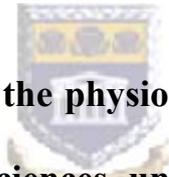


**HEALTH PROMOTION NEEDS OF YOUTH WITH  
PHYSICAL DISABILITIES WITH SPECIFIC REFERENCE TO  
SPINAL CORD INJURY IN THE WESTERN CAPE – SOUTH  
AFRICA.**

**BY**

**EMMAH NJOKI**



**A mini thesis submitted to the physiotherapy department, faculty of community and health sciences, university of Western Cape, in partial fulfilment of the requirements for Master of Science degree in physiotherapy.**

**November 2004**

**Supervisors:**

**Mrs. J Frantz**

**Prof. R MPofu**

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**KEY WORDS**

Health promotion

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Spinal cord injury

Health promoting behaviours

Quality of life

Secondary Conditions

Physical activity

Lifestyle

South Africa



## ABSTRACT

Approximately 500 South Africans mainly youth, sustain a spinal cord injury every year leading to severe lifetime physical disabilities. With advances in medicine and assistive technologies, these youth are able to reach adulthood. Research in other countries indicate that youth with physical disabilities including those with a spinal cord injury are at significant risk for secondary complications, which are related to poor choices of lifestyle. Most of these secondary conditions can be prevented by a choice of health promoting behaviours fostered through health promotion programmes. This study aimed to determine participants' health promotion needs by exploring their health-related behaviours and influencing factors. A qualitative approach that utilised face-to-face and focus group methods of data collection was used. Data were drawn from ten participants, selected through Conradie Spinal Rehabilitation Unit, using purposive sampling. Audiotape recorded interviews were transcribed verbatim. Strong themes that ran through the data were identified.

The results of the study revealed that participants were involved in risky health behaviours including sedentary lifestyles, use of alcohol, tobacco and drugs. Participants identified various factors that influenced their choice of the behaviours that they were involved in, including personal struggles with identity, adjustment issues, psychosocial difficulties that they experienced in the process of adjusting to a new identity, peer influence, intrapersonal, interpersonal and environmental barriers. Social support from family, friends, health care professionals and other people with spinal cord injury, was identified as being a major resource that influenced a choice of positive health-related behaviours.

## Introduction

Participants' perceived needs included access to information about exercises, the dangers of substance usage (alcohol, tobacco and drugs), sexuality issues, employment opportunities, transport issues and support groups. It is recommended that rehabilitation professionals integrate health promotion strategies tailored to specific spinal cord injured individuals' needs, early into their rehabilitation programmes.



**DECLARATION**

I hereby declare that **“Health Promotion needs of Youth with Physical Disabilities with Specific Reference to Spinal Cord Injury in Western Cape-South Africa”**, is my own work, that it has not been submitted for any degree or examination at any other university, and that all the sources used or quoted have been indicated and acknowledged by complete references.

Emmah NJOKI

Signature.....

November 2004

Professor R. MPOFU

Witness.....



Mrs Jose FRANTZ

Witness.....

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**TABLE OF CONTENTS**

TITLE PAGE	i
KEY WORDS	ii
ABSTRACT	iii
DECLARATION	v
ACKNOWLEDGEMENTS	vi
TABLE OF CONTENTS	vii

**CHAPTER ONE: INTRODUCTION**

1.0 INTRODUCTION	1
1.1 BACKGROUND	1
1.2 STATEMENT OF THE PROBLEM	5
1.3 RESEARCH QUESTIONS	6
1.4 AIM OF THE STUDY	6
1.5 SPECIFIC OBJECTIVES	6
1.6 SIGNIFICANCE OF THE STUDY	7
1.7 DEFINITION OF TERMS USED IN THE THESIS	7
1.8 OUTLINE OF CHAPTERS	9



**CHAPTER TWO: LITERATURE REVIEW**

2.0	INTRODUCTION	11
2.1	SPINAL CORD INJURY	11
2.2	IMPACT OF SPINAL CORD INJURY	12
2.3	THE CONCEPT OF HEALTH PROMOTION AND DISABILITY	15
2.4	HEALTH PROMOTION AND PHYSIOTHERAPY	17
2.5	HEALTH PROMOTION NEEDS OF PHYSICALLY DISABLED PERSONS	18
2.6	FACTORS INFLUENCING HEALTH PROMOTING BEHAVIOURS	21
2.7	CONCEPTUAL MODEL OF HEALTH PROMOTION AND DISABILITY	23
2.7.1	Contextual factors	25
2.7.2	Antecedent influences	25
2.7.3	Health promoting behaviours	26
2.7.4	Quality of life	27
2.8	SUMMARY	28



**CHAPTER THREE:        METHODOLOGY**

3.0	INTRODUCTION	30
3.1	RESEARCH SETTING	30
3.2	SELECTION OF SUBJECTS	31
3.3	INCLUSION CRITERIA	32
3.4	STUDY DESIGN	32
3.5	DATA COLLECTION	33
3.5.1	Procedure	34
3.5.2	Face-to-face interview	34
3.5.3	Focus group discussion	36
3.6	DATA VERIFICATION	36
3.6.1	Credibility	36
3.6.2	Transferability	37
3.6.3	Dependability	37
3.6.4	Confirmability	38
3.7	PILOT STUDY	38
3.8	DATA ANALYSIS	38
3.9	ETHICAL CONSIDERATIONS	39
3.10	SUMMARY	40



**CHAPTER FOUR: RESULTS**

4.0	INTRODUCTION	41
4.1	PARTICIPANTS' DEMOGRAPHIC AND DISABILITY-RELATED INFORMATION	42
4.2	HEALTH-RELATED BEHAVIOURS AND INFLUENCING FACTORS	44
4.2.1	PERSONAL INFLUENCES	44
	4.2.1.1 Loss of an independent and able identity	45
	4.2.1.2 Adjusting to a new identity	49
4.2.2	SOCIAL SUPPORT	54
	4.2.2.1 Emotional support	54
	4.2.2.2 Instrumental support	56
	4.2.2.3 Informational support	57
4.2.3	BARRIERS TO POSITIVE HEALTH-RELATED BEHAVIOURS	60
	4.2.3.1 Intrapersonal factors	61
	4.2.3.2 Interpersonal factors	63
	4.2.3.3 Environmental factors	66
4.3	PERCEIVED NEEDS	67
	4.3.1 Health-related needs	67
	4.3.2 Other general needs	70
4.4	SUMMARY	72

**CHAPTER FIVE: DISCUSSION**

5.0	INTRODUCTION	73
5.1	GENERAL FINDINGS RELATED TO DEMOGRAPHIC FACTORS	73
5.2	PARTICIPANTS' HEALTH-RELATED BEHAVIOURS AND INFLUENCING FACTORS	74
5.2.1	Participation in physical activity and influencing factors	74
5.2.2	Substance usage and influencing factors	79
5.3	SOCIAL SUPPORT	83
5.4	PERCEIVED NEEDS	85
5.5	RELEVANCE TO PHYSIOTHERAPISTS AND OTHER REHABILITATION PROFESSIONAL	87



**CHAPTER SIX: SUMMARY, CONCLUSION, AND  
RECOMMENDATIONS**

6.0	INTRODUCTION	89
6.1	SUMMARY	89
6.2	CONCLUSION	90
6.3	RECOMMENDATIONS	91
6.4	LIMITATIONS OF THE STUDY	92
	REFERENCES	94

APPENDICES

Appendix A: Letter to the Deputy Director of the Rehabilitation Unit at Conradie

Hospital

Appendix B: Consent form

Appendix C: Letter of information

Appendix D: Semi-structured interview schedule



## **CHAPTER ONE**

### **INTRODUCTION**

#### **1.0 INTRODUCTION**

This chapter begins with a description of the vulnerability of youth with spinal cord injuries to secondary complications, which could be as a consequence of the direct impact of the physical disability or poor lifestyle habits. The available statistics and the situation of people with disabilities in South Africa including those with a spinal cord injury are highlighted. The significance of the study is explained and the research questions, aim and the objectives of the study stated. The chapter ends with a definition of terms used in the study, and an outline of the chapters.



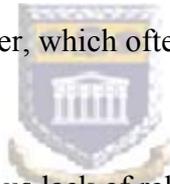
#### **1.1 BACKGROUND**

Spinal cord injury (SCI) usually caused by trauma often results in severe lifetime physical disabilities and occurs most frequently to young people (Wood-Dauphinee, Exner & the SCI Consensus group, 2002; Nesathurai, 2000). Individuals abruptly become seriously disabled, with the extent of paralysis involvement being dependent on the level and completeness of the injury (Hampton & Marshall, 2000; Chase, Cornille & English, 2000; Wood-Dauphinee et al., 2002). Through recent advances in medical science and assistive technologies, these young people are able to survive into adulthood, unlike a few decades ago when death was the norm rather than the exception due to secondary complications after the injury (Nesathurai, 2000; Chase et al., 2000; Hulsebosch, 2002).

The process of transition to adulthood is challenging for all youth, but for youth with physical disabilities the challenges are even more daunting (Blomquist, Brown, Peersen, & Presier, 1998). For instance spinal cord injured youth often face extraordinary problems including, medical complications arising from the direct impact of the disability such as pain, spasticity and infections (Levins, Townson, Mah-Jones, Bremner, & Huston, 2001; Krause, Coker, Charlifue, & Whiteneck, 1999). These secondary medical problems combined with other stressors, for example identity problems, architectural accessibility difficulties and negative societal attitudes, augment the usual problems experienced by youth without disabilities (Blomquist et al., 1998; Whiteneck, Charlifue, Frankel, Fraser, Gardner, Gerhart, Krishnan, Menter, Nuseibeh, Short, & Silver, 1992). The tasks of these youth therefore, when superimposed on the kind of limitations created by physical disabilities, often lead to self-doubt along with difficulties in coping, psychosocial adjustment problems sometimes leading to depression and isolation (Zacijek-Farber, 1998). The latter author further states that, the possible resultant state of self-doubt and sometimes depression or isolation often contributes to inconsistent personal care and severe behavioural and adjustment problems, which may lead to other avoidable secondary complications. Blomquist et al. (1998) thus argue that, in order for youth with disabilities to reap the full benefits of adult life, they not only have to master self-sufficiency and independent living but also have to maintain good health.

Research in countries like Canada, Australia and the USA have shown that youth with physical disabilities including those with a spinal cord injury are at significant risk for secondary complications such as, respiratory problems, heart disease, stroke and emotional

disorders (Hogan, McLellan & Bauman, 2000; DeVivo, Krause & Lammerste, 1999; Steele, Kalnins, Jutai, Stevens, Bortolussi & Biggar, 1996). These secondary complications may present early or become evident later in their lives resulting in deterioration in health status, functional capacity and quality of life (Steele et al., 1996). Moreover, many of these secondary problems are related to poor lifestyle habits including sedentary lifestyles, smoking, alcohol and drug use (Hogan et al., 2000; Messent, Cooke & Long, 1999; Steel et al., 1996), and can be prevented by a habitual lifestyle that involves health-promoting behaviours (Breslow, 1999, Pruitt, Wahlgren, Epping-Jordan, & Ross, 1998). Breslow (1999) points out that the choice of lifestyle of an individual affected by a disability often has an impact on his/her quality of life. A habitual lifestyle that involves health-promoting behaviours certainly enhances an individual's health status while practising health-risk behaviours poses a potential danger, which often results in poor health conditions.



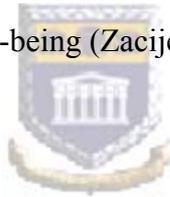
Although South Africa has a serious lack of reliable information on the statistics and nature of disability, the Quadriplegic Association of South Africa (2002-3) estimates that every year approximately 500 South Africans sustain a spinal cord injury as a result of trauma often leading to severe lifetime physical disabilities. Many of these injuries occur in young people aged between 15 and 29 years. Hart and William (1994) have observed that there is a disproportionately high causative incidence of violent injuries, particularly gunshot wounds, among South African spinal cord injured individuals. Bhagwanjee and Stewart (1999) argue that factors such as poverty and the continuing spiral of violence may have contributed to a greater prevalence of disability than has been estimated in South Africa.

## Introduction

The White Paper on Integrated National Disability Strategy (Office of the Deputy President, 1997) notes that despite a high percentage of people with disabilities in South Africa estimated by research to be approximately 12%, few services and opportunities in the areas of employment, education, sport and recreation, exist for them to participate equally in society. People with disabilities are therefore excluded in the mainstream of society and experience difficulty in accessing fundamental rights. In addition, the White Paper identifies youth with disabilities as a particularly vulnerable group of the disabled community, who are less likely to access youth development programs and are as such in need of special attention. However, although there has been a heightened interest in research on health status and other areas of need of able-bodied youth, David and Jansen (1999) and Bhagwanjee and Stewart (1999) point out that there is a paucity of information generally, on the status of people with disabilities in South Africa. According to Bhagwanjee and Stewart (1999), this paucity of reliable information has impacted severely upon the planning and development of services and intervention strategies for people with disabilities, especially youth with disabilities. In this regard, these authors point out that, research should agreeably be targeted at this high-risk group noting that it would be prudent to conceptualise this vexing and complex issue within a health promotion framework.

