making and moral support is important, since often these families travel long distances to give emotional and moral support to the patient, all of which places another financial burden on them. The social worker should have knowledge of community resources and explore avenues, such as finding an alternative accommodation near the hospital until the patient's situation is stabilised. In the hospital where the researcher is working families who live far away are accommodated in the unit for the time being until the patient is stabilised. This is very helpful and facilitates the provision of support for the patient by his/her family.

#### **3.8.1.5 Supportive Counselling**

The Oxford Dictionary (1990:264), defines supportive counselling as a method of approaching difficulties in adjustment that helps the client work out his/her own problems. In assisting the patient and his/her family to adjust to the disability the social worker employs all the skills related to counselling, such as allowing the patient and family members to vent feelings and concerns. One aspect that should be important to the social worker is fostering hope to both the patient and the family. Hope can be fostered by encouraging both the patient and family members to develop internal locus of control as explained in the preceding sections. It is also important for the social worker not to give the patient and family members any false hope, which means that the reality of the patient's condition must be taken into consideration.



According to Norris (1994:188), the social worker can instil hope by allowing the patient to take the lead. By giving the patient and his/her family the opportunity to talk and listen actively, the social worker is in a position to respond appropriately. Good listening makes for efficient teaching and intervening appropriately. According to the researcher, by allowing the patient to take a lead enhances his/her sense of control and independence.

Another principle to be observed by the social worker in facilitating adjustment to spinal cord injury is maintenance of his/her sense of dignity (Krause, 1998:52). Patients' sense of dignity simply means being polite and thoughtful, drawing a curtain if his/her body is going to be exposed.

Gill (1997:290), mentioned that these small details can afford a patient a sense of stability, fosters the feeling that he/she is still a human being in spite of the disability.

Another aspect that the social worker should focus on is to encourage positive and realistic expectations on the part of the patient. Gill (1997:292), mentioned that the social worker should realise that there is much even a severely injured patient can achieve. Such active coping style can be fostered by cognitive restructuring where the patient is encouraged to think realistically as this has shown to result in positive outcomes. According to Gill (1997:294), cognitive restructuring is a form of therapy that can help a patient with tetraplegia to restructure his/her thoughts to cope with the disability and live a more satisfying life.

In conclusion, during the acute phase of the illness the social worker must play an active role in facilitating successful adjustment to spinal cord injury. During this phase it is vital to assist the patient and family members with coping skills to restore the pre-crisis situation, patient involvement is important to prepare him/her for the learning that is to take place in the secondary phase of the injury, which is rehabilitation. By doing that the social worker utilises the principles of the eco-systems model where change is focused on the patient and his/her family. Much as we need to change the environment, and to be attuned to the individual's needs, at the same time the individual with tetraplegia also needs to change and prepare him/herself to meet the environmental demands.





### **3.8.2. Social Work Intervention during The Rehabilitation Phase**

Social work intervention during this phase will be discussed with respect to the following aspects: Individual therapy, sex therapy, consideration of financial aspects, employment aspects, family intervention and group therapy.

#### **3.8.2.1 Individual Therapy**

According to Krause (1998:365), rehabilitation is the process of learning to live with a disability in one's own environment. This author mentioned that when a patient with tetraplegia has achieved medical stability, a rehabilitation programme will be outlined to teach the person how to manage the activities of daily living and the techniques required to enter the outside world.

Krause (1998:366), further explained that at this time the person is no longer the passive recipient of treatment but must become an active participant in the learning process of adjusting to spinal cord injury. This is also the period during which the patient and the family begin the first steps to eventual adjustment to the disability.

Individual therapy forms the basic foundation for social work intervention. Hepworth and Larson (1993:20), define individual therapy as a face-to-face contact aimed at assisting the individual to cope more efficiently with any type of problems that impair social functioning. The main aim is to assess strengths and weaknesses of the patient with tetraplegia to foster independence to cope with the challenges of being a patient with tetraplegia.



Using the ecological model of intervention the social worker will focus on assisting the patient with tetraplegia to develop the necessary skills required to master the activities of daily living. Counselling will focus on exploring the patient's feelings about the physical losses, such as being unable to control one's bladder, bowel, or transferring in and out of bed. If these feelings are not addressed properly they may become problematic for a patient whose main priority is to return to the pre-injury phase (Belciug, 2001:170).

Other than helping the patient with tetraplegia to reduce feelings of frustration and anxiety related to the physical losses, the social worker needs to educate the patient about the right way of caring for him/herself. The patient with tetraplegia needs to have knowledge of his/her treatment and to be able to utilize this in the learning process of the rehabilitation phase (Belciug, 2001:172)

There are some important issues that the social worker should discuss with the patient to assist him/her to arrive at the right decisions. For instance, one of the areas that are affected in the patient's life is inability to control bladder and bowel with the resultant incontinence that can embarrass the patient in front of other people. These are issues to be explored with the patient. One of the decisions the patient with tetraplegia has to make is to either let one of the family members take care of this aspect or to get a caregiver from outside to assist him/her with bowel and bladder control regime. Often this is a difficult decision for the patient with tetraplegia because bladder or bowel management is a personal matter. Other individuals may feel that their privacy is violated (Stevens & Stiens, 1997:48).

It is important to note during intervention that tetraplegia as a condition differs according to the level of injury. Most physical assistance is provided to those patients who have sustained high level of the lesion (i.e. C1, C2 or C3). Those who have sustained low lesion need minimal assistance with the activities of daily living. Therefore, thorough assessment and exploration of the patient's condition is imperative for the social worker to render efficient and appropriate service (Stevens & Stiens, 1997:50).



According to Anderson (1997: 249), effective and early intervention by the social worker promotes the following: coping skills; inspires hope; restores self-esteem; fosters self-care and decision-making skills.

It is evident from the above that the social worker has to do a thorough assessment of the patient's strengths and weaknesses, for appropriate intervention, an intervention process that is responsive to the needs of the patient.

### **3.8.2.2 Sex Therapy**

Sex is another physical loss experienced by the patient with tetraplegia. According to Stevens & Stiens (1997:65), sexuality is affected through limitation of movement, sensation and excretory functions. Stevens & Stiens (1997: 66), mentioned that sexuality has an impact on the person and therefore requires reformulation of body image, identity and interpersonal repertoires. The social worker can assist the couple to maintain their sexual relationship by opening up communication between the couple to explore and assess what they want to achieve concerning their sexual relationship. Therefore, the social worker can contribute to the achievement of adjustment to sexuality by encouraging functional independence, positive body image, sensual exploration and respect for personal boundaries (Stevens & Stiens, 1997:75).

Other than focusing on fostering adaptive behaviour towards sexuality, Cesar, Yaravon, Haud and Hayet (2002: 45), provide some guidelines that the social worker can utilise in offering counselling to the couple to achieve intimate sexual relationship. These may include use of electrical and vibratory vacuum devices or injectable vasoactive medication to induce erection.