The present study therefore, aimed to determine health promotion needs through an exploration of health-related behaviours, and factors that serve to influence the selection and use of behaviours of physically disabled youth with spinal cord injury. While there are many health-related behaviours, this study focussed mainly on participation in physical activity and substance usage. Recent studies that have been conducted in other parts of the world, for example Canada and Australia, have shown the aforementioned behaviours to be

some of the major contributing factors for the development of secondary conditions namely respiratory problems, heart disease and urinary tract disorders among adults with a spinal cord injury (Craig, Hancock & Dickson, 1999; Davies & McColl, 2000). The personal and financial consequences of these secondary conditions to the individual, his or her family and the society as a whole are considerable. However, most of them can be significantly delayed or prevented through health promotion interventions especially designed for youth, when they are laying the foundation for their adult lifestyles (Pruitt et al., 1998; Steele et al., 1996). Moreover, the combination of a relatively young age at injury, coupled with the physical and psychological effects of the residual disability, makes health promotion strategies such as physical fitness activities, stress management and elimination of substance usage vitally important to reducing the risk of secondary complications and promoting overall health and well-being (Zacijek-Farber, 1998; Stuifbergen, 1996).



### **1.2 STATEMENT OF THE PROBLEM**

There is a paucity of information on issues surrounding the health promotion needs of physically disabled youth with spinal cord injury in South Africa. It was therefore worthwhile to explore the health promotion needs of this unique sub-population of the society.

### **1.3 RESEARCH QUESTIONS**

1. What are the health-related behaviours of physically disabled youth with spinal cord injury with reference to participation in physical activity and substance usage?
2. What factors serve to influence the selection and use of the health-related behaviours described by physically disabled youth with spinal cord injury?

### **1.4 AIM OF THE STUDY**

The aim of this present study was to determine the health promotion needs, through exploration of the health-related behaviours of physically disabled youth with spinal cord injuries and their influencing factors.



### **1.5 SPECIFIC OBJECTIVES**

- 1.5.1 To explore the health-related behaviours of physically disabled youth with spinal cord injury with reference to participation in physical activity and substance usage.
- 1.5.2 To explore factors that may serve to influence the selection and use of health-related behaviours described by physically disabled youth with spinal cord injury.
- 1.5.3 To identify issues that may need to be targeted in health promotion programmes of physically disabled youth with spinal cord injury.

## 1.6 SIGNIFICANCE OF THE STUDY

Given the paucity of information on the status of people with disabilities in the country, the findings of this study will contribute to the knowledge of health-related behaviours of physically disabled youth with spinal cord injury in South Africa and subsequently their health promotion needs. Through increased knowledge of health promotion needs of physically disabled youth with spinal cord injury, it is envisaged that improvements in health education and disease prevention programmes will improve the quality of life for this unique sub- population. According to Li and Yoshida (1998), physiotherapists are in an ideal position to increase their efforts in health promotion by utilising strategies that promote wellness in addition to their interventions directed at secondary prevention in specific conditions. It is hoped that from this study, intervention programmes addressing specific health promotion needs of physically disabled youth with spinal cord injury will be integrated into their rehabilitation programmes.

## 1.7 DEFINITION OF TERMS USED IN THE THESIS

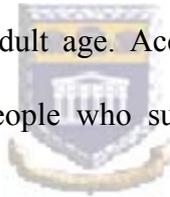
**Health promotion:** Is defined as “activities directed toward increasing the level of well-being and actualising the health potential of individuals, families and communities/societies” (Breslow, 1999). Health promotion stresses the need to enhance each person’s commitment to a healthy lifestyle that can prevent secondary disability and promote quality of life (Stuifbergen, Greg, & Roberts, 1997; Stuifbergen & Rogers 1997).

**Health-promoting behaviours:** Include but are not limited to, participation in physical activity or exercise, maintaining body mass, seeking of social support, stress management and elimination of substance abuse (Fowler, 1997; Stuifbergen & Rogers, 1997).

**Lifestyle:** A person's lifestyle comprises the aggregate of an individual's actions and behaviours of choice which can affect health-related fitness and health status (Bouchard, Shepherd, & Stephens, 1993).

**Quality of life:** The definitions and descriptions of quality of life include both objective (income, living situations and physical functioning) and subjective (individual's perception of important life domains and satisfaction with those domains) indicators of physical and psychological phenomena (Stuifbergen & Rogers, 1997).

**Youth:** The South African Pocket Oxford Dictionary 3<sup>rd</sup> edition, defines youth as the period between childhood and adult age. According to the Quadriplegic Association of South Africa majority of the people who sustain a spinal cord injury are youth aged between 15 and 29 years.



**Spinal cord injury:** Is defined as permanent paralysis, to a greater or lesser extent, as a result of damage to the spinal cord. Depending on the level of injury, the paralysis is described as *tetraplegia (or quadriplegia)* referring to all four extremities (both the arms and legs) affected, and *paraplegia* referring to paralysis in the lower part of the body from approximately the waist down (O'Hare & Hall, 1997; Hampton & Marshall, 2000).

**Disability:** Is any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered typical for a human being (Chase et al., 2000). In the International Classification of Functioning, Disability and Health (ICF) (2001), the term disability serves as an umbrella term for impairments, activity limitations or participation restrictions.

**Physical activity:** Is defined as “bodily movement produced by skeletal muscles that requires energy expenditure” and may bring about physical fitness and health related benefits (Cooper, Quatrano, Axelson, Harlan, Stineman, Franklin, Krause, Bach, Chambers, Chao, & Alexander, 1999).

**Health promotion needs:** These are needs from the perspective of an individual, which are aimed at increasing and maintaining an individual’s participation in activities designed to enhance his/her quality of life status (Stuifbergen, Seraphine & Greg, 2000).

## **1.8 OUTLINE OF CHAPTERS**

In chapter one the background of the current study is described. The vulnerability of youth with spinal cord injuries to secondary complications due to, either the direct impact of the disability or poor lifestyle habits is described. The statistics and the situation of people with disabilities including those with a spinal cord injury are explained. The significance, aim and objectives of the study are presented.

Chapter two presents a review of literature that is pertinent to this study. Some of the issues highlighted include, the impact of the resultant disabilities after a spinal cord injury and the health promotion needs of individuals with physical disabilities including those with spinal cord injuries. The concept of health promotion in relation to disability and physiotherapy are also reviewed.

In chapter three the methodological issues of the present study are highlighted. The research setting, selection of subjects, inclusion criteria and study designs are described. A

description of the pilot study and analysis of data procedure are outlined. The chapter ends with an explanation of the ethical considerations.

In chapter four, the results from the individual and focus group interviews are presented. A description of participants' specific health-related behaviours and the factors that influence the choice and use of the behaviours are presented.

In chapter five the major findings are summarised and discussed with a comparison to previous research in the area. An effort is made to discuss how participants' health promotion needs could be addressed through health promotion interventions. The relevance of the findings to physiotherapist and other rehabilitation professionals is also discussed.



Chapter six summarises the important points of the current study. Recommendations related to the findings are also proposed and the limitations of the study highlighted.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.0 INTRODUCTION**

This chapter reviews literature related to the impact of the resultant disability after a spinal cord injury, the lifestyle patterns and behaviours of individuals with physical disabilities, mainly those with spinal cord injuries. Literature on several health promotion needs and the concept of health promotion in relation to disability and physiotherapy is also reviewed.

#### **2.1 SPINAL CORD INJURY**



Spinal cord injury is a severe traumatic disability that in most cases occurs suddenly mainly affecting young males (Hampton & Marshall, 2000; Morris & Marshall, 1997). There is no cure as yet for a spinal cord injury and the results of the injury are considered permanent (O'Hare & Hall, 1997). Depending on the level and the completeness of the injury to the spine, the resultant disability is described as tetraplegia (also referred to as quadriplegia) or paraplegia (O'Hare & Hall, 1997; Wood-Dauphinee et al., 2002). Tetraplegia/quadriplegia refers to impairment or loss of motor and/or sensory function in the arms, trunk and legs while paraplegia refers to impairment in the lower part of the body with the arm function being fully or partially spared (O'Hare & Hall, 1997; Bromley, 1998; Quadriplegic Association of South Africa, 2002-3.). Some of the most common causes of spinal cord injury are motor vehicle accidents, falls, sports-related injuries, and violence related injuries including gunshot wounds and stab wounds (Hulsebosch, 2002; Quadriplegic Association

of South Africa, 2002-3). In South Africa gunshot injuries have been reported as the leading cause of the injury (Hart & William, 1994).

## **2.2 IMPACT OF SPINAL CORD INJURY**

It is clear that spinal cord injury is a devastating problem that may substantially impact on many facets of an individual's life, including social roles, personal goals and future life expectations (Wood-Dauphinee et al., 2002; Conroy & McKenna, 1999). The resultant morbidity immediately, dramatically, and often permanently changes the survivor's lifestyle and occupation (Morris & Marshall, 1997). Rehabilitation programmes aim to enhance adjustment to life following spinal cord injury by equipping the individual with the skills and resources required for community re-integration (Conroy & McKenna, 1999). However, despite the intensive efforts of rehabilitation through education and functional skills training, people with spinal cord injury experience a range of short-and long-term physical and psychosocial difficulties once they return to the community (Kendall, Ungerer & Dorsett, 2003).

The physical, social and emotional adjustments, which determine the eventual successful outcome following the injury, vary considerably from person to person with some making satisfactory adjustments whereas others remain chronically distressed (Chase et al., 2000). Factors such as architectural barriers, discriminatory society attitudes and unemployment have been identified as some of the distressing physical and social adjustment problems that spinal cord injured individuals encounter once back in the community (Levins, Redenbach & Dyck, 2004; Anderson & Vogel, 2002). In addition, Pruitt et al., (1998) note

that, a variety of factors relating to the experience of spinal cord injury potentially have an effect on an individual's psychological adjustment. Some of the factors reported by individuals with a spinal cord injury include, fear of rejection by partners or peers, poor coping skills and a struggle with self-identity (Craig et al., 1999; Brown, Bell, Maynard, Richardson & Wagner, 1999; Carpenter, 1994; Levins et al., 2004). Sexual dysfunctions following spinal cord injury have also been reported especially by men as being contributing factors to psychological trauma (Sipski, 1997; Brackett, Nash & Lynne, 1996). North (1999) points out that the resultant marked changes in body image after a spinal cord injury may cause significant psychological adjustment problems to some individuals. Depression and anxiety have been described as some of the major psychological reactions to spinal cord injury in several studies. For instance, in a longitudinal study investigating anxiety and depression over the first two years of spinal cord injury, Craig, Hancock and Dickson (1994) found that, about 30% of spinal cord injured persons had significantly raised levels of anxiety, depressive mood and feelings of helplessness in comparison to age, education and sex matched non-disabled controls. Similarly Kennedy and Rogers (2000) found a consistent pattern of high levels of anxiety and depression, longitudinally in a sample of individuals with a spinal cord injury. Many clinicians have viewed anxiety and depression as an inevitable consequence of spinal cord injury, given the dramatic changes that come with the injury (Brown et al., 1999).

The literature concerning the long-term psychological consequences of spinal cord injury indicates that, substance usage (tobacco, alcohol and drugs) and sedentary lifestyles have become an increasing area of concern among individuals with spinal cord injuries (North, 1999; Steele et al., 1997; Heinemann, 1995; Radnitz & Tirch, 1995). For instance some

individuals with spinal cord injury have been found to use drugs such as marijuana as a method of stress management and controlling spasticity (Heinemann, 1991; Malec, Harvey & Cayner, 1982). Heinemann, Keen, Donohue and Schnoll (1988) found that among individuals with a recent spinal cord injury a desire to be sociable was cited by most individuals (61%) as their main reason for drinking. According to Radnitz and Tirch (1995), spinal cord injured individuals face special risk factors for developing a substance usage problem, in addition to those that confront the general population. These include medical and social characteristics and intrapersonal factors unique to individuals with spinal cord injuries. For instance, Kolakowskyhayner, Gourley, Kreutzer, Marwitz, Meade, & Cifu (2002) conducted a study to identify the population at greatest risk of post-injury substance abuse, among young persons with brain injury and those with spinal cord injury. They found significant levels of both alcohol and drug use among spinal cord injured individuals compared to persons with brain injury, particularly those that were troubled by pain. In addition some studies have reported tobacco use rates among spinal cord injured individuals as high as the ones in the general population (Davies & McColl, 2002; Almenoff & Spungen, 1995). Indeed tobacco use has been found to be positively associated with a risk of cardiovascular, respiratory and urinary tract morbidity in the spinal cord injury population (Davies & McColl, 2002).

There is some indication that, youth with physical disabilities, including those with a spinal cord injury that report high levels of psychosocial distress, also spend more time engaging in sedentary activities (Hogan et al., 2000; Steele et al., 1996).

Substance usage, including tobacco smoking, drug and alcohol use and a sedentary lifestyle are major risky health behaviours that form part of an unhealthy lifestyle leading to the development of chronic secondary problems (Steele et al., 1996). Health promotion is strongly associated with personal lifestyles and involves two main processes: Stopping negative or unhealthy behaviours such as smoking, alcohol consumption, or sedentary behaviours and starting positive health-related behaviours such as regular exercise and good dietary practices that promote health (Nahas, 2003). The practice of health-promoting behaviours has been acknowledged as a valuable and important strategy to maintain the independence and quality of life of persons with disabling conditions (Stuifbergen, 1995; Breslow, 1999). However, persons with disabilities including those with a spinal cord injury are rarely included in health promotion research and intervention programmes. Consequently little is known about their health promotion needs and the factors influencing their health-related behaviours (Stuifbergen & Becker, 1994).



### **2.3 THE CONCEPT OF HEALTH PROMOTION AND DISABILITY**

Health promotion is a multidimensional concept that applies to all individuals regardless of age or disability (Fowler, 1997). The definition of health promotion as “activities directed toward increasing the level of wellbeing and actualising the health potential of individuals, families and communities/societies,” is similar to the goal of rehabilitation (Breslow, 1999). The goal of rehabilitation is to assist an individual with a disability to gain independence and functional skills for use in activities of daily living (Kendall et al., 2003; Zacijek-Farber, 1998). Similarly, the concept of health promotion emphasises self-care rather than expert care and promotes an active, independent attitude toward health care (Breslow,

1999; Smith 2000; Stuijbergen & Rogers, 1997). Health promotion strategies therefore should ideally be an integral part of the rehabilitation process (Stuijbergen & Rogers, 1997; Zacijsk-Farber, 1998).

Access to knowledge and resources provides individuals with physical disabilities including those with a spinal cord injury the basis for a choice of health promoting behaviours to sustain and enhance their quality of life (Stuijbergen & Rogers, 1997). However, in developing countries including South Africa, people with disabilities are largely without access to, or knowledge of, the most basic health and social services (Bhagwanjee & Stewart, 1999). Health care professionals interested in providing health promotion services to enhance the rehabilitation of people with physical disabilities find the information specific to health promotion needs critically lacking (Stuijbergen & Rogers, 1997; Rimmer, 1999). This is mainly because researchers have paid significant attention to initial rehabilitation, short-term medical, functional, and psychological outcomes and even to predicting the long-term costs of spinal cord injury. They have devoted considerably less attention to long-term health outcomes of people with physical disabilities through health promotion (Whiteneck et al., 1992). Consequently, people with physical disabilities including those with a spinal cord injury, often face challenges of promoting their health and maintaining their quality of life with little help from rehabilitation professionals (Stuijbergen & Rogers 1997). For instance in a study by Pentland, McColl and Rosenthal (1995), persons with a long-term spinal cord injury reported a lack of information and research available to plan services that are designed to meet their needs.

## 2.4 HEALTH PROMOTION AND PHYSIOTHERAPY

Injuries to the spinal cord usually result in life-long physical disabilities that impact on a person's quality of life (Yen, Chua, & Chan, 1998). Among many people with disability there is a belief that the emphasis in health care has been directed at the primary prevention of disability rather than at prevention or reduction of secondary health conditions (Patrick, 1997). This means that interventions are based on assessment, diagnosis and treatment with specific therapy programmes (White Paper on Integrated National Disability Strategy, 1997). However, with the emergence of the social model of disability, models of analysis are shifting away from a focus on individual pathology and illness, to analyses that seek to identify and eliminate social processes that create disadvantage for people with disabilities (Hogan et al., 2000; Frieg & Hendry, 2001). Instead of focusing on the narrow clinical aspects of the disability, individuals are viewed as fully capable of health and wellbeing within the context of their disability (Stuifbergen & Rogers, 1997). In this emerging paradigm shift from disease and disability prevention to prevention of secondary conditions in people with disabilities, physiotherapists and other rehabilitation professionals can play an important role in the integration of health promotion strategies into their rehabilitation programmes and possibly extend them to the community (Rimmer, 1999; Li & Yoshida, 1998). Moreover, physiotherapists are among the first health care providers to treat spinal cord injured individuals and often spend a long time with them. Physiotherapists therefore commonly establish a trusting relationship with these individuals that lasts long after discharge from the hospital or the rehabilitation setting (Brackett et al., 1999). In addition, Frieg and Hendry (2001) noted that in view of primary health care delivery in South Africa,

it is the role of the physiotherapist to deliver community based rehabilitation services to persons with disabilities. In this regard, as Noreau, Dion, Vachon, Gervais, & Laramee (1999) argue, physiotherapists should extend traditional rehabilitation programmes from the walls of the rehabilitation unit and develop new approaches to facilitate and encourage a choice of health promoting behaviours among young people with spinal cord injuries so as to prevent secondary problems. Delay or prevention of secondary problems through the practice of health promoting behaviours, not only results in maintained quality of life but also may significantly reduce overall health care costs for the spinal cord injury population and the society as a whole (Pruitt et al., 1998).

## **2.5 HEALTH PROMOTION NEEDS OF PHYSICALLY DISABLED PERSONS**



A number of health promotion needs of people with physical disabilities including those with a spinal cord injury have been identified in several studies. For instance, in a recent study of health promotion needs assessments of young people with disabilities including those with physical disabilities in Canada, Hogan et al. (2000) using a cross-sectional descriptive design, found a high level of substance usage and involvement in sedentary activities among these young people. These authors concluded that community-based health promotion interventions are required to address the health promotion needs of physically disabled young people in order to prevent the onset of secondary disease processes. In another study of 86 long-term spinal cord-injured persons in America, Heinemann, Doll, Armstrong, Schnoll and Yarknoy (1991) found that 69% of subjects used alcohol or drugs prior to injury and increased the consumption post injury. In the same study 16% of the subjects reported needing treatment for alcohol or drug abuse, but only

7% actually received substance abuse therapy. These authors felt that staff in rehabilitation programmes may have obstacles in dealing with substance-abusing persons, such as limited training and uncertainties as to how to intervene and recommended staff education on this subject.

According to Hubbard, Smith, and Mohammad (1996), the degree of an individual's substance use (alcohol, drugs and tobacco) not only plays a role in the development of secondary/additional disabilities, but it may also prove important in the physically disabled individual's quality and speed of rehabilitation. As is suggested by Heinemann et al. (1991) substance abuse may also delay the emotional healing that is necessary following a disabling condition like a spinal cord injury. Health promotion interventions in areas such as substance abuse are therefore vital among individuals with physical disabilities including those with a spinal cord injury.



Other studies have identified health promotion needs in areas such as physical activity. For instance, Steele et al. (1996) reviewed the health promotion needs of young people with disabilities, as part of a Canadian study (n=104). School attending young people with congenital and physical disabilities, were identified as being more sedentary engaging in less exercise, while reporting higher rates of psychosomatic symptoms than their able-bodied peers. The authors concluded that, Canadian young people with disabilities were at significant risk for secondary disabilities and recommended that health promotion strategies for youth with physical disabilities be fostered early in their lives. Another study by Edwards (1996), sought to determine both the health care actually received by adolescents and young adults with a spinal cord injury and the services they desired but did not obtain.

His findings suggested that the general health promotion needs of these individuals were the same as for the general population and, although disability related topics were discussed with the health care providers, information on health promotion was not received. In the same study, some of the respondents (43%) identified planning an exercise programme and referral to a fitness centre (26%) as their main health promotion needs.

Physical activity is widely recognised as an important behavioural characteristic for health promotion and disease prevention (Nahas et al., 2003; Pate, Pratt & Blair, 1995; Bouchard et al., 1993). The benefits of physical activity for individuals with disabilities have been reported in a number of studies. Some of the principal benefits reported include, increased health-related fitness, movement skills, independent functioning, prevention of obesity and other chronic illnesses (Kosma et al., 2003; Noreau & Shephard, 1995). Physical activity has also been shown to improve endurance capacity and muscular strength in individuals with a spinal cord injury (Dallmeijer, Hopman, Van As & Van der Woude, 1996). With regard to the less tangible psychological and social benefits of physical activity for people with disabilities including those with spinal cord injuries, decreased anxiety, depression and increased positive mood, self-esteem and self-confidence have been reported (Kosma et al., 2003; Noreau & Shephard, 1995). In a study involving individuals with spinal cord injuries, Taylor and McGruder (1996) described physical activity in the form of sea kayaking as assisting in the construction of a positive new identity, noting that through the new achievement of kayaking, these individuals were able to redefine themselves in terms of their self-perceptions and their abilities. Gurney, Robergs, Aisenbrey, Cordova and McClanahan (1998) argues that, maintaining high levels of fitness may be more important for spinal cord injured individuals who, by nature of their disability and environmental

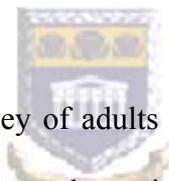
barriers, are profoundly sedentary and prematurely develop different medical conditions that are often associated with a lack of exercise. According to Dearwater, LaPorte, Cauley and Brenes (1979) and Hjeltnes and Vokac (1979), ordinary manual wheelchair propulsion and performance of the activities of daily living, in general, are insufficient to maintain physical fitness since it has been shown that activity count and circulatory strain for persons with spinal cord injury are low compared to able-bodied individuals. These authors argue that, additional aerobic exercise, several times each week may be needed if persons with spinal cord injury are to reach and maintain the level of physical fitness that is desirable for their health and function.

In summary, although the negative effects of substance abuse and the benefits of physical activity are well documented, the few studies available indicate that, youth with physical disabilities including those with a spinal cord injury are at risk for the development of secondary disabilities as a result of poor choice of lifestyle health behaviours and other influencing factors. In order to be able to plan suitable health promotion programmes for physically disabled individuals including those with a spinal cord injury, it is important for health professionals to understand the factors influencing a choice of health promoting behaviours from these individual's perspective.

## **2.6 FACTORS INFLUENCING HEALTH PROMOTING BEHAVIOURS**

Although some studies have examined factors that may influence one or more components of health-promoting behaviour among specific subgroups of people with chronic disabling conditions (Stuifbergen & Becker, 1994; Stuifbergen, 1995; Stuifbergen et al., 2000), few

studies have looked at the factors influencing a choice of health-promoting behaviours among people with physical disabilities particularly those with a spinal cord injury. Consequently little is known about factors influencing their health-promoting behaviours. The studies available have identified several factors that influence a choice of various health promoting behaviours of people with chronic disabling conditions and/or physical disabilities. For instance, Stuifbergen et al. (2000), in a quantitative study using an explanatory model of health promotion and quality of life in chronic disabling conditions, found that severity of illness or disability had direct effects on barriers to health-promoting behaviours, and indirect effects on self-efficacy and acceptance of illness. According to these authors, realistic acceptance of illness or disability was proposed as a direct positive influence on health-promoting behaviours.



In a national cross-sectional survey of adults with physical disabilities, Kosma, Cardinal, and McCubbin (2003) used the transtheoretical model to determine the most influential factors in physical activity for adults with physical disabilities. The results indicated that behavioural processes of change, self-efficacy, and decisional balance were very important to physical activity participation.

Other factors beyond the personal level have also been identified as influencing factors for health-promoting behaviours. In a qualitative study to clarify an explanatory model of health-promoting behaviours and quality of life in individuals with chronic disabling conditions, individuals with multiple sclerosis identified social support as an important resource for a choice or use of health-promoting behaviours (Stuifbergen & Rogers, 1997). Weinert (1983) in his study of 149 families, in which one spouse had multiple sclerosis also

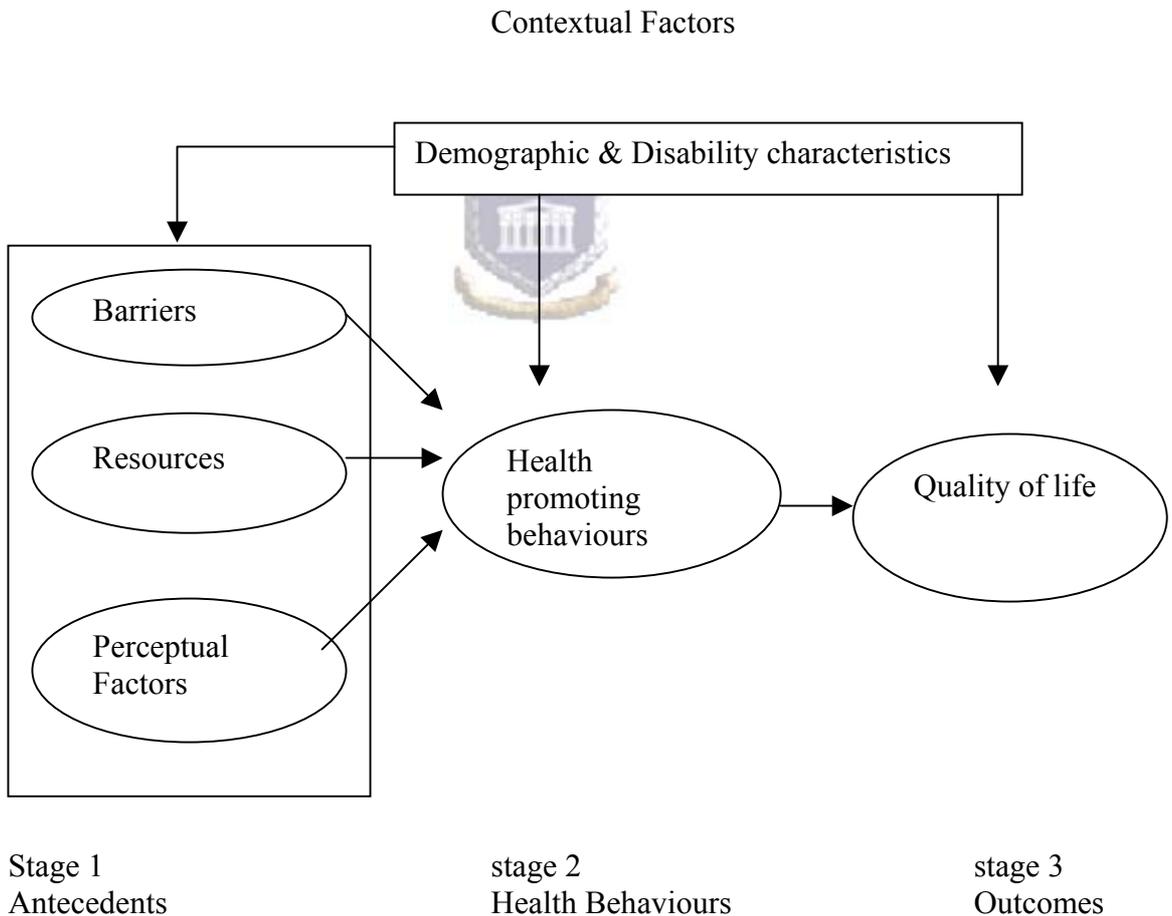
found that, social support had a consistent and positive impact on participation in health-promoting behaviours. Barriers, which may arise from people's internal cognitions, from significant others and from the environment, have also been found to influence the choice of a particular health promotion option for example exercises (Stuifbergen, 1995). Some of the barriers identified include, fatigue, lack of money, lack of motivation, effects of the disability and transportation (Zemper, Tate, Roller, Forchheimer, Chiodo, & Nelson, 2003; Taylor et al., 1999; Stuifbergen & Rogers, 1997).