Instruction in engaging in sexual intercourse by inserting a flaccid penis into vagina to provide physical unity and the opportunity for stimulation with clitoral pressure and friction may be interesting to the couple. Other methods that the couple can try are kissing, hugging, touching and cuddling. The couple can also be taught to use side to side sexual position or one in which the partner with less mobility is on the bottom.



The couple can also be encouraged to use oral genital contact as each can share the sensation of the contact (Stevens & Stiens,1997:69). All these methods can be made available to the couple to explore and assess which one will be best for them.

Opening and exploring opportunities with the couple by the social worker will enable them to decide what will work for them.

### **3.8.2.3 Consideration of Financial Aspects**

Finance is another factor that is altered in patients with tetraplegia. According to Gill (1997:35), adequate finance is a major factor in determining patients' successful rehabilitation and adjustment, but many people with tetraplegia are living in poverty. Gill (1997:36) mentioned that not only do patients and their families have to cope with all the stresses of the injury, but at the same time, they may also have to live on a reduced or no income at all because the breadwinner is disabled. In many situations, the earning capacity of patients with tetraplegia will be dependent for long periods on welfare benefits administered by the Department of Social Security. The researcher has observed that most of these grants are inadequate to meet both the needs of the patients with tetraplegia and their families. If one has provided service to people with tetraplegia one will realise that it is very expensive to live as a disabled person. Therefore, thorough assessment and exploration of the patients' background is important for the social worker to understand their needs and to assist them accordingly. Most of the patients sustain the injury due to motor vehicle accidents, therefore knowledge of the resources such as Road Accident Funding can be utilised to assist the patients with claiming benefits and compensation.



#### **3.6.2.4 Employment Aspects**

Employment is another aspect that is altered in the patient with tetraplegia. According to Gill (1997:38), employment is possible for even the severely disabled person. During hospitalisation the person's employment will be suffering because of the long-term hospitalisation.

Employing the principles of the eco-systems model immediately after the injury, the social worker should notify the employer about the patient's hospitalisation. Other than notifying the employer about his/her employee's admission to the hospital, there are some technicalities that the social worker needs to facilitate. Knowledge of the labour relations legislation will empower the social worker to be able to advocate for the patient so that he/she can be provided with benefits related to the workforce. The use of resources such as the Department of Labour could assist the social worker to facilitate this process.

According to Whiteneck (1997:191), intervention by the social worker to foster adaptive adjustment towards disability and orientation towards the future is to assess the patients' interests and motivation to return to work. The social worker should during the counselling session explore the patient's future goals regarding work. If necessary, all patients should be motivated to see work as an important aspect that will assist them to acquire their independence and to realise that they are still valuable members of society. At the same time, the social worker should not overlook the patient's level of disability as this has an influence in his/her chances of returning to work. The researcher realised that those who possess qualifications, such as professionals are usually able to return to their previous work unlike unskilled persons, for whom it may be harder.

The latter group cannot return to their previous jobs because their physical status does not tally with the challenges of their work. Currently the government has embarked on intersectoral collaboration with various sectors to make sure that the needs of patients with tetralpegia are being met (White Paper on Integrated National Disability Strategy, 1997:42).



The social worker should use this opportunity and identify those who can return to work and negotiate with skills development departments to assist the employers to make the necessary adjustment to the workplace to enable the person with tetraplegia to resume his/her employment. Employers also need to be educated about the patient's condition to prepare them to be attuned to his/her needs. As mentioned earlier, thorough assessment of the patient's situation is important.

Some patients may wish to change careers or acquire new skills to be able to fit in the open labour market. The social worker can liaise with skills development departments, organisations dealing with people with physical disabilities to assist with the provision of career guidance and training and to help the person with tetraplegia in finding employment. In this way, both the social worker and the patient are manipulating the environment to be attuned to the needs of the changed tetraplegia person. This is the essence of the ecological model.

### **3.8.2.5 Family Intervention**

Counselling and education should also be provided to the family to teach them about the patient's condition and how to provide care to him/her. The social worker should always be cautious of the level of the patient's injury for the facilitation of appropriate intervention. With this knowledge the social worker will be able to prepare the family to ensure appropriate support for the patient.

According to Boothe (1999:5) and Potten, Soclen, Drukker, Reulen and Drost (1999:15), care of the patient with tetraplegia within his/her family should involve the following:

General care which should include teaching the family the appropriate skills for bathing the patient, skin inspection particularly pressure sore parts. The clothes should be made of the natural fibre because many patients sweat extensively and men should be provided with trousers that are not tight to avoid pressure sores.



#### □ **Bladder management**

In addition to general care, Boothe (1999:7), mentioned that the family should be educated about the procedures for managing the bladder such as tapping and expressing the bladder at regular intervals to achieve good bladder emptying. The family also needs to understand that patients with high lesion (complete tetraplegia) can often tap for themselves but they will be unable to fit the condom or leg bag or to empty the bag, hence assistance in this regard is needed. The best method for bladder management in women with high lesion is an indwelling catheter. This method relieves the family from the strain of having to transfer the patient on and off the toilet every four hours of the day.

Family members and caregivers should be informed on how the bladder of a person with tetraplegia functions so that proper assistance could be given to him/her.

#### □ **Bowel management**

As already indicated patients with low lesion (i.e. incomplete tetraplegia) need minimal assistance with bowel as long as they have access to a toilet with a padded seat to prevent pressure sores from prolonged sitting. However, patients with complete tetraplegia need assistance to do manual evacuation on the bed (Boothe,1999:10). This needs to be discussed with the family and if necessary, the family should consider the possibility of getting a helper to assist and relieve, and alternate with the family in providing care to the patient. The researcher has observed that it is strenuous for families to provide care to a highly dependent person on a permanent basis. At the beginning, most families reject the suggestion of getting outside help because of being overly protective and feeling guilty. The social worker should assist them to decide by giving them information about the physical and emotional exhaustion involved in caring for a highly dependent person. At other times, the family and patient refuse outside help because of financial constraints.



Exploration of the family's circumstances is important to offer appropriate intervention. The family needs a considerable amount of support from the social worker.

□ **Mobility**

As already indicated mobility in patients with low tetraplegia is possible as they can transfer into and out of bed, or manoeuvre the wheelchair. In contrast, patients with high tetraplegia need to be helped with getting in and out of bed, bathing, or even eating (Grundy, 2001:86).

Information on how to handle and assist the patient with tetraplegia in the execution of his/her daily activities is important and thus helpful to family members and caregivers.

□ **Home modifications**

According to Black, Sipski and Strauss (1998:240), most houses are unsuitable for people who are using wheelchairs and home modification is important. The social worker together with the occupational therapist can visit the patient's home and assist with some modifications of the home to be attuned to the needs of the patient with tetraplegia.