## **2.7 CONCEPTUAL MODEL OF HEALTH PROMOTION AND DISABILITY.**

The general conceptual model used in this study represents a synthesis of findings from the review of the literature (Stuifbergen, 1995; Stuifbergen & Rogers, 1997). Stuifbergen (1995) proposed a three-staged model comprising of factors (contextual and antecedents) that influence health-promoting behaviours and thus quality of life. Contextual factors which include demographic characteristics (e.g., age, gender, employment status) and disability-related characteristics (e.g. level of injury to the spinal cord and duration of the resultant disability) are believed to have a potential influence at each stage of the model. These factors are visually represented as influences on antecedents, mediating health behaviours, and quality of life outcomes. The model proposed three antecedent factors that influence health-promoting behaviours, namely the concepts of barriers, resources, and perceptual factors. According to Stuifbergen (1995), the antecedent factors influence health promoting behaviours and consequently the outcome of quality of life. The Stuifbergen (1995) model does not indicate the relationship between demographic and individual disability-related characteristics with other antecedent factors, such as resources, barriers and perceptual factors.

Figure 2.1: below illustrates the three-stage conceptual model of health promotion and quality of life for people with life-long physical disabling conditions: Adapted from Stuijbergen and Rogers (1997). The model specified the influence of demographic and disability-related characteristics on specified antecedent factors and the direction of the predicted relationship between these factors and health-promoting behaviours, all of which influence the outcome of quality of life (Stuijbergen & Rogers, 1997).

FIG 2.1



### **2.7.1 Contextual factors**

Contextual factors include individual and disability-related characteristics that may directly or indirectly influence, health-promoting behaviours and quality of life (Stuifbergen & Rogers, 1997). For instance, traumatic spinal cord injury often causes severe physical disabilities, with the degree of functional impairment being dependent on the level and completeness of the injury, leading to either tetraplegia or paraplegia (Wood-Dauphinee et al., 2002). The Majority of the spinal cord injuries occur mainly in young people, predominantly men, most with active lives still before them (Quadriplegic Association of South Africa, 2000-3). The residual disability accompanying spinal cord injury, often leads to changes in the usual patterns of daily living, psychosocial adjustment difficulties and in some cases, low self esteem or depression (Wood-Dauphinee et al., 2002). Age at the time of injury, extent of functional impairment and injury level have been shown to be associated with adjustment to spinal cord injury and consequently health-related behaviours (Davies & McColl 2002; North, 1999).

### **2.7.2 Antecedent influences**

Antecedent factors include the barriers, resources and perceptual factors that influence an individual's choice of health promoting behaviours (Stuifbergen & Rogers, 1997). Barriers, defined as perceptions regarding the unavailability, inconvenience, or difficulties of a particular health-promoting option have been related to a lack of participation in exercise programs, poor skin care as well as adaptation to behaviours such as alcohol and tobacco use (Stuifbergen & Rogers, 1997; Stuifbergen et al., 2000).

A variety of resources, including income and social support are related to the selection and use of health-promoting behaviours and health outcomes (Stuifbergen & Rogers, 1997). Social support is frequently described as having an important positive effect on psychological distress following stressful life events such as spinal cord injury (North, 1999). For instance, a recent study by Hampton (2001) found social support to be the most influential factor on quality of life of young Chinese adults with spinal cord injury. Tangible resources, for example the possession of a wheelchair, have been related to outcomes of health behaviours including functional disability, good adjustment, participation in physical activity, and good quality of life (Schoppen, Boonstra, Groothoff, De Vries, Goeken, & Eisma, 2001). Perceptual factors, including specific self-efficacy for health practices and perceived demands of disability, have been reported to influence the likelihood of engaging in health promotion behaviours (Stuifbergen & Rogers 1997).



### **2.7.3 Health promoting behaviours**

Health-promoting behaviours (stage 2 of the model) include, engaging in ongoing behavioural, cognitive and emotional activities, to promote health and wellbeing (Stuifbergen, 1995). These include participation in physical activity, good eating practices, seeking of social support, elimination of substance abuse and stress management (Fowler, 1997, Stuifbergen & Rogers, 1997).

For both the general population and people with disabilities, engagement in health-promoting behaviours is fundamental. This entails participation in activities designed to enhance the quality of life and well-being while refraining from risk lifestyle behaviours,

which often result in a deterioration of health (Steele et al., 1996; Fowler, 1997; Hogan et al., 2000). Steele et al. (1996) points out that although risk lifestyle behaviours are detrimental to the health of all individuals, when combined with the already compromised health and medication regimens of persons with physical disabilities, they might pose an even greater risk to health. Some studies have shown that people with disabilities desire and choose health-promoting behaviours (Stuifbergen & Rogers, 1997). For instance adolescents and young adults with spinal cord injuries identified planning an exercise programme and referral to fitness centres as their main health promotion needs in a study by Edwards (1996).

#### **2.7.4 Quality of life outcomes**

Quality of life is the proposed outcome of the previously discussed model. Quality of life is becoming an important issue for the growing numbers of individuals who need to adapt to severe and chronic disablement, such as spinal cord injured individuals (Wheeler, Krausher, Cumming, Jung, Steadward & Cumming, 1996). One common approach to determining quality of life, especially among people with disabilities, is to measure functional status (Stuifbergen & Rogers, 1997). By doing this, assessments rely on the assumption that a decrease in functional status corresponds to a decrease in the quality of life (Tate, Kalpakjian & Forchheimer, 2002; Stuifbergen & Rogers, 1997). However Tate et al. (2002) points out that these measures do not consider the significance attributed to exact domains of life. He argues that there may be approximately similar physical functioning among individuals with a spinal cord injury, but with great variations in quality of life depending on various changes in life circumstances. Tate et al. (2002) thus, recommend subjective

evaluation to individuals' quality of life noting that they represent individuals' perceptions of important life domains, commonly referred to as subjective quality of life or subjective well-being and satisfaction with the domains they judge as critical to their quality of life.

Studies conducted with other groups of people with chronic disabling conditions for example multiple sclerosis, have identified linkages between quality of life and fatigue, self-help, self-esteem and perceived support (Stuifbergen, 1990). Stuifbergen and Rogers (1997) thus point out that, people living with a chronic disabling condition must manage a wide variety of disease-related, intrapersonal, and environmental demands to maintain their quality of life. Engaging in health-promoting behaviours is one recommended strategy for managing disease symptoms and enhancing quality of life.



As Tate et al. (2002) put it, there is a growing consensus that quality of life is a fundamental issue for persons with spinal cord injury. Indeed, because the life expectancy for persons with spinal cord injury has increased substantially over the last few decades, quality of life issues have become essential

## **2.8 SUMMARY**

This chapter has attempted to review the literature with regard to research relevant to this study. Most of the literature reviewed focussed on international studies owing to limited research on the subject in South Africa. The literature reviewed highlight important issues that need to be focussed on, in relation to health promotion for individuals with physical disabilities especially those with spinal cord injuries. In this chapter, the conceptual model

## Literature Review

of health promotion reviewed, illustrates the interplay among contextual factors, antecedent influences, health promoting behaviours and the subsequent outcome of quality of life. The literature provided the theoretical and scientific basis for the study. On the basis of this foundation, chapter three shall discuss the methodology utilised in the study.



## CHAPTER THREE

### METHODOLOGY

#### 3.0 INTRODUCTION

This chapter outlines the methodology used in the study, in which a qualitative approach utilising face-to-face and focus group methods of data collection was used. The research setting, selection of subjects, the inclusion criteria and study designs are described. A description of the pilot study, data collection methods and data analysis procedure is outlined. The chapter ends with an explanation of the ethical considerations.

#### 3.1 RESEARCH SETTING



Study participants were recruited through Conradie Hospital Spinal Rehabilitation Unit<sup>1</sup>. Conradie Hospital is a secondary level government health institution located in Pinelands-Cape Town, and is the biggest spinal rehabilitation unit in South Africa. The spinal rehabilitation unit serves the whole of the Western Cape region and patients are referred from other hospitals mainly within the Western Cape after acute-phase management has been completed and they are ready for intensive, comprehensive rehabilitation. Occasionally referrals are received from other neighbouring provinces like the Northern Province or the Eastern Cape. The unit has approximately 160 beds. A multidisciplinary team comprising physiotherapists, occupational therapists, nurses, social worker, dietician and doctors provide individualised rehabilitation programmes for each client. The average

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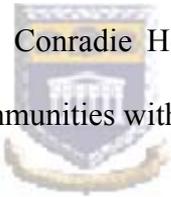
<sup>1</sup> Conradie Hospital Spinal Rehabilitation Unit's name and location, changed from the month of October 2004, to Western Cape Rehabilitation Centre (the Amalgamated Conradie-& Karl Bremer Rehabilitation Units) now located in Mitchells Plain.

length of stay during rehabilitation for individuals with a spinal cord injury ranges from three to six months, depending on the level and severity of the injury. During the rehabilitation period individuals are allowed to go home over the weekends so as to familiarise themselves with the home environment in preparation for discharge. Once they complete their rehabilitation programmes, they are discharged back to either their homes or institutions like Cheshire homes or special schools. The communities (home, Cheshire home, special school) within the Western Cape Province, to which these youth were discharged, were the ultimate setting for this study.

### **3.2 SELECTION OF SUBJECTS**

Purposive sampling of participants was used to achieve a diversity of the sample and maximum information about the phenomena. According to De Vos (2001), purposive sampling is based on the judgement of the researcher, in that a sample is composed of elements that contain the most characteristic, representative or typical attributes of the population. Ten participants who fitted the inclusion criteria were selected through the hospital's medical records department. Where a phone number was indicated in the records, these individuals were contacted by phone and for those who had no phone addresses, they were personally visited in their homes or school for an explanation of the study details. Those youth who agreed to participate in the study were recruited. The sample contained 8 males and 2 females. Out of the 10 participants, 8 were again purposively selected for a focus group interview. It was the initial plan of the researcher to have six participants in the focus group although 8 participants had been contacted to cater for any that would have failed to arrive. However all of those selected arrived for the focus group discussion.

### **3.3 INCLUSION CRITERIA**

Because the study was exploratory, inclusion criteria were broad. According to the Quadriplegic Association of South Africa (2000-3), most of the people who sustain a spinal cord injury are aged between 15 and 29 years. Using this guideline for age, inclusion criteria required that participants be youth aged between 15 and 29 years, English speaking and be physically disabled with a traumatic spinal cord injury not less than six months post injury. The length of time after the injury was selected to avoid individuals in the crisis stage that follows the injury and also so as to have participants who had completed their inpatient rehabilitation, since the study focus was on health promotion and coping in the long-term. Participants thus had to be youth who had completed their inpatient rehabilitation programmes in the  Conradie Hospital Spinal Rehabilitation Unit and had been discharged back into the communities within the Western Cape Province.

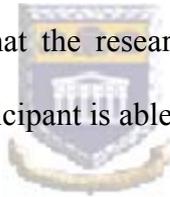
### **3.4 STUDY DESIGN**

This was a descriptive and exploratory study that utilised a qualitative approach. One of the major distinguishing characteristics of qualitative research is the fact that the researcher attempts to understand people in terms of their own definition of their world (De Vos, 2002). According to Rubin and Rubin (1995), qualitative approach allows the researcher to share the world of others, to find out what is going on and understand why people behave the way they do. It is a useful method to identify themes related to health behaviours. For these reasons, a qualitative approach considered ideal for this study was utilised in order to present the participants true perspective of their health promotion needs. This was provided

by a valid reflection of the participants' health-related behaviours that they were involved in and the factors that influence the choice and use of these behaviours.

### **3.5 DATA COLLECTION**

Using a semi-structured interview schedule (**Appendix D**) informed by existing literature on the subject, face-to-face interviews were conducted with ten individuals to obtain in-depth descriptions of the participants' health-related behaviours, and the reasons for their engagement in certain behaviours. De Vos (2002) describes semi-structured face-to-face interviews as purposeful conversations that help researchers to gain a detailed picture of participant's perceptions or accounts of, a particular topic. He adds that, these types of interviews allow flexibility in that the researcher is able to probe particular interesting avenues that emerge, and the participant is able to give a fuller picture.



A focus group interview was carried out on completion of the face-to-face interviews. Focus groups create a process of sharing and comparing among the participants (De Vos, 2002). According to Krueger and Casey (2002), the researcher creates a permissive, non-threatening environment in the focus group that encourages participants to share perceptions, points of view, experiences, wishes and concerns without pressure to reach a consensus. Focus groups have several advantages including; eliciting candid and frank discussions by fostering an open atmosphere: encouraging spontaneous discussion about defined topics; and revealing culture-specific values and beliefs about health behaviours (Krueger & Casey, 2002; De Vos, 2002). In addition, De Vos (2002) points out that, people are more likely to self-disclose or share experiences and feelings in the presence of people

whom they perceive to be like them in some way. For these reasons, a focus group as a choice of method was utilised to create a dialogue for ideas and points of view that might not have been elicited through individual interviews. The combination of these methods was used to offer a complimentary effect.