Modifying the home may include the following: adjustment of entrances to be smooth to accommodate the movement of a wheelchair. Modification of the bedroom such as removing unnecessary furniture to make space for the wheelchair, modifying the bathroom by creation of a standard height toilet to be used with a commode chair. The kitchen should also be changed to be attuned to the needs of the patient with tetraplegia. All appliances used should be made available and recommendations be made for access of a patient with tetraplegia.

Home modifications also need assessment by the social worker because some families may find it difficult to modify their homes because of financial constraints. Therefore, recommendations for modifying the home should be done according to the financial status of the family.





### **3.9 GROUP THERAPY**

Kaplan and Saddock (1991:55) defined group therapy as a treatment method in which people with a common problem are placed in a group guided by the therapist to help one another to effect change. By using a variety of techniques, the leader uses group members' interactions to effect change. According to Kaplan and Saddock (1991:63), group therapy with tetraplegia patients provides positive power of sharing together, identifying together and helping one another along their different paths and towards adjustment.

The social worker should therefore formulate a group for patients with tetraplegia to provide them with an opportunity for self-exploration, greater understanding and to reduce their sense of isolation and at the same time foster a sense of power, control and support.

#### **3.9.1 Social work during discharge**

This is the last phase of the rehabilitation process. According to Rena *et al.* (1996: 321), discharge planning is the sum total of efforts aimed at planning for the individual's return to his/her environment with the least amount of dislocation. Hepworth and Larson (1993: 198) mentioned that by solving as many problems as possible before discharge minimises the trauma of the patient's resuming life outside the unit.

There are some important adjustments that the social worker should assist the patient with tetraplegia and his/her family to achieve successful family integration. Preparing the patient for the discharge involves offering him/her home passes by the social worker and team members to evaluate and monitor how successful he/she will adjust at home (Rena *et al.*, 1996:345).



Intervention during this phase involves active involvement of the social worker to deal with certain issues that the individual and his/her family have to address. For instance in the situation of a person who is married the social worker should realise that the issues of resuming spouse's role are extremely important. It can be difficult for both the patient and the spouse to prepare and to start their relationship where they have left off before the injury. So many things would have changed since the injury and the couple needs to be prepared and discuss these issues and how to handle them (Rena *et al.*, 1996:348).

Other than focusing on enhancing the couple's marital relationship, the other area that the social worker needs to deal with is preparing children for the arrival of their parent. Often children do not understand why the other parent is no longer able to resume some of his/her previous roles. They maybe surprised by his/her using a wheelchair and having to be assisted with the activities of daily living. Even though they might have been counselled about their changed circumstances, the reality of their parent coming home, as a different person might be traumatic to them. The social worker must be prepared to handle these reactions from children and to answer their questions (Hammel, 1996:709).

Finally, Hammel (1996: 710) provides some guidelines that social workers can utilise to facilitate reintegration into the community. These are:

- Early and frequent community visits where the patient can be assisted to identify social and physical barriers in his/her environment and devise appropriate strategies.
- Early links with peer groups to provide support and valuable information concerning resources.
- Early identification of community services such as occupational therapist physiotherapist, social workers and health nurses.
- The social worker must also provide the patients with tetraplegia with a guide to resources so that they are kept well informed about support groups; benefits form the department of social security and other community and commercial resources.



It is important for the social worker to prepare the patient's discharge well in advance. In fact, this planning must begin as soon as the patient is put on the rehabilitation programme. All stakeholders such as family members, social workers at the community and community nurses should be involved to make the patient's reintegration into the community smooth and to ensure continuity of the service once he/she is discharged.

### **3.10 CONCLUSION**

Spinal cord injury is a devastating and traumatic experience for the patient with tetraplegia and his/her family. It poses a crisis to the individual and his/her family because they have never prepared for its occurrence. The onset of spinal cord injury poses a crisis that disturbs the equilibrium that existed in the family. Due to the nature of the trauma and emotional turmoil experienced, the patients' coping mechanisms are destroyed.

The onset of spinal cord injury is accompanied by a variety of emotional reactions. Many patients with tetraplegia and their families display a variety of emotions such as shock, denial, anger, anxiety and frustrations. These emotions continue throughout the period of hospitalisation unless proper counselling is provided to the patients and their families.



There are a variety of implications accompanying spinal cord injury. These are disturbed work, altered marriage relationships, sexuality, physical limitations and a variety of other psychological disturbances.

Due to the emotional reactions and the psychological problems that accompany spinal cord injury, guidelines for medical social work intervention are necessary. Social work intervention is needed during the admission (acute phase of the illness), hospitalisation (rehabilitation phase) and the discharge phase where the social workers have to deal with a variety of feelings experienced by the patients with tetraplegia and prepare him/her for the realities outside the hospital.

The following chapter deals with the empirical findings regarding the psychosocial problems experienced by black patients with tetralpegia once discharged from the hospital.

## **CHAPTER 4**

### **THE EMPIRICAL FINDINGS.**

#### **4.1 INTRODUCTION**

In this chapter the research methodology pertaining to the study is first described briefly. It is then followed by the research findings, which are described and analyzed according to the themes extracted from the information provided by respondents regarding their experiences.

#### **4.2 RESEARCH METHODOLOGY**

Applied research as a type of research was used in this study. It is defined by Fouché & De Vos (1998:) as research which aims to improve or bring immediate change to the clients or subjects. Phenomenology, as a research strategy, was used to explore the psychosocial problems encountered by black patients with tetraplegia once discharged from hospital. The phenomenological approach was found to be suitable for this research as it enabled the researcher to understand and interpret the meanings that respondents gave to the problems they encountered at home. According to Fouché (2002:74), phenomenology is an approach which is concerned with reality constituting interpretive practices.

In this study, the total population consisted of all patients with tetraplegia who attended the spinal cord clinic at Dr George Mukhari Hospital on Thursdays between October 2004 to April 2005.

Non-probability sampling, specifically availability sampling which is defined by Bless and Higson –Smith (1995:95), as the process of taking all cases at hand until the sample reaches the desired size, was used. The researcher interviewed all patients with tetraplegia who were available at the spinal cord clinic until the desired sample of ten patients was reached. According to Grinnel (1993:116), in- depth interview is a process of gathering data from respondents about their personal encounters, oral histories, biographies and life histories. In-depth interviews were conducted to collect information from respondents. The researcher facilitated the interviews and a tape recorder was used to capture data, after permission was given by respondents.

The aim and objectives of the study were explained to the respondents before the interviews commenced. Confidentiality, anonymity and privacy were ensured by means of voluntary recruitment and informed consent. The interviews were based on the following one central question: “How can you explain your life as a wheelchair bound person after you were discharged from the hospital”. The debriefing of respondents was done immediately after the data collection session was completed. This was done because of the emotional disturbance that was evoked by participating in this study, as this was very painful for the respondents.

## **4.3 RESEARCH FINDINGS**

As this is a qualitative research, data were analysed and interpreted qualitatively through themes extracted from the massive information. Themes and categories of the psychosocial problems encountered by black patients with tetraplegia once discharged from the hospital are highlighted. To emphasise the responses of the respondents' verbatim responses are provided.

### **4.3.1 Central Themes**

Themes were used to analyse the data collected from the in-depth interviews. The themes will be discussed next.

#### **4.3.1.1 Physical environment**

Most of the respondents reported that they are living in shacks, which are too small to accommodate the movement of a wheelchair. They reported that because of lack of money no modifications were done to their shacks to erect ramps and enlarging entrances to enable them to have access in and out the shacks. Some of the respondents said this:

*“Most of the time I remain where they have left me because it is difficult for me to struggle through an unaccommodating entrance”.*

*“Mekhukhu ya rona e mentye e bile e tsenya lerole. Fa e le mariga e tsididi, fa e le selemo e fisa mo go feteletseng. Ke ka moo motho a lwaletseng sa ruri ka gore go se mowa o o tshwanetseng.*

*“Ga re na di toilet tse di berekisang metsi. Toilete ke ya mokoti e ne e kgakala le mokhukhu. Fa o tshwaregile go ya toilete ke bothata mo bathong ba ba go thusang.”*

According to the social model of disability (White Paper on an Integrated National Disability Strategy, 1997:68), patients with tetraplegia are often challenged by the physical and social environment, which are discriminatory towards them. This model calls for immediate removal of barriers from the environment to make it user friendly towards patients with tetraplegia through the creation of compatible space, ramps, grades and surfaces to enable them to access the benefits enjoyed by other members of society.

In the researcher's opinion, the poor socioeconomic circumstances of many patients with tetraplegia are entrenching their physical disabilities. From the researcher's experience in working with them, many of them are living in conditions where there are no resources at all. The majority of them are living in places where there is no running water, electricity and flushing toilets. That is why some of them end up dying because they cannot simply cope without adequate resources.



#### **4.3.1.2 Experience of the condition**

All respondents experienced their new condition as difficult and frustrating. They also felt useless and as if they had been punished. They felt that having to summon help on the activities of the daily living such as being assisted with washing, going to the toilet or eating was tiresome and compelled them to be at the mercy of their families and other people. Respondents expressed their feelings as follows:

*“I am just like a dead person”*

*“I am useless”.*

*“Who cares about a cripple like myself?”*

*“I am a burden to people”.*

These statements are supported by Steins et al (1997:65), who acknowledge that tetraplegia is a condition that places a patient in an awkward position where he/she has to depend on other people’s help in order to survive. Patients with tetraplegia do not have control of their lives and this is often frustrating to them.

#### **4.3 1.3 Emotional response to the injury**

Respondents were struggling to come to terms with their disabilities. The manner in which they sustained the injury had an influence on their adjustment. Respondents who sustained the injury due to motor vehicle accident perceived their injuries as natural but they also perceived themselves as victims. For example, they said the following:

*“I was hit by a mere boy who did not have a driver’s license and he sustained no injuries.”(Anger displayed by the respondent)*

*“ What is frustrating is that I am the only one who was injured, the rest got out free and uninjured ”. (Respondent felt sorry for himself)*

Respondents who sustained the injury due to gunshots put the blame on themselves. They regretted having gone out with friends/girlfriends on that day.

*“I was shot while my friend and her boyfriend were in the middle of an argument. Should I have known that they were going to fight I couldn’t have gone out with her.”*

*“I should have listened to my sister when she said my girlfriend was not faithful to me .I was shot because of them”. “I was shot while accompanying my girlfriend to the shops but to my surprise nothing happened to her, as if these people were sent by someone specifically to target me.”*

These statements are supported by Counsell *et al* (1997:430) who mentioned that people who grieve a loss usually experience a number of emotions such as anger, sadness, anxiety, despair and guilt.

These statements clearly show that respondents are still experiencing a variety of emotions and this is displaced on other people. They need professional help to assist them deal with these emotions. Maybe they were not properly empowered and rehabilitated to deal with their emotions prior to their discharge from hospital.

#### 4.3.1.4 Denial

As already indicated, most of the respondents were injured a long time ago, but the researcher found that it was difficult for them to accept that they are permanently disabled. This was demonstrated by the following expressions:

*“Who said I am permanently disabled?”*

*“Time will tell”*

*“I have seen people throwing their wheelchairs away and being able to walk again”.*

*“Lona lo buwa fela.Kana go thlolwa go twe motho o golofetse. Nengneng o mmone a tsamaya. Dilo tse di itsiwe ke Modimo eseng motho wa lefathse.”*

These statements are supported by Hammel (1996:44) who explained denial as an emotional reaction preventing a person from facing the sudden changes in him/herself and the future implications. In the researcher’s opinion denial is used positively by respondents to help them to block the experience of the unpleasant event and to carry on with their lives and one should not blame them for this. The helping process should place more emphasis on reality and allow them to accept it in their own pace.

#### 4.3.1.5 Feelings of helplessness

When asked about their future plans, respondents indicated that with their condition there was nothing left of them. The following excerpts illustrate this sense of helplessness:

*“There is nothing that I can do”*

*“I don’t know why I am still living”*

*“ What could be done by a cripple like myself?”*

Hammel (1996:28) supports the above and states that patients with tetraplegia experience incredible loss of control of their lives and the environment and have to depend on the outcomes of choices made by other people.

This often frustrates them and makes them feel useless and helpless. This clearly shows that the experience of tetraplegia is devastating and has enormous implications for those facing it, as it leaves a person with an uncertain future.

#### **4.3.1.6 Depression**

During the interviews, respondents also expressed feelings of loss of their independence, and the reality of getting assistance in everything they do from other people was depressing them. These are some of their responses:

*“It is over with me”.*

*“Gago sepe se nka sedirang. Sa me fela ke go itshwela ”*

*Ke eng se nka se dirang ka matsogo le maoto a a sa direng”*

*“Go thata go nna segole jaaka nna. Batho ba aga ba ntha bare go tla loka. Fela fa o lebeletse go tla loka eng ka gore la re nka se thlole ke kgona go tsamaya”*

These sentiments are supported by Barbeau and McFayden (2003:25), who mentioned that depression is a normal response to a traumatic event. It is seen as internalised anger,

sadness over loss. Patients with tetraplegia continue to work hard to deal with their disability in spite of the emotional turmoil facing them. These statements clearly demonstrate that respondents are overwhelmed and are not coping well with their disabilities.