The use of multiple methods is called triangulation. De Vos (2002) indicated that in triangulation, multiple methods of data collection are used with a view to increasing reliability of the study findings.

### **3.5.1 Procedure**

Fieldwork began by training a research assistant who was also the moderator for the focus group discussion. The training was aimed at making her understand the research topic, her role in the study and the aim and ethical principles of the study.

### **3.5.2 Face-to-face interviews**

During initial contact, the researcher explained the details of the study to potential participants and if they agreed to participate in the study an appointment for an interview at mutually acceptable times and locations (home, school, Cheshire home) was made. Participants were asked to agree to a one-hour audiotape interview. At the first interview informed consent was obtained and for the participants who were under 18 years of age their parents signed the consent forms. During the interviews, participants were informed that they were not going to be judged and that there were no right or wrong answers to the

questions. They were encouraged to talk openly about how they managed their health within the context of their disability, health-related behaviours that they engaged in and factors that influence the selection and use of these behaviours.

The interview was a guided, purposeful conversation, which began with a ‘grand tour’ question to introduce the general topic of the interview while still allowing each participant to talk about the topic in his or her own way (Stuifbergen & Rogers, 1997). According to Stuifbergen and Rogers (1997), the ‘grand tour’ question is a descriptive question with repeated phrases, expanding on the basic question that typically asks for a description of how things usually are. It helps in setting the tone of the interview and lets participants determine what is most important for them to tell about living with a lifetime disability. Consequently the grand tour question for this study was, “*Tell me what it’s like for you to live with a spinal cord injury; how does spinal cord injury affect your life?*” The rest of the interview guide consisted of a series of open-ended, broad and non-directive questions with probes that aimed at eliciting in-depth descriptions of the health-related behaviours and the reasons for involvement in the various behaviours. Non-directive open-ended questions require a detailed answer rather than a specific piece of information or a simple ‘yes’ or ‘no’ (Hammell, Carpenter & Dyck, 2002). On some occasions only a few questions were sufficient to produce a wealth of information and insights. Ten interviews were conducted with each interview lasting about 45 minutes to one hour. All were audio-recorded to ensure accuracy in data collection.

### **3.5.3 Focus group discussion**

The focus group discussion took place after the completion of the face-to-face interviews. The group comprised of 8 participants, the researcher and the moderator. The focus group discussion was conducted for about two and a half hours in a convenient, comfortable place and the discussion was audio-recorded to ensure accuracy in data collection. According to De Vos (2002), one distinctive feature of a focus group is the technique of open-ended questions. The questioning route is a sequence of questions in complete, conversational sentences, for example the first question for the focus group discussion was “when you hear of healthy living, what comes to mind?”

## **3.6 DATA VERIFICATION**



To increase the trustworthiness of the study findings, the criteria of credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985) were met through the use of several strategies.

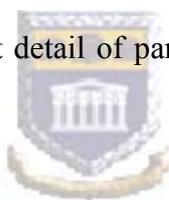
### **3.6.1 Credibility**

To ensure credibility, the chosen methods and procedures for identifying participants were described. Approximately two weeks after the interviews were completed, transcribed data were presented to a sample of five participants to validate emergent categories and themes and confirm the accuracy of the interview transcripts (member checking). Participants confirmed the accuracy of their transcripts and the interpretation of their comments.

Transcribed data from the interviews were also peer reviewed by the researcher's supervisor. According to Lincoln and Guba (1985), The credibility of an account is determined by the accuracy with which it reflects the lived experience of an individual. In this study, participants gave a description of the health-related behaviours they were involved in, within the context of their disability and factors influencing the choice of their different behaviours.

### **3.6.2 Transferability**

This study utilised multiple methods of data collection (face-to-face and focus group interviews), which strengthens the study's usefulness for other settings. In addition the results section provides sufficient detail of participants' verbatim quotations to permit the reader to assess transferability.



### **3.6.3 Dependability**

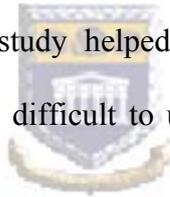
Dependability is analogous to reliability (De Vos, 2000). The enthusiasm from participants to participate in the study, the very vocal, emphatic, informative responses during the individual and focus group interviews, support the honesty of the responses. The telephone calls or personal visits to the participants prior to the interviews provided an opportunity to inform the respondents about the purpose and content of the research without giving details of the questions. This gave them the opportunity to think about their views and experiences but did not allow for detailed, prepared answers.

### **3.6.4 Confirmability**

This is the corresponding concept to objectivity (De Vos, 2002). The process of data collection and analysis are described so that the reader can follow the research trail. Findings and conclusions can be justified in relation to the material.

### **3.7 PILOT STUDY**

The interview questions were pre-tested on three physically disabled youth with spinal cord injury who were not included in the study but had the same characteristics as those in the main study. The aim of the pilot study was to assess the clarity of the questions contained in the interview guide. The pilot study helped refine the interview guide by rephrasing questions that respondents found difficult to understand. The order of the questions was also slightly modified.



### **3.8 DATA ANALYSIS**

The analysis of the data began with transcription of the interviews. All audiotaped data were transcribed verbatim. Transcriptions were compared to audiotape recordings to verify accuracy. Each transcript was carefully read through and scrutinised. After reading the transcriptions of interviews several times, analysis of the interview data began with content analysis. According to Patton (2002), content analysis usually refers to analysing text for example interview transcripts, through data reduction and sense-making effort that involves

taking a volume of qualitative material and attempting to identify core consistencies and meanings. Data were coded into broad categories as dictated by the research questions, for example, “what factors have served to influence participants’ involvement in certain health-related behaviours?” During the initial category coding, the researcher identified and coded major themes in each interview. Emerging themes were written in the margins of each interview transcription. All the themes were listed and then grouped into categories. The second stage of analysis involved identifying information units (Rees & Bath, 2001). According to Rees and Bath (2001) an information unit is any smallest amount of information that is informative by itself. Information units were categorised into themes related to health-related behaviours with specific reference to physical activity and substance usage, reasons for engaging in various behaviours and factors that influence involvement in the behaviours described. Four general themes were established and compared to literature-based concepts. The four themes that emerged from the cyclic and reflective data analysis process are presented in the results chapter.

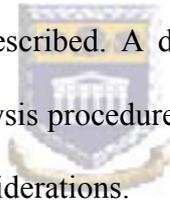
### **3.9 ETHICAL CONSIDERATIONS**

The researcher obtained permission from the Faculty’s Higher Degrees Committee. Further permission was obtained from the Deputy Director of the Rehabilitation Unit at Conradie Hospital (**Appendix A**). In addition, written and informed consent was requested from the participants partaking in the study (**Appendix B**). Along with the consent form, a letter explaining the details of the study was presented to the participants (**Appendix C**). In the letter, the aim of the study was included, and it was explained that, participation was entirely voluntary and that participants had the option of withdrawing from the study at any

time if they so wished. Participants were assured of confidentiality and anonymity throughout the study. During the research process, the research assistant and the moderator were introduced to the participants prior to the commencement of the face-to-face interviews and the focus group discussion. The results of the study will be made available to the Deputy Director, Conradie hospital on request and all other stakeholders.

### **3.10 SUMMARY**

This chapter has outlined the methodology used in the study, in which a qualitative approach utilising face-to-face and focus group methods of data collection was used. The research setting, selection of subjects, the inclusion criteria and study designs are described. A description of the pilot study, data collection methods and data analysis procedure is outlined. The chapter ends with an explanation of the ethical considerations.



## CHAPTER FOUR

### RESULTS

#### 4.0 INTRODUCTION

The purpose of this chapter is to present the findings that emanated from the study using a narrative report writing style and more specifically to report the outcome of the process of data analysis. The demographic profile of the participants including age, gender, education level and disability-related data are outlined. A description of participants' specific health-related behaviours and the factors that influence the choice and use of these behaviours are presented concurrently. Participants' views are presented through the use of descriptive statements illustrated by selected verbatim quotations from the transcripts of the interviews to emphasise the themes highlighted. The quotations from the individual and focus group interviews are presented together in a complementary manner. In presenting the quotes, the precise language and phrases as were used by youth with spinal cord injury were preserved. However, the order of the narratives was sometimes slightly altered to aid the flow of ideas and avoid unnecessary repetitions. Pseudonyms are used throughout the chapter to protect the anonymity and confidentiality of the participants.

#### **4.1 PARTICIPANTS' DEMOGRAPHIC AND DISABILITY-RELATED INFORMATION**

The sample consisted of 10 physically disabled youth with spinal cord injury residing within the Western Cape Province. Participants ranged in age from 15 to 21 years, with a mean age of 16.5 years. There were eight male and two female participants. The causes of the injuries in the study sample included gunshot wounds (n=5), diving accidents (n=2), a rugby injury (n=1), fall from a tree (n=1) and a car accident (n=1). Paraplegia was the resulting disability for 6 youth and quadriplegia for 4 youth. The time since injury ranged from one year prior to the study to twelve years. Eight out of the ten participants had resumed school after the injury, of which seven were in special schools and one was in a mainstream school. Out of the two participants who had not resumed school, one was staying at home with his father and the other one in a Cheshire home, which is a residential institution for people with disabilities.

**Table 4.1 Demographic profiles of the participants (n=10)**

Participant Name (a)	Age	Gender	Type of resultant disability	Cause of injury	Years post injury	Level of education
Sophie	15 years	Female	Paraplegia	Gunshot wound	2	Grade 8
Edwin	20 years	Male	Tetraplegia	Diving accident	5	Matric
Gideon	19 years	Male	Tetraplegia	Diving accident	1	Matric
Nathan	21 years	Male	Tetraplegia	Rugby injury	1	Matric
Leonard	19 years	Male	Paraplegia	Fall from a tree	4	Matric
Vincent	17 years	Male	Paraplegia	Gunshot	8	Grade 10
Peter	15 years	Male	Paraplegia	Car accident	12	Grade 8
Tony	21 years	Male	Tetraplegia	Gunshot	2	Matric
Samson	19 years	Male	Paraplegia	Gunshot	2	Matric
Vivian	15 years	Female	Paraplegia	Gunshot	2	Grade 8

*a) Pseudonyms are used for all participants*

## **4.2 HEALTH-RELATED BEHAVIOURS AND INFLUENCING FACTORS**

This study aimed to determine health promotion needs of physically disabled youth with spinal cord injury, by exploring their health-related behaviours and the factors that may influence the choice and use of the behaviours described. The participants' health-related behaviours explored included participation in physical activity and substance usage. The results from the individual and focus group interviews have been reported using the following four major themes that emerged from the study:

- Personal influences,
- Social support,
- Barriers to positive health-related behaviours and
- Perceived needs.



These themes encompassed a number of sub-themes that are presented below.

### **4.2.1 PERSONAL INFLUENCES**

The theme of personal influences, describes participants' statements about their personal struggle with adjustment to a "new identity" after the injury, which negatively or positively influenced their involvement in various health-related behaviours. Central to personal influences was the issue of participants' self-identity, which was linked to their pre-injury identity and the struggle to adjust to a new identity post-injury. Participants' self-identity was associated with how

they previously defined themselves in terms of their independence and what they could do (an “able” identity) and the role physical activity played in their lives. Participation or lack of participation in physical activity and substance usage paralleled the identity adjustment. These issues will be presented under the following two sub-themes: loss of an independent and able identity and adjusting to a new identity.

### 4.2.1.1 Loss of an independent and able identity

This sub-theme describes participants’ statements about the loss or perceived loss of identity related to their independence and the physical abilities to participate in activities that were significant to them prior to the injury. In the individual interviews, when asked to describe what it is like to live with a spinal cord injury... all the study participants, regardless of their age, circumstances of the injury or resulting disability, reported experiencing a personal struggle with their ‘new identity’ to some degree after their injury. For instance, **Leonard** (paraplegia) expressed his struggle with identity and the uncertainty experienced, by saying,

*...When I was still in the hospital and the time for discharge came, I felt like not going home... ‘Is this the way I have to lead my life now?’ ‘How will my friends treat me?’...Because I was always the rough one... ‘And will they be against me now that I am sitting in the wheelchair?’*

## Results

**Tony** (tetraplegia) expressed his struggle with identity by talking about his previous independence. He related,

*It is difficult sometimes you get pressed down emotionally...seeing people walking around you, doing things you used to do...looking at the television at people doing things and you know you used to do those stuff but now you can't...*

**Gideon** (tetraplegia) also said,

*Sometimes it (spinal cord injury) has ups and downs sometimes you get frustrated and knowing that you know if you are like able you would do things yourself but now you have to wait for somebody to come and do things for you...*



Other participants reported missing the activities that had helped define their pre-injury identity. The overall sense of loss or perceived loss of activities that were meaningful to them appeared to play an important role in their adjustment, as some participants, notably males related that participation in physical activity was of substantial importance to them prior to the injury. For instance, **Samson** (paraplegia) expressed feelings of frustration at his loss of ability to participate in the sport activity that he was involved in prior to the injury by saying,

## Results

*It's difficult (long pause) mh...mh its frustrating coz you know you can't do things that you love to do...like rugby you see, I am crazy about rugby...you see at first I used to feel very frustrated and lonely, you know when I got injured... you see I used to play rugby and I was fit and big... but when I got injured and they (health professionals) explained to me everything ...what I will be able to do and what I won't be able to do and that affected me you know, I won't be able to walk again...means I won't be able play rugby again like before (shakes head)...do all the stuff I like to do...*