#### **4.3.1.7 Hope**

Some of the respondents still have hope that their situation will change, and they will be able to use their hands and legs. Others confided to the researcher that if things could be reversed they would be grateful if they could at least be able to use their hands (become paraplegia) be able to manipulate the environment, gain independence and self-confidence. Feelings of hope were expressed as follows:

*“Very soon I shall be able to walk as there is some movement from the legs.”*

*“As long as I attend treatment I shall be able to walk”.*

*There is nothing impossible in front of God. With his help I will be able to walk again.”*

*“Lona ko sepetelele lo mpoleletse gore ke golofaletse sa ruri .Ntate o ke tsamayang ko gone ompoleletse gore kgobalo ya me ke maneelelwa . Ka jalo otl;a leka go nthusa gore ke kgone ke boele ke tsamaye.”*

The researcher deduced that respondents’ hopes to regain their neurological functioning were influenced by the onset of spasms (involuntary muscular contraction). When this happened respondents associated it with the returning of their neurological functioning.

These feelings of hope are supported by Yaggie *et al.* (2002:802), who mentioned that hope as displayed by patients should not be treated as denial to accept their conditions. Hope should indeed be seen as strength to rely on and to keep on working despite the many frustrations facing them. In the researcher's opinion, hope as expressed by respondents could be used by the social worker to motivate patients to realise that they have the potentials to experience a meaningful life in spite of the physical limitations imposed on them by the disability.

#### **4.3.1.8 Adjustment at home**

Most of the respondents could not cope with their disabilities at home, as they were faced with a variety of problems from their families. The type of support received from families influenced their adjustment.

There were respondents who were supported by their families. The only problems experienced were that their families were not sufficiently equipped to handle the issues of the right time to change napkins, emptying urine bags, and turning them for pressure relief.

Respondents also mentioned that for them to be able to regulate urine a catheter, which needs regular check up, is inserted in them to assist in this regard. Most of them have lost their employment since they were injured. Hence, they did not have money to hire special transport to take them to and from the hospital.

They ended up defaulting treatment and experience health-related problems, such as catheter blockage, urinary tract infections, fever and pressure sores. The following excerpts demonstrate this:

*“My sisters took turns to look after me, but they did not understand the necessity of checking me regularly.*

*“My mother is not working and she is always around willing to help me, but sometimes she gets so busy with her house chores and she forgets about me and therefore I ended up having pressure sores because I was afraid to complain to her”.*

*“My family found it difficult to take me to the hospital for medical check up as they did not have money. I nearly died because I couldn’t pass urine as my catheter got blocked.”*

According to Gill (1999:65), the support system plays a vital role in assisting patients with tetraplegia to adjust to their condition, hence the family members should be empowered with the skills necessary to accomplish the activities of the daily living to assist the patient in coping.

However, Boothe (2002:54) mentioned that adjustment is not related to accomplishing activities of the daily living only. This author asserts that adequate finance is a major factor in determining the patients’ level of successes to adjustment. Many patients with tetraplegia are defaulting treatment, and are experiencing health-related problems because the majority of them have lost their employment after the injury as a result, there is no money to attend treatment.

The respondents with little or no family support at all had trouble in adjusting to their disability at home, as they were facing problems of rejection of different kinds from their families. These respondents were from single parent families. Their mothers were breadwinners and they were employed as domestic workers and earned meager salaries. Respondents' parents were residing at their workplace to save money for transport. Respondents were the ones who were looking after their siblings during the absence of their parents. When respondents sustained the injury, things changed as the mothers were compelled to leave employment to look after the entire families. This created problems for them and they were ridiculed for letting the family suffer by sustaining the injuries. Respondents from this category felt that life after disability was impossible. Their experiences are reported as follows:

*“Sometimes I feel I am nagging because people turn away whenever I call them for help”.*

*“My family didn't want anything to do with me. Relatives were not prepared to take me to their homes, hence the reason I ended up at this horrible place (old age home).”*

*“Ka fa gae bare ke lwaletse sa ruri. Ba re ga ba na chelete ya go nkisa sepetelele kgapetsakgapetsa. Ba re ke morwalo mo go bona ebile ga ba sa thlola ba kgona go dira sepe fa ese go nthlokomela.”*

*“Mama ontheetse are ke bone gore ke tswa jang ka bogole jwa me gonne ene a ka se tlogele tiro ya gagwe ka ntlha ya me.”*



Gill (1999:2) reiterates the abovementioned by stating that when something traumatic happens to one member of the family, the whole family is negatively affected. Parents who have a young adult child suffering from spinal cord injury are forced to re-establish the role of parenting. This author mentioned that they may become bitter and angry about the circumstances and they may feel that their years of parenting are behind them and are therefore looking forward to retiring, or enjoying their grandchildren. Gill (1999:4) also mentioned that parents usually look forward to their children to be there for them when they age, not vice versa.

The other category was of respondents who could not cope with the disability due to the loss of one parent. These respondents depended on the support provided by their brothers, sisters or the fathers. Their mothers had passed away due to ill health. Support from these people was not enough as the fathers had remarried and busy with their newly established families.

The respondents were emotionally disturbed and they saw death as the solution to their problems. They could not face the reality of losing their beloved mothers. They felt that the mother was the key person in one's life and if she is no longer there, life as a disabled person was not worth living. They reported that the fathers were always busy with other things. They spent valuable time with friends drinking beer or focusing on extramarital relationships, or their new families. The following responses emphasize this perception:

*“ My father does not care about me, he either spends time with friends drinking beer or with his girlfriend.”*

*“My mother was the only one who was looking after me since she passed away no one was keen to look after me.”*

*“My sister could not assist as her husband wouldn’t allow her to do so, if she insisted it was going to cause problems for her.”*

*“I wish I was dead because there is no reason for me to live.”*

*“My father said to me he didn’t kill my mother and I felt hurt”.*

*“It is painful not to have a mother because if she was alive I wouldn’t be suffering ”.*

According to Krause *et al.* (1994:646) spinal cord injury imposes multiple stresses, not just on the patient but also on the family. These authors argued that the impact is far reaching as relationships and roles may radically change. Chronic health problems, feeling of frustration, isolation, resentment and guilt are reported to be experienced by family members.

The above clearly demonstrate that family members /caregivers are often neglected by the team and this result in the above mentioned problems because they were not properly empowered to deal with the challenges related to the patients’ conditions. The researcher is of the opinion that if the team thoroughly assessed, some of the above-mentioned problems could have been identified and properly addressed, before the patient could be discharged.

#### 4.3.1.9 Marital Relationship

Respondents explained that since they became disabled, things have changed drastically in their marriages. Some of the problems experienced were lack of respect from their partners, they are impatient towards them, and they expect them to do the things that cannot be done by a person on a wheelchair.

*“ She is disrespectful to me since I became disabled, she talks to me as if I am a child.”*

*“She always grumbles whenever she has to turn me or assist me to eat.”*

*“Her family is always here, we do not have privacy, when they are around she refuses to turn me or check my napkins.”*

*.She told me that she is tired of tolerating the bad smell from my waste”*

The above is supported by Gill (1999:10) who states that when people marry they commit themselves to each other, but as soon as the one partner becomes disabled this commitment is often challenged. The healthy spouse becomes frustrated and considers his/her own needs. This stressful event may lead to divorce.