Similarly **Nathan** (tetraplegia) who was injured while playing rugby related,



*...First I would do everything on my own, now I must always depend on other people to do things for me...you see for me I wasn't the kind of person before the injury that likes to stay in the house or stuff like that...I would like to go out with my friends like over the weekends...we used to do sports like cricket, athletics ...I used to like sports but now I can't do that (play sports) now I can only sit and watch them I cannot join them...*

For most of the participants in this study, physical activity was connected to their identity prior to the injury. From **Nathan** and **Samson's** daily rugby practices to **Edwin's** frequent swimming and **Gideon's** daily soccer games with friends, it was clear that, physical activity played a large role in the daily lives of most of the participants pre-injury. However this changed after the injury. More than half of

## Results

the participants reported having resorted to sedentary activities such as, watching television, listening to music, sitting and chatting with friends, playing cards and computer games during their leisure time. When asked to describe the sorts of things they did in a day, 'during a typical morning...afternoon...evening', Participants gave responses such as:

*...I wake up go and take a bath and go to school...then when I am not in class, I sit and chat with my friends...when I am at home I do my homework and then listen to the radio or watch TV with my brother...weekends we play computer games with my brother or just watch TV...Edwin (tetraplegia).*



Another participant who gave a contrast of the sorts of things he did prior to the injury and post-injury related,

*It is different, in the past I used to do a lot of things... but now in a split second my life changed...after school, study time is three to four and then after that I watch TV or sometimes we sit together with my friends and just chat...then I have my dinner and I sleep (pause) it is a boring life man! It is boring weekends it is really, really boring cause most of my friends are not there so most of the time I sleep...Nathan*

**Tony** who was staying in a Cheshire home at the time of the study also narrated,

*In the morning I wake up...eat my breakfast then listen to music and watch TV most of the day...watch a movie...then maybe go outside and sometimes there's a lot of girls that come to visit me and we sit and chat after that at 5pm we have our supper afterwards we go and sit outside again and we continue talking with the girls. After that I come in and watch my favourite soap and then I watch the news, listen to music then go to bed and sleep again and it starts all over...*

#### **4.2.1.2 Adjusting to a new identity**

This sub-theme describes participants' statements about their struggle and strategies used in their attempt to adjust to a new identity. Adjusting to a new identity after the injury was described as a difficult process; many participants described how the injury served to shatter their self-perception. Some participants related experiencing negative emotions such as frustration, stress, boredom and loneliness during this process. Several participants discussed how they had resorted to behaviours such as the use of tobacco, alcohol and drugs as a strategy for coping with these emotions. For instance **Samson** said,

*You see I get bored and stressed sometimes...and smoking (pause) smoking calms the nerves man! ...When you are feeling stressed...like when I am watching rugby and I see my favourite players and it's like not better than I play it and I say he should have done that and not that...then I light a cigarette...*

## Results

Further emphasis was given on the use of alcohol and drug substances as a coping strategy during the focus group discussion, where group support apparently made the participants more brave and nonchalant in reporting their involvement in these substances. For instance **Gideon** said,

*You see Miss, it is difficult...you see when you are sitting in the wheelchair sometimes you feel (pause) ...shame for yourself, you know you feel frustrated and just to cool off your mind a couple of beers will help, you wont think so much about the frustrations...*

**Vincent** (paraplegia) nodded his head agreeing with **Gideon** and said,



*Yea taking alcohol is not bad you know just to be cool...to soothe your mind... ah man! Just to cool off...like me when I am sick I drink whisky just to clean my chest and (laughs) and keep my brain clear I also smoke 'okapipe' (a drug as explained by another participant in the group) sometimes and I sleep good man! ...*

**Samson** also said,

## Results

*Dagga<sup>2</sup> (illicit drug) smoking is good...people smoke it to meditate clearly, you know instead of taking a beer if you are feeling depressed...you take dagga to meditate clearly...*

For other participants, although initially having experienced this struggle with identity, they reported having reached a stage at which, they moved on to re-establish a new sense of self. These participants discussed the importance of accepting themselves as they are and moving on with their lives. To these participants this was achieved by a change of attitude, and they talked of the significant role that positive attitude played towards this acceptance. For instance **Tony**, whose injury was related to violence while involved in a robbery, reported that after accepting his ‘situation’, he felt that the time after his injury was a time for “some positive changes in my life”. He related how he had stopped smoking and reduced his alcohol consumption after the injury, saying,

*I love myself more, I appreciate everything more than before... and I am more positive inside me about the future, I could never feel better than I feel now...I am a much better person now and I approach everything differently unlike before...you know when I look at the stuff I did, I tell myself I could have done better now...you see like now I think if I drink myself very drunk, I can fall off my chair...*

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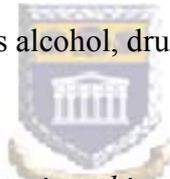
<sup>2</sup> Dagga is the commonly used word for Marijuana in South Africa

## Results

For some of the participants, it appeared as if this acceptance was some kind of resignation rather than a realistic acceptance of the disability. For instance **Leonard** remarked,

*...It's not nice ...you can't run up the stairs, run here, run there...but now with a positive attitude ...now I just go on with my life...it is done it is done...*

Several participants talked about strategies to improve one's attitude or outlook, including attending to spiritual life and self-determination. **Edwin** described how spiritual beliefs impacted his interpretation and response to situations including involvement in behaviours such as alcohol, drugs and tobacco usage and stated,



*...I motivate myself by seeing things as they come and believing in God...you see like we used to smoke dagga, cigarettes and drink (alcohol) with my cousins after my injury... but now I've stopped all those things because it is against my Christian faith...*

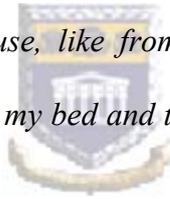
**Peter** (paraplegia) talked of his determination to move on with life saying,

*You see it's just the same, its just my physical...just that you can't walk but I am determined to move on with my life...you just need to be positive*

## Results

Physical activity was linked to identity for the majority of participants prior to the injury. Similarly, some form of physical activity also appeared to play a role for some participants in the process of adjusting to a new identity, although the actual level and way in which it played a role were different for each person. For instance, **Samson** stated,

*You see at first I used to feel shame for myself all the time, you know you think now I am paralysed and a lot of stuff man! But when I accepted myself the way I am, now I am okay...not to say I don't usually think about those things because I wasn't born in a wheelchair...but I never feel that because I won't walk again I shouldn't do things, you know keep myself fit...I will do all the things that paraplegics can do...You see, now I do exercises here in the house, like from my wheelchair to the floor and climbing from the floor to my bed and to the wheelchair and push ups and they are very hard..."*



When questioned about how often he did it he responded,

*Mostly when I am bored maybe at night, not everyday.*

**Gideon** reported having changed his personal attitude after resuming physical activity with encouragement from his family by saying,

*...I play quad rugby now and once in a while I lift weights...in 'Proteus' sports club, I go practice from 9am...you see when I was in Conradie...I was like in the environment of disabled people so when I came home over*

## Results

*the weekends...I would feel like everybody is staring at me and I never used to like going to places...but now I am more positive...*

When asked how often he went to the club, he responded

*Only on Saturdays and Sunday I rest*

### **4.2.2 SOCIAL SUPPORT**

This was the next major theme to be identified. Beyond the personal level, the study revealed that there is a second tier of individuals who can have a sizeable impact on the health-related behaviours that youth living with a spinal cord injury choose to engage in. These include family, health care professionals and friends including other people living with a spinal cord injury. These individuals can facilitate or hinder a choice of positive health-related behaviours. Collectively, these individuals constitute the participants' social support. All data related to social support were coded into this one broad theme. Three sub-themes were identified namely: emotional support, instrumental support and informational support.

#### **4.2.2.1 Emotional support**

The sub-theme of emotional support describes participants' statements about the feeling of being cared for through encouragement and having someone to talk to. Many participants referred to family and friends as being "very supportive" and

## Results

“always being there for you”. They talked about the support offered by family and friends as being an important resource in coping with stress and emotional difficulties. For instance **Nathan** who said he had resorted to drug use after his injury but later stopped with encouragement from his family, described how his family and friends helped him to get through the “frustration” of coming to terms with his “new identity” and related,

*The first few months I couldn't cope...I was very frustrated and there's a time that I was smoking dagga with my friends... and I felt very weak...and my brother and my parents advised me to stop...now I have met other friends who are also in the wheelchair and they motivate me...they tell me I need to look at life positively...and my family...they have really been good to me, they have supported me really through all these... you see you don't feel like nobody is caring for you...I think the support from the family is the most important for someone who is paralysed*

Similarly, **Peter** who described his family as being ‘always there for me’ stated,

*...Having a supportive family helps a lot you know a family that encourages you all the time they don't put you down...*

**Tony** also said,

## Results

*Now I have made other friends, that are sitting in the wheelchair like me and it's nice we talk a lot and make jokes and encourage each other and that makes me feel better...*

### 4.2.2.2 Instrumental support

This sub-theme describes participants' statements about support involving the provision of tangible assistance. Social support was often described by participants as more than just someone to talk to, but having someone with whom to do activities with. Family and friends provided this instrumental support for activities in ways such as doing it with them and providing transport. One participant who had resumed physical activity after the injury, described himself as being actively involved in sports and said,



*My family and friends always encourage me...you see the way they know me they know I am a kind like of an active person so they have help me get into sports they encourage and even come with me to the sports club...and I need to be encouraged **Graham**.*

**Peter** also said,

*Yea my family supports me a lot... you see like when I needed transport to go to Vistanova (school) and they did everything that they could to get me transport...that was two weeks ago*

Others felt they owed independence attained after the injury to their friends and family. Statements made demonstrate the powerful influence that others have. For example, **Vivian** (paraplegia) narrated,

*The people that are my friends and even my family have been there for me ...supporting me...you see at first they used to do everything for me, wash me...push me around and stuff...but they have encouraged me to push my own wheelchair, wash my self...now I feel I am not so dependent on them, you see like now I am doing ballet dancing...I feel family support is important and it helps me get through because if ever I was just alone then I wouldn't have been able to do whatever that I am doing now...I wouldn't be who I am now.*



#### **4.2.2.3 Informational support**

The sub-theme of informational support describes the advice or knowledge gained by participants' through health professionals, friends and family.

Health care professionals, including doctors, physiotherapists, nurses, social workers and occupational therapist were cited as significant sources of informational support. For instance **Gideon** said,

*...People in the hospital like physios, nurses; they used to tell us about pressure sores and that we must turn regularly not to lie too long on one*

## Results

*side...yea and not to smoke...they also gave us some sort of booklet with information of how to eat properly and stuff...*

Similarly **Tony** said,

*When I was in Conradie, the physiotherapist and the occupational therapists, they used to tell us like smoking is bad for your health and about bedsores... and they gave us a booklet with some information (pause) but I have not read all of it yet (smiles) I am lazy to read*

One participant explained how she had stopped smoking 'dagga' following advice from the doctors while she was in the hospital and related,

*I've stopped smoking dagga because it is very unhealthy...the doctor, they just told me they asked did I smoke now dagga, so I said yes and they said no I must stop smoking dagga because it is very unhealthy... now I am only smoking cigarettes **Sophie** (paraplegia).*

**Nathan** also said,

*...You see when I was in Conradie they showed us a videotape about the things that you mustn't do and the things that you must do when you got spinal cord injury...smoking is bad they say especially if you have got a problem with your lungs...and a lot of other stuff about how to take care of the catheter, about pressure sores...*

## Results

For some participants, the experiential knowledge of other people living with spinal cord injuries made them valued sources of informational support. For instance, **Edwin** said of his friends,

*...I have a friend who is long in the wheelchair, he is now eleven years in the wheelchair and he gives me a lot of advice...what to do and what to avoid...like stuff to do with the catheter...also here in school the friends that I have, ...we tell each other if something works for us...for example if it is something for the skin...*

There was however some negative influence discussed in terms of informational support and health-related behaviours, in that some participants reported having gotten information that led to their involvement in alcohol and drugs usage. For instance during the focus group discussion **Leonard** who reported usage of alcohol, related how his granny told him that it is healthy to take brandy (alcoholic drink) by saying,

*...Now and then you must drink brandy for your heart...clean brandy, coz it makes your heart strong...my granny told me that brandy keeps the heart healthy, you know especially after eating those fatty foods it helps in cleaning the heart...*

He also noted how had gotten involved in drugs as a result of advice from his friends by saying,

## Results

*...I've tried dagga (pause) clean dagga ...my friends say it is a special remedy and it gives you a clear memory and stuff like that...makes you think better but only when you don't mix with cigarettes...so they told me to try...but when I tried just after I came out of hospital, I found that it makes you eat a lot and I said no this is not for me so I stopped.*

Similarly **Tony** who reported having reduced his alcohol consumption post-injury and “only” drinking over the weekends with his friends “about seven glasses maximum” said,

*...Some people I talk to and stuff, friends that are in the wheelchair that are drinking alcohol say that alcohol helps with the bladder (pause) it prevents bladder stones...you see cause you will urinate a lot...*



The comments of **Leonard** and **Tony** are unsettling as they outline a justification for the use of alcohol and drugs due to misconceptions held by people close to them.

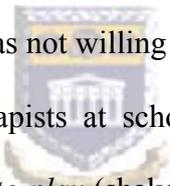
### **4.2.3 BARRIERS TO POSITIVE HEALTH-RELATED BEHAVIOURS**

This was the other major theme that emerged from the study findings. It describes participants' statement about intrapersonal, interpersonal and environmental factors that inhibit the selection or use of positive health-related behaviours.

#### 4.2.3.1 Intrapersonal factors

This sub-theme describes participants' statements about internal factors that inhibited a choice of positive health-related behaviours such as participation in physical activity. These factors consisted of perceived difficulty of some physical activities, activity preferences, lack of motivation and lack of time.