It could thus be said that the type of marital relationship that existed before the injury will determine the success or failure of the marriage. Aspects such as conflict, disloyalty and lack of trust between couples are likely to influence the marriage negatively and the healthier spouse may not see the need to support the injured spouse.

#### 4.3.1.10 Stigma

Respondents mentioned that when they were discharged from the hospital, adjustment was difficult. Members from the community and neighbours came to visit, not with the intention of giving them support but to confirm their suspicions that they were actually disabled and using wheelchairs. Some pretended to be worried, concerned and even felt sorry for them. Respondents mentioned that this frustrated them because they wanted to be treated like dignified human beings. They did not want people to feel sorry for them and they wanted to be called by their names and not be stigmatised. Respondents mentioned this:

*“They called me a cripple”.*

*“Ga ke thlole ke le motho .Ke bidiwa ka mabitsobitso.”*

*“Ba kgwathakgwathana ka wena fela fa o feta o kare o setshegiswa sa bona.”*

According to the White Paper On Integrated National Disability Strategy (1997:4), people with tetraplegia have been excluded and are discriminated by the society. They are labeled and stigmatized as being dependent and in need of care. The overall impression deduced is that the community in general is not supportive towards people with disability. This might be because of ignorance.

#### 4.3.1.11 Sexuality

The type of marital relationship that existed before the accident contributed towards adjustment to the disability. The respondents who did not experience problems in their marriages reported that their inability to engage in physical sexual activity created problems for themselves because they are suspicious that their partners might be having extra marital relationships.

They become worried and suspicious whenever the partners are being delayed at the shops, attending community affairs such as funerals, social clubs or attending the church. Some of their comments in this regard were:

*“She always takes a long time when she went to the shops, maybe she is seeing someone.”*

*“My wife is not complaining about my condition but I suspect that she might be getting sexual gratification somewhere”.*

The respondents who experienced marital problems prior to the accident reported that the inability to engage in physical sexual act due to loss of movement and penile erection was a problem and made things worse. The partners started to play truancy by not sleeping at home regularly and to give lame excuses for this behaviour. They told them that they could not continue to stay in relationships where their sexual needs were not satisfied.

Respondents mentioned that this was very painful and one could see from their facial expressions that they were hurt. Other respondents mentioned that the partners have deserted them while the others remained in the marriage but continued with this negative behaviour.

The respondents whose partners remain in the marriage but continued flirting with other men mentioned that this was killing them emotionally; they felt helpless, useless and worthless because with their condition, there was nothing that they could do and this was indicated by the following expressions:

*"She said she has found a real man to satisfy her sexual needs, unlike a cripple like myself".*

*"She said to me I am half a man."*

*"She is being brought home by men in fancy cars and I am expected to say nothing".*

*"O ntheetse are ke monna ka gore banna ba thlokwa.Sa me ke go thlola ke goeditse ke sa fetse."*

*"Ke tla reng fa a tsamaya a ntlogela ke lala ke le nosi . Kana fa nka bua ke tla feletsa ke beditswe ka tlelapa."*

*"Kana mosadi fa a ratana o kotsi.Ka re le go go bolaya a ka go bolaya .Nna fa a seyo mo gae ke a itidimalela ga ke batle go bolaiwa."*

The respondents who were not married mentioned that they have problems regarding their changed sexual status. They mentioned that as men they were planning to marry and to start families. This implied that their future was lost as no one would agree to marry someone who could not meet her sexual needs.

They also mentioned that even though they were not planning to marry, being able to perform sexually is nevertheless an important aspect in one's life to satisfy one's sexual needs. These are some of their responses:

*“A man is supposed to proof his manhood by engaging in sexual intercourse”.*

*“If you cannot engage in sexual intercourse women will always dump you.”*

*“No one will agree to marry someone who will not satisfy her sexual needs”.*

*“Ke mang a ka dumelang go ratana le serepa se tshwana le nna .”*

*“Ka re banna ba mmitsa ontse o na le ene go go bontsha gore ga o sepe.Go ne ke nnete gone ga go sepe se nka modirelang sona fa ese go molebelela fela.”*

It is stated by Steven *et al.* (1997:65), that sexuality, through the limitation of movement and sensation has a devastating impact on the sexuality of the couples. Many couples reported to have fear of separation and a high sense of dependency because of the injury. As indicated in the preceding paragraph, the type of marriage that existed prior to the injury will determine whether the healthy spouse will continue to stay and provide care to the injured partner in spite of the frustrations being brought by the disability. However, if there were problems before the injury, then this would be pay back time to the healthy spouse, as he/she will start to look for sexual gratification somewhere else.

#### 4.3.1.12 Quality of life

Respondents reported that their life styles have changed since they became disabled. They reported that their independence and the quality of life they used to enjoy, such as spending time with friends, attending social clubs, going to church, attending sport activities, community activities such as weddings and funerals were all lost and this is emphasised by the following statements:

*“ Since I became disabled I am just like a child, my family always do things for me and I only attend those activities approved by them”.*

*“I am not allowed to attend certain functions because people feel I will embarrass them with my urine bags or making accidents in front of other people”.*

*“I once attended a party with a brother who acted as if I was not there and I ended up messing myself up and was I very frustrated and angry “.*

*“The presence of me and my wheel chair make people not to feel free. That is why I prefer to stay at home and not to disturb anyone.”*

*“Ka dinako dingwe o bona batho ba ntse ba sebaseba fa o ba leba ba dira o kare ntse ba sa bue sepe. Ke ka moo ke itunnang fo gae ke tlogele go sotlwa ke batho ke sa ba dira sepe.”*

The above experiences are reiterated by Hicken, Putzeke and Richards (200:977), who mentioned that patients' dependence on others, individualised bladder and bowel management which maybe time consuming reinforce the patient's avoidance behavior



and decrease his/her likelihood to become involved in social activities and thus impact negatively on his/her overall quality of life.

The researcher is of the opinion that if families/caregivers adhere to proper bowel and bladder procedures the patient with tetraplegia will not have related accidents in front of other people. Proper adherence to the required procedures will indeed improve their quality of life. The community should incorporate patients with tetraplegia in their social activities and encourage them to become involved rather than to judge them. This will boost their morale and increase their quality of life.

#### **4 3.1.13 Isolation**

Respondents were also concerned about the inability to control bowel and urine. Other than causing health problems respondents mentioned that this physical loss forced them to stay behind whenever there are some occasions to attend in fear of having accidents in public and embarrassing themselves. Hence, they became isolated. One of the respondents mentioned this:

*“ I often do not recognize any pressure from urine or faeces, hence I end up having accidents during the presence of other people. I prefer to stay at home and not to attend any event from the public.”*

*“O tla reng fa batho ba go katoga ba dira o kare ga o teng. Ka methla fa go le meletlo ke itshalla ko gae ke tlogele go nna se kgoreletsi sa batho.”*

*“Ka dinako dingwe o tla bona fela batho ba tshwara dinko ke bo ke itse gore ke itshenyeditse.Go botoka fa ke itunetse ko gae ke kgaotse go nna setshego sa batho.”*

It is stated by Hicken *et al* (2001:978), that many patients with bladder and bowel incontinence developed fear of accidents and embarrassment about leaking stoma and dependence on diapers. This eventually led to their social isolation and impaired relationships.

Strict adherence to bowel and bladder schedules by family members and caregivers will prevent the patient with tetraplegia from having accidents in public and thus boost his/her confidence and minimize his/her isolation.

#### **4.3.1.14 The Caregiver**

Some respondents mentioned that their caregivers were impatient, neglected them and hence the ill health they experienced, such as pressure sores.

They mentioned this:

*“You feel you are at the mercy of other people”.*

*“Ba go tlogela fela ba ikele dikarateng ebile ba sa kgathalele gore ojele kgotsa jang.”*

*“Fa o ba bitsa ba a tshaba ba dire o kare ga ba go utlwe.”*

*“O tla bo o sale o ntse foo o kare o setshwantsho go se ope yo o kgathalang.”*

*“ Ba go rata fela tsatsi le o tswang modendeng.Fela fa chelete e fela ba go patlalela.Ka nako e go di pressure sores le tlala di a gakala.*

It is stated by Kreuter, Sullivan, Dallof and Siosteen (1998:254), that society as a whole tends to reject people with physical disability. Thus, many relationships between people with spinal cord injury and caregivers are characterised by intense feelings, resentment, irritability and hostility.

From the researcher's experience of working with spinal cord injured patients caregivers are given little support by the multidisciplinary team. Many hospitals are only relieved if a caregiver is available for their patients. How the caregiver is going to cope is another thing and no one is concerned about it. As a result, caregivers are overwhelmed and tend to displace their frustrations on the patients.

There is a need from the multidisciplinary team to visit both the patients with tetraplegia and their caregivers at home to monitor the situation.

At other times, hospitals depend on the support from local clinics and community resources, which are ill equipped to deal with the problems of patients with tetraplegia. This calls for collaborative effort to ensure that the patients are provided with appropriate care and the caregivers are provided with support.

#### **4.3.1.15 Finance**

Most of the respondents have lost employment since they were injured. They mentioned that they experience health-related problems, such as catheter blockage, which can be fatal because it needs to be regularly changed at the hospital, but due to lack of funds,

they are unable to go on their appointment dates. Respondents mentioned that the inaccessibility of public transport lead them to opt for special transport which is expensive. They end up defaulting treatment and developing complications such as urinary tract infections, blocked catheter and fever.

The other problem they mentioned is the inability to control bowel. They mentioned that they are supposed to maintain good bowel using proper suppositories. Most of the time, they experience constipation because they do not have money to purchase the devices to regulate the bowel. This caused problems of ill health, such as faecal impaction, which needs professional intervention.

The other problem they mentioned is lack of food because there is no money to purchase this. Respondents mentioned that often a day would pass without having something to eat which could result in malnutrition.

*“Ga ke na chelete ke tlatla ka eng chekaong.”*

*“Phenshene e ke e golang ke e nnyane, E fela ka yona nako e ke tswang go e gola. Ya go tla sepetlele ga e thlole e le teng ke mathata fela.”*

*“Ka nako dingwe ke leka go a dima chelete mo bathong gore ke tle chekaong. Fela go nna thata gore ke e busetse ka gore ga ke bereke. Ko bo felong o fithlela o thlobogane le batho o kare ga o battle go ba duela.”*

Gill (1999:39), asserts that adequate finance is the major factor in determining patients' successful adjustment to the disability, but many people with tetraplegia are living in poverty. Gill (1999:40) further stated that patients and their families have to cope with all the stresses of the injury, but at the same time they may also have to live on a reduced or no income at all. In many situations, the earning capacity of patients with tetraplegia will depend for long periods on welfare benefits administered by the Department of Social Security.

This clearly shows that patients with tetraplegia are living under hard conditions because of lack of adequate income. Others are working in sheltered employment, which does not provide them with enough income to meet the economic challenges. There is a need to revise the economic policies to enable persons with tetraplegia to purchase basic physical needs at a reduced price.

#### **4.1.3.16 Employment**

Respondents reported that they have lost their work since they became physically disabled. They experienced work-related problems such as unwillingness from the employers to pay the benefits, such as sick leave and unemployment insurance fund (UIF). Instead of helping or supporting them, they expect them to report to work irrespective of their condition. The employers were also not prepared to re-schedule and place them in positions that will match their physical status. This was one of the aspects that discouraged them from returning to work.

They also mentioned that even if there was an opportunity to retain one's work they felt demotivated by the reality of having to carry catheters and urine bags around and to deal with fecal incontinence, which was an embarrassment. One respondent mentioned this:

*“A urine bag is an embarrassment, especially when using public transport”.*

*“Most of the employers are afraid to employ someone like me. They think that I will complicate and put them in trouble.”*

*“Lekgowa la me le mpusitse fela fa a bona ke sikere catheter. A re ke tsamaya ke yo batla madi a a amogelwang ke digole jaaka nna.”*

*“Makgowa ba gana go re thapa. Ba re bona ba lebeletse profit. Jaanong rona le di wheel chair re tlo ba senyetsa nako.”*

*“Lekgowa laka o ganne go mpusetsa mo tirong ya me. A re a ka se kgone ka motho yo o tshwanetseng go thinya tiro a eya chekaping kgapetsakgapetsa.”*

These statements are supported by the White Paper on Intergrated National Disability Strategy (1997:2), which points out that patients with tetraplegia are excluded from the open labour market due to a variety factors, such as inaccessible public transport, and an inaccessible and unsupportive work environment.

The discriminatory laws of this country towards people with disability lower their morale. The researcher is of the opinion that for them to succeed and regain their independence, people need to change their negative attitudes towards them. Society needs to address their basic needs so that they can feel important and be helped to take part in

the activities of society, such as going to work. This can be done through the creation of programmes, such as training and job opportunities for them.

#### **4.1.3.17 Transport**

Transport was another factor that respondents experienced as problematic. They reported that they are using public transport to go for medical appointments and other related things. They felt discriminated against as most taxi drivers pass them without giving them a ride. They felt they are being discriminated against because of being in a wheel chair.

The other factor mentioned was that taxi drivers are eager to make money. Instead of wasting time to pick up one person with his wheel chair, which was going to consume space, they prefer to pick as many people as possible in order to collect more money.