Although opportunities for participation in physical activity existed, some participants expressed uncertainty as to their physical abilities to participate in some of the available activities, citing them as difficult. For instance **Nathan** who used to play rugby prior to the injury perceived quad rugby<sup>3</sup> as a difficult sport activity for him post injury and was not willing to try. He related,



*You see they (physiotherapists at school) want us to play quad rugby (pauses) but I don't want to play (shakes head) you will just struggle with the ball or something like that as you try to pass it on (shakes head) it is frustrating, you see it's not like before, I cannot play like before, it looks so difficult to me to play rugby, you struggle with the ball...maybe if I get strong in my arms or something then I will play again but not now...*

**Edwin** also said,

*Last year I played quad rugby, but this year my health wasn't so good, I had an operation; my one kidney...so I told them (team mates) I can't play*

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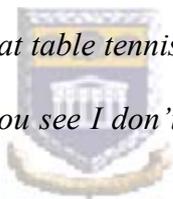
<sup>3</sup> Quad rugby is rugby that is played by individuals with quadriplegia/tetraplegia

## Results

*now because my body isn't so strong now...you see I wanted to start swimming this year...I don't want to play wheelchair rugby anymore now I think it is too difficult for me...*

For some participants, even though they were interested in participating in physical activity, unavailability of the activities they preferred and lack of motivation, acted as a barrier to participation in physical activity. For instance during the focus group interview **Leonard** pointed out,

*To stay healthy one must take up sport activities ...although here in school they don't have the activities I like at the moment and I feel my talent goes to waste...I am very good at table tennis and wheelchair tennis...but now I am not doing anything...you see I don't feel motivated to play basket ball and that's all there is now...*



**Samson** who used to play rugby prior to the injury also said,

*You see I used to play basketball in Conradie that is where I learnt how to play it, but basket ball is not one of my favourite games I prefer rugby...but you see the rugby that is played now for people like us, is for quadriplegics only and I am not a quadriplegic...*

He further noted,

## Results

*...You see sometimes when you are all alone; you don't feel motivated to exercise a lot you know like to do sports...it is nice to have someone to encourage you and remind you man!*

A few participants mentioned lack of time due to too much homework as a barrier to participation in physical activity. For example **Sophie** said,

*Sometimes I go for basketball here in school maybe once a week...you see I could go everyday but I can't because I always have a lot of homework...you see every teacher will give homework and we have like seven teachers and we must do homework with everyone of them...*



### 4.2.3.2 Interpersonal factors

The sub-theme of interpersonal factors describes the negative influence that the general society's attitudes and peers had on participants. Participants talked about the general insensitivity and the negative perceptions that they felt people in the society had towards them. They discussed how this negatively impacted on their choice of health-related behaviours such as physical activity. For example with regard to participation in physical activity, **Leonard** narrated,

*You see there by us there's no gym...so during the holidays I used to go to a gym there by my friends place, you know just to lift weights and stuff...*

## Results

*the people there then stare at you the whole time and I don't like people staring at me and I am very short tempered I get angry very quickly... so now I don't like to go anymore...*

Another participant said,

*The people here when you are disabled they don't look at you like the same way they used to, they look at you and they feel shame for you like I am dead...like I am some kind of freak **Samson***

**Peter** noted how he stopped wheeling himself in the malls because of the attitudes from the general public:



*...I don't like going to many places cause people stare at you all the time and I don't like that, it feels like a humiliation when people stare at you, you feel like a nobody, like you are from a different planet...you see I used to go wheeling myself in the malls with my friends on weekends... in fact that's the biggest stress that makes me not like going to the malls anymore*

Not only did participants relate being affected by the attitudes of society at large, but also by those of their family and friends. **Gideon** noted,

*... Some people they are always creating sympathy, sympathy...and you don't want sympathy, you just want them to treat you like a normal*

## Results

*person...it is okay if they help me 'mos' (surely) but it is also good to give me a chance to try something on my own...like my family, say for instance I want to transfer from one place to the other, they want to help all the time, they are afraid I am gonna hurt my self...*

To some participants, peers had a negative influence on them in that they mentioned the use of alcohol and tobacco most often in the context of socialising. For instance **Leonard** who described his first day in school as a “blue Monday” due to hangovers said,

*...I take now and then my beer or cider on Saturday, Sunday with my friends...that's how I ... we enjoy life when I feel I am getting drunk now stuff like that I stop and go home...just to fit in with my friends and to socialise...you see socialising is very important it helps you stay positive...*

**Sophie** also said

*...Yea sometimes also we smoke (cigarettes)...just for fun when we are socialising...but I want to stop before my mother finds out and I will be in trouble (laughs)...you see I had stopped smoking but I have just started again middle of last year...I just kept on feeling like I wanted to do it (smoke) again and again...especially when I am with my friends...*

#### 4.2.3.3 Environmental factors

The sub-themes of environmental factors describe participants' statements about the physical barriers that inhibited their participation in physical activity. These consist of accessibility problems due to rough roads, lack of facilities and lack of transport. A few participants mentioned rough roads as being a barrier to physical activity. One participant said

*You see you can't just get out like whenever you want...to go for exercises or whatever...cause you see like the road here is not good for me you know there's eh...I have spasms and when you know going on a road like this one they start doing their thing...it must be tar road...but these roads are rough...so I must go with some on to push me...and there's not always someone...**Samson***



Other participants mentioned a lack of facilities for exercises and a lack of transport as some of the reasons as to why they were not participating in physical activity. For instance one participant who was staying in a Cheshire home at the time of the study said,

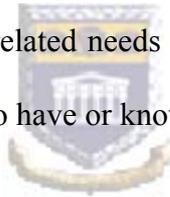
*...As for the exercises there are no facilities for exercises here...they only play dominos there in front... and another problem we struggle with is transport because I am interested in doing some exercises...but they say that there's no transport to take us to the chase classes ...**Tony***

**Vincent** who had changed school from a special to a mainstream school, also mentioned a lack of facilities as being a barrier to physical activity

*You see when I was in the other school, St, Josephs I used to play basketball...but this year I didn't play...because I don't have a team to go to, there are no places for sports for people sitting in the wheelchair in this school...and there's no transport to take me to the other team in that school...If I can get a team I can play basket ball because I like it*

### 4.3 PERCEIVED NEEDS

This theme describes the health-related needs as well as other general needs that participants reported as desiring to have or know more about.



#### 4.3.1 Health-related needs

Participants expressed a desire to get information on health-related behaviours such as exercises, diet, drinking alcohol, smoking and sexuality issues. With regard to information on exercises, many participants expressed a desire to know more about exercises that they could participate in. For instance **Samson** said,

*...You know another friend of mine who is also sitting in the wheelchair told me that the hospital he was in, in PE (Port Elizabeth), they showed*

## Results

*him a video there of paraplegics from Australia, how they keep themselves fit with activities he said...they were sixteen paraplegics and they did hiking with the wheelchair, yoo! I didn't believe him cause ah...I never thought that paraplegics can do that kind of sports so I think it would be nice you people (health professionals) to tell us man! Or to organise such kind of exercises or even others to keep the paraplegics going man! ...*

During the focus group discussion, **Tony** also said,

*...Yea I think you need to give us information on how to make our lifestyle more effective like with involvement in sports...*



**Sophie** nodded her head in agreement and added,

*Yea, exercises and also the diet, what to eat so that you don't gain weight 'mos' (surely)...*

**Gideon** also said he desired to get information on “healthy diet” and related,

*...They (health professionals) told me while I was in Conradie (hospital) that I am a little bit underweight and I have low blood pressure...so I would like advice on diet, healthy diet for people with spinal cord injury...*

## Results

With regard to alcohol, cigarette smoking and drugs, some participants reported a desire for information on the dangers associated with these substances and how to quit behaviours such as smoking. For instance during the focus group **Samson** said,

*I am a smoker yea, (laughs) and I don't want to say its good or bad man!  
You know I was smoking before my injury and as you know with quitting  
smoking it is not that easy (pause) maybe you should give me...us  
information on such stuff man!*

**Peter** who had chosen to abstain from alcohol, cigarette smoking and drugs, extended his comments beyond his personal experience to observation of others engaging in these substances, with concern saying,



*You see some people think drinking (alcohol) and smoking is cool, but it  
isn't, you see I have seen what these things do to people around here...my  
neighbours...in school they talk about some of these things but they should  
be more specific...say more... to make people stop using these things  
...you see some of my friends in school smoke and drink...*

Some participants expressed a desire for information on sexuality issues. For instance **Gideon** said,

*...I would like to know if I am a quadriplegic do I stand a chance of  
making a baby...and any information on sex*

**Samson** also said,

*Sex (pause) its not the way I used to do it at first you know...you see I broke up with my girlfriend because she wasn't comfortable wit the way I made love to her...you see when I used to play rugby my friends used to say that sex is good for health (laughs) so I would like to get some information on sex matters...*

#### **4.3.2 Other general needs**

Participants presented several views on other areas of need that they felt were essential to them including, employment opportunities, transport issues and support groups.



As regards employment opportunities, **Peter** said,

*I would like to know about job opportunities for us people with disabilities, cause even now I am studying, I don't know if when I finish I will get a job, I am just studying...*

**Nathan** also said,

## Results

*I would like any information on job opportunities for disabled people, I dream to become a marketing manager one day now that I am paralysed (pause) I need to know whether it is possible for me to get a job...*

With regard to transport, some participants felt that the government should put measures in place to have them accommodated within the public modes of transport. For instance **Peter** said,

*Maybe the government should intervene so that we can have transport that can carry someone in a wheelchair while also carrying normal people, cause these things affect people in wheelchairs...you see because sometimes I feel like I am a prisoner because these taxi (public vehicles) drivers they speak a lot of nonsense about wheelchairs saying it scratches their seats...*

With regard to support groups, many participants emphasised the need for a support group. In fact, most of those who talked about it were adamant that forming a support group would be the best strategy for discussing issues pertaining to them. One participant said,

*You see I would like to get to other people with disabilities so we can discuss our problems together, you see I was thinking about forming a group where disabled people come together discussing their problems, socialising, playing games but I don't know people who I can go to, I don't*

## Results

*have the resources...because I know how it feels to be disabled...sometimes people say they know how you feel but they are not in the situation that you are and so they can never say they know the way you feel...Tony*

During the focus group discussion, **Samson** echoed similar sentiments,

*I think the best way to get the best information, is from spinal cord injury people, because they have experienced that (spinal cord injury)...you know its better...so I would like information on how we can get together like this (focus group).*



### 4.4 SUMMARY

In this chapter the findings are presented using four themes that emerged from the study. Participants' views are presented through the use of descriptive statements illustrated by selected verbatim quotations from the transcripts of the interview to emphasise the themes highlighted. A description of participants' health-related behaviours and the factors influencing their choice are presented. The main findings drawn from the study are summarised and discussed with a comparison to previous research in the area, in the next chapter.

## **CHAPTER FIVE**

### **DISCUSSION**

#### **5.0 INTRODUCTION**

To be able to design health promotion programmes for youth with physical disabilities with specific reference to spinal cord injury, one must first determine their health promotion needs. In this study this was done through an exploration of the health-related behaviours and the factors that serve to influence the selection and use of the behaviours described. The study elicited some informative first-hand accounts of physically disabled youth with spinal cord injury about the health-related behaviours they engaged in and the influencing factors. In this chapter the major findings are summarised and discussed with a comparison to previous research in the area, where relevant and applicable. The relevance of the findings to physiotherapists and other rehabilitation professionals is also discussed.

#### **5.1 GENERAL FINDINGS RELATED TO DEMOGRAPHIC FACTORS**

The findings of this study corroborate several demographic trends reported consistently in the spinal cord injury literature: the mean age of the participants was low, congruent with the commonly observed trend in spinal cord injuries. The ratio of eight males and two females in the study depicts a high male/female ratio as is typically encountered in the spinal cord injury population. Spinal cord injury occurs most frequently in young males (Nesathurai, 2000; Quadriplegic

Association of South Africa 2002-3). The leading cause of the injury in the study was gunshot wounds. This is similar to an epidemiological study done by Hart and William (1994) who observed a disproportionately high incidence of violent injuries particularly gunshot wounds among South African spinal cord injured individuals. As these authors concluded, this could be ascribed to the general escalation of violence in the country as is evident in the news.

## **5.2 PARTICIPANTS' HEALTH-RELATED BEHAVIOURS AND INFLUENCING FACTORS**

The findings of the study indicate participants' involvement in risky health-related behaviours influenced by various factors as discussed below.

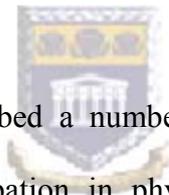


### **5.2.1 Participation in physical activity and influencing factors**

Although a majority of the participants in this study reported that physical activity was of substantial importance to them prior to the injury, many of them reported having resorted to sedentary leisure activities after the injury. This finding is congruent with other studies that have identified high frequencies of sedentary leisure activities in youth with physical disabilities. For instance in a study of lifestyle health behaviours of 11 to 16-year-old youth with physical disabilities, Steele et al., (1996) found that, these youth were involved in sedentary leisure activities and less exercise. Similarly Hogan et al., (2000) in their study of health promotion needs of young people with physical disabilities, reported a high level

## Discussion

of sedentary activities. Despite documented benefits of physical activity for people with physical disabilities including those with a spinal cord injury (Kosma et al., 2003, Rimmer et al., 1996), it is clear from a number of studies that, habitual physical activity is a missing component in the lives of most persons with physical disabilities (Cooper et al., 1999, Rimmer et al., 1996). Considering that exercise and activity are of prime importance in rehabilitation of individuals with physical disabilities including those with a spinal cord injury, physical inactivity that is persistently evident among these individuals is of concern to rehabilitation professionals. To be able to promote physical activity among these individuals, it is essential that rehabilitation professionals understand more fully the factors that enable or discourage these individuals' participation in physical activity.