Respondents reported that as an alternative to sort out their problems, they use special transport, which is expensive, and they end up defaulting treatment. These are some of their responses:

*“They just pass as if you are not existing.”*

*“They are always running after people to collect money.”*

*“They don’t want to waste time on us and the tiresome wheel chairs.”*

*“Fa o bone tshono ya go pegiwa banamedi ka wena ba sonya dinko o kare wa ba nkgela.”*

*“Special transport le yona e batla chelete e ntsi. Ke tla e duela ka eng ke senang ke senang.”*

It is stated by the White Paper On Integrated National Disability Strategy (1997:5), that people with disability are facing problems with regard to public transport because this has been reinforced by society’s negative attitudes, discrimination and exclusion of people with physical disabilities from participating in society’s activities. Hence, transport officials treated them as if they do not exist because this has been the practised norm.

It can thus be said that the love of money has blinded transport officials to forget about ubuntu (cognizance of the other human beings) and to look down at persons with tetraplegia. As already indicated, resources from the environment such as public transport must be made available and accessible to patients with tetraplegia so that they can start to exercise their choices and become active members of society.

#### **4.4 SUMMARY**

In this study, patients with tetraplegia who attended the spinal cord clinic at Dr George Mukhari Hospital between October 2004 to April 2005 were interviewed. The findings of the empirical study indeed revealed that patients with tetraplegia are faced with massive problems once they are discharged from the hospital.





They could not cope at home as they experience multiple problems, such as family rejection and neglect, loss of parents due to death, poverty and ill health due to financial and employment problems.

In the following chapter, the conclusions and recommendations are presented.



## **CHAPTER 5**

### **SUMMARY, CONCLUSIONS, RECCOMENDATIONS AND CONCLUDING STATEMENT**

#### **5.1 INTRODUCTION**

The psychosocial problems encountered by black patients with tetraplegia within their homes, and the guidelines on social work intervention in the spinal unit are described in this chapter. Important information drawn from the literature study and empirical data is also described in this chapter. The summary of the study is outlined first, and is followed by the conclusions drawn from the study. The researcher's recommendations towards an improved social work service delivery in the spinal unit are provided. Finally a concluding statement is made.

#### **5.2 SUMMARY**

The purpose of this study was to explore the psychosocial problems encountered by black patients with tetraplegia within their homes after they had been discharged from the hospital. These objectives were met by means of a thorough literature study on the subject and an empirical study. The objectives of the study were as follows:

- To gain knowledge and explore tetraplegia as a condition. This was met by means of a literature study in chapter two and consulting experts in the field.
- To provide a broad theoretical framework on tetraplegia as a condition and social work intervention regarding patients with tetraplegia. This was met by means of a literature study provided in chapter three.



- To explore the psychosocial problems encountered by patients with tetraplegia. This was met by means of an empirical study described in chapter four.
- To provide recommendations for social work intervention regarding patients with tetraplegia. This objective is achieved in chapter five.

This dissertation consists of five chapters, which are divided as follows:

- ❖ Chapter one- forms the general orientation to the study, and it consists of motivation, problem formulation, purpose and objectives of the study, research methodology and ethical aspects relevant to the study, as well as definition of the key concepts and the organisation of the research report.
- ❖ Chapter two- consists of introduction to tetraplegia as a phenomenon, definition of concepts, causes of spinal cord injuries, management and treatment of spinal cord injuries with emphasis placed on tetraplegia as a condition.
- ❖ Chapter three- consists of the psychosocial problems encountered by patients with tetraplegia and their families, emotional reactions and adjustment towards spinal cord injuries. Theories for social work intervention regarding patients with tetraplegia are provided.
- ❖ Chapter four- consists of the interpretation of the results of the empirical study.
- ❖ Chapter five- consists of summary, conclusion, recommendations and a concluding statement.



### 5.3 CONCLUSION

The following conclusions are drawn from the literature study and the empirical study:

- Spinal cord injury, especially tetraplegia, is an uncommon condition that has an impact on the injured person.
- There are a variety of factors, which could be attributed to the onset of spinal cord injury.
- Tetraplegia could be prevented by provision of protective measures such as immunisation, protection against accidents, gunshots and protection against occupational hazards.
- Patients with tetraplegia need to be provided with information regarding their condition to improve their knowledge and facilitate participation in their daily care.
- This could be done by a dedicated team, which is prepared to involve the patients and their families in the rehabilitation process.
- Tetraplegia is perceived as some sort of punishment and thus triggers a variety of emotional reactions from the patients.
- Tetraplegia imposes multiple stresses not just for the patient but also to family members as they too experience feelings of frustration, isolation guilt and resentment.
- The onset of tetraplegia results in a variety of psychosocial problems encountered by both the patient with tetraplegia and his/her family members which are:



- Negative marital relationships and desertion by the healthy spouses.
- Disturbed family relationships.
- Negative self-esteem and lack of self-confidence due to physical limitations.
- Poor quality of life.
- Stigmatization by the community and discrimination from the public.

Despite the many years after patients have been injured they still believed and hoped that their situation would change and be able to walk and use their hands again.

- Tetraplegia triggers psychological, social and financial problems, therefore social work intervention could ensure that the patients' psychosocial problems are explored and attended to.
- The involvement and intervention of the social worker is important, as it would help the multidisciplinary team to understand the psychosocial problems encountered by patients and their families.
- Provision of a holistic approach through the use of the ecological approach discussed in chapter three emphasises the complementary roles of the person and his environment and the tasks of the multidisciplinary team, is the best method to improve the health and well being of patients with tetraplegia.



## 5.4 RECOMMENDATIONS

The following recommendations are made in the light of the above-mentioned conclusions.

- There is a need for the social worker who is stationed in the spinal unit to identify the psychosocial problems encountered by patients as early as possible so as to address them properly.
- The social worker needs to make team members aware of these problems so that they can understand the patient with tetraplegia and to treat him/her in totality.
- The community and the public at large need to be educated about tetraplegia as a condition so that they are able to understand the person with tetraplegia to be able to give him/her support.
- The use of the ecological model, which is holistic in its approach, should be adopted in order to attend to the psychosocial problems of patients with tetraplegia.
- Since the study cannot be generalised due to the small sample, further research with larger population sample is necessary to enable generalization of the results.
- Since exploratory research aims at developing further hypotheses for further research, the following hypotheses were formulated as a proposal for further studies:



- If the social worker can identify the psychosocial problems of patients with tetraplegia as early as possible and intervene promptly then their health and well-being can be maintained.
- If the multidisciplinary team could be attuned to the psychosocial problems encountered by patients with tetraplegia then they will be provided with comprehensive services.
- If the community can be educated about tetraplegia, stigmatisation and discrimination will be alleviated.

## **5.5 CONCLUDING STATEMENT**

This study showed that patients with tetraplegia encountered a variety of psychological, social and financial problems. Therefore, the social worker stationed in the spinal unit should do routine assessment of all patients both admitted in the hospital and those attending the spinal cord clinic to identify these problems and address them promptly.

As an integral part of the multidisciplinary team, the social worker has to advocate for the psychosocial needs of the patients. The use of a holistic approach will ensure that patients with tetraplegia receive a comprehensive quality service.







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