Participants in this study described a number of factors that influenced their participation or lack of participation in physical activity. Many participants recognised that there was an impact created by their own attitudes related to their self-identity often stemming from the difficult process of adjusting to a “new identity” after the injury. According to Wiechman and Williams (1997), identity can simply be defined as the answer to the question, “Who am I?” These authors explain that, “what we are results from the roles we carry out”. They suggest that the importance placed on roles, leads individuals to become overly dependent on them such that any alteration in roles can become the source of a great deal of stress. Many participants in this study who were previously involved in sports reported having resorted to sedentary lifestyles after the injury as they believed that they had lost the ability to participate in physical activity. Being still young

## Discussion

and active, this sense of loss of identity related to their independence and ability was a devastating experience for them. The degree to which the participants attributed responsibility to these factors was unexpected.

This finding indicates a need for individual health promotion interventions during rehabilitation, focused on helping youth with spinal cord injuries refine and develop their identity after the injury by making them aware of their abilities and encouraging them to participate in alternative physical activity or sports. Physiotherapists and other rehabilitation professionals should integrate such interventions into their goals of treatment from the onset of the rehabilitation program so as to, as Stuijbergen and Rogers (1997) puts it, promote an active independent attitude towards health care among these individuals. Furthermore, given the importance attached to physical activity in the formation of pre-injury identity by some of the participants in this study, such health promotion interventions would be essential to these individuals in the process of adjusting to a new identity.

The struggle with a new identity after the injury has been reported in other studies. For instance, Carpenter (1994) in her study of exploration of the experience of ten individuals following spinal cord injury noted that the issues of redefining self-identity and establishing a new identity were a common experience. Recently Levins et al. (2004) in their exploration study of the experience of physical activity through the perspective of individuals with a spinal cord injury, found the issue of self-identity to be an important factor that

## Discussion

influenced participation in physical activity. According to French and Phillips (1991), the change in body image after a spinal cord injury may cause significant psychological trauma and individuals may require psychological intervention in order to help them reintegrate the loss of their former body image and its effects into the new state.

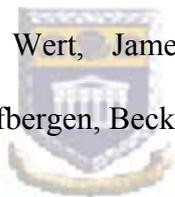
Although a few participants reported having resumed participation in physical activity in the process of adjusting to their “new identity”, the level and frequency of participation was inadequate when compared to the recommended levels and frequency, either every day or three times a week (Rimmer, 2000). For instance, some participants viewed activities of daily living such as transfers to and from the wheelchair as their primary component of their physical activity.



Rimmer (2000) reported that most people with physical disabilities live a sedentary lifestyle, and those who participate in exercise programmes, do so at a less than the recommended intensity. According to Washburn et al., (2002), low levels of physical activity in persons with physical disabilities may decrease their aerobic capacity, muscular strength, endurance, and flexibility, all of which have the potential of restricting functional independence and increasing the risk for chronic disease and secondary complications. It is therefore imperative that physical activity be encouraged among these individuals, as chronic disease and secondary complications are likely to result in unfavourable social and economic effects that may affect their quality of life as they make the transition to adulthood.

## Discussion

In addition to identity adjustment, the participants in the study mentioned other factors at the personal level that acted as barriers to participation in physical activity. These included, perceived difficulty of some physical activities, lack of motivation, activity preferences and lack of time. This finding is congruent with results in a number of other studies. For instance, lack of motivation was identified as a major barrier to physical fitness by a majority of participants (54%) in a study sample of adults with spinal cord injuries (Zemper et al., 2003). Activity preferences, perceptions regarding the difficulty of a particular health-promoting activity and lack of time have also been identified as barriers to participation in physical activity in a number of studies (Taylor, Yancey, Leslie, Murray, Cummings, Sharkey, Wert, James, Miles, & McCarthy, 1999; Stuifbergen & Rogers, 1997; Stuifbergen, Becker & Sands, 1990)



Several participants described a number of other factors well beyond their control that had a profound influence on their ability to participate in physical activity. From accessibility problems to a lack of transport and negative societal attitudes toward them, participants illustrated the profound capability of society to influence them negatively in relation to physical activity participation. Other studies have found these factors to be influencing factors to participation in physical activity. For instance a study by Levins et al. (2004) found environmental factors such as problems with accessibility and attitudinal problems from the society to be some of the major barriers in physical activity participation in a sample of spinal cord injured individuals. Similarly individuals with Multiple

Sclerosis identified lack of accessible facilities and lack of transport as some of the major environmental barriers to participation in physical activity (Stuifbergen & Rogers, 1997). To promote regular physical activity for people with physical disabilities and especially those with a spinal cord injury before sedentary preferences become habits, barriers such as the ones mentioned in this study need to be eliminated.

### **5.2.2 Substance usage and influencing factors**

Participants in this study talked extensively about their involvement in substance usage including the use of alcohol, drugs and tobacco. Although some participants had stopped substance usage by the time of the interview, almost all of the participants in this study reported having used one or more of the substances mentioned above at some time in their lives after the injury. Some of the participants reported having been involved in substance usage even before the injury. Substance usage has been found to be prevalent among youth and adults with various types of physical disabilities including those with a spinal cord injury in a number of studies. Some studies even reported higher rates of substance usage including the use of tobacco and alcohol among students with disabilities compared to their non-disabled peers (Hogan et al., 2000). In a study of recently injured individuals with a spinal cord injury, Heinemann et al., (1990) found increased consumption of alcohol, drugs and tobacco use in a majority of the participants (73%) post-injury in comparison to the general population.

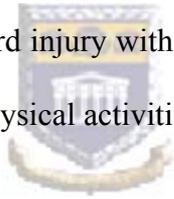
## Discussion

Participants cited several factors that directly or indirectly influenced their use of alcohol, drugs and tobacco. Many participants in this study described the adjustment to a “new identity” after the injury as a difficult process, which was accompanied by a range of psychosocial difficulties such as frustration, loneliness, stress and boredom. Most of the participants attributed their involvement in substance usage to these psychosocial difficulties, citing substance usage as a coping strategy. This finding is congruent with other studies that indicate that psychosocial issues among spinal cord injured individuals such as loneliness, stress and social isolation are linked to the use of substances like alcohol, tobacco and drugs. For instance, individuals with a spinal cord injury have been found to use marijuana for stress management (Heinemann, 1991). In another study of individuals with recent spinal cord injuries by Heinemann (1988) a desire to be sociable was cited by most individuals (61%) as a reason for drinking.

This finding raises concern because, contrary to beliefs held by some participants in this study that, the use of alcohol, tobacco and drug substances help in coping with the psychosocial difficulties, researchers have found that, persons with spinal cord injury who continue to use alcohol or drugs post-injury are at risk for negative outcomes (Kolakowskyhayner et al., 2002, Heinemann et al., 1990). Of primary importance is the effect on their health. According to Radnitz and Tirch (1995), spinal cord injured individuals who use alcohol, drugs and tobacco are susceptible to the same medical problems such as cardiovascular, respiratory and liver problems, as individuals without spinal cord injury who use these

## Discussion

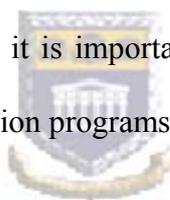
substances. Moreover substance usage when combined with the effects of a spinal cord injury makes these individuals more vulnerable to certain physical problems. For example, drinking large quantities of alcohol results in too much urine, which may stretch the bladder to the point where the individual loses important reflexes that help in the control of urinary function (Radnitz & Tirch, 1995; Tate, 1993). Additionally spinal cord injured individuals who use alcohol and drug substances may neglect self-care by for example sitting in the wheelchair for too long without turning, which may lead to the development of pressure sores. Substance use among individuals with spinal cord injuries has also been associated with adverse rehabilitation outcomes, higher rates of depression and stress levels and poorer physical health (Tate, 1993, Heinemann et al., 1990). In addition Tate (1993) notes that, persons with spinal cord injury with drinking problems spend less time in productive activities such as physical activities.



In order to prevent the long-term consequences of substance usage such as secondary medical problems and poor quality of life of physically disabled youth with spinal cord injury, rehabilitation professionals need to incorporate health promotion strategies designed to discourage substance usage early into their rehabilitation programmes (Steel et al., 1996). As is evidenced by the accounts of the participants in this study, it is not enough to simply advise spinal cord injured youth to avoid substance usage. Rehabilitation professionals including the physiotherapist should focus their interventions on all aspects of an individual including self-perception and specific risk factors to substance usage such as the psychosocial difficulties highlighted by participants in this study. Appropriate

interventions should foster positive attitudes towards the lives of these individuals early in the rehabilitation programme. In addition these individuals need to be educated about the effects of alcohol, tobacco and drug substances on their health.

Another factor that influenced participants' involvement in substance usage rather indirectly was peer influence. A number of participants often mentioned alcohol and tobacco usage in the context of socialising with peers. Moore and Polsgrove (1991) note that both peer pressure and social isolation resulting from a disabling condition have often been suggested as risk factors for substance usage. Since substances such as alcohol and tobacco are very much a part of the social and recreational activities that spinal cord injured individuals are encouraged to participate in, in the community, it is important that rehabilitation professionals extend health promotion intervention programs into the community.



### **5.3 SOCIAL SUPPORT**

Participants in this study talked broadly about social support as a major resource that facilitated a choice of positive health related behaviours. This consisted of emotional, instrumental and informational type of support. Sources of support that were mentioned by participants consisted of family, friends and health professionals including physiotherapists, doctors, nurses and social workers. Family and friends were frequently mentioned as the main sources of emotional and instrumental support through ways such as having someone to talk to, being a source of encouragement and also doing activities together. Many of the participants emphasised the extreme importance of emotional support to their

## Discussion

sense of well-being. Social support has been reported as an important resource by people with chronic disabling conditions and physical disabilities including those with spinal cord injuries, in a number of other studies. For instance, in a study by Hampton (2001), social support was found to be the most influential factor on quality of life of young Chinese adults with spinal cord injuries. In a study by Stuijbergen and Rogers (1997) individuals with multiple sclerosis identified social support as a major resource enhancing a choice of health-promoting behaviours.

Given the importance attached to social support from family and friends by participants, there's a need for rehabilitation professionals to target family and friends by involving them early during the rehabilitation process so that they can access relevant information as one of the strategies for health promotion intervention.



Health professionals including doctors, physiotherapists, nurses, occupational therapists and social workers were the major sources of informational support. Many participants reported having received information concerned with their health, although it seemed there had been more emphasis on specific spinal cord injury complications such as care of the skin, bladder and prevention of pressure sores. It appeared participants had scanty knowledge on the importance of physical activity participation, the dangers and the consequences of substances like alcohol, tobacco and drugs. However, although a majority of the participants continued to engage in health-risk behaviours even when they possessed some knowledge about the dangers of these behaviours, a few had stopped their pre-injury health-risk behaviours following the advice from the health professionals.

## Discussion

This indicates that individuals with spinal cord injury can change behaviour because of education provided by rehabilitation professionals

The involvement in health-risk behaviours by some participants once back in the community could probably be attributed to lack of follow ups after discharge as most participants reported having received the information while in the hospital. Another possibility would be that, while in the hospital participants have to grapple with a lot of information given to them, such that, information on health-related behaviours received then, may be at times ineffective in influencing a choice of health promoting behaviours once they go back to the community. In addition conflicting information offered by friends could also be a contributing factor. Rehabilitation professionals may therefore need to extend their services to the community, into which the spinal cord injured youth are discharged, so as to continue with provision of relevant information to these youth as one of the health promotion strategies. Kendall et al. (2003) points out that, rehabilitation professionals should develop appropriate discharge planning procedures for individuals with spinal cord injuries and foster links with community systems for continuity of care.

Overall, like in other studies (Stuifbergen & Rogers, 1997; Stuifbergen & Roberts, 1997), social support seemed to be one of the most important resources that facilitated a choice of positive health-related behaviours among the participants in this study. Therefore, social support is clearly an important mechanism through

which youth with spinal cord injury can be encouraged to participate in positive health-related behaviours by rehabilitation professionals.

#### **5.4 PERCEIVED NEEDS**

One of the major health-related needs expressed by participants in this study was a need for information on exercises, in which they could participate. This is not surprising, given that most of the participants in the study were young and had been physically active prior to the injury. This finding is congruent with that of a study involving adolescents and young adults with a spinal cord injury, by Edwards (1996), who found that, majority of the respondents in the study identified planning an exercise program and referral to a fitness centre as their main health promotion needs. This finding poses a challenge to the rehabilitation professional to assist young spinal cord injured individuals by offering information on physical activity and encouraging them to participate in alternative sports.

With regard to substance usage some participants desired to get help with quitting smoking and others suggested that information on the dangers of substance usage be taught in school. In a study of individuals with spinal cord injury most (69%) of whom reported having increased consumption of alcohol after their injury 16% of the subjects reported needing treatment for alcohol or drug use (Heinemann et al., 1991). Health promotion interventions for spinal cord injured youth need to

## Discussion

include special programs in the area of substance use so as to be able to offer substance abuse therapy when required.

Other areas of need perceived as essential by participants in this study included sexuality issues, diet, employment opportunities and transport issues. Rehabilitation professionals need to encompass all these needs in their health promotion interventions.

The need for a support group was mentioned by a number of participants especially in the focus group discussion where participant discussed their issues openly as they felt at ease with each other and a number of them at the end of it wanted to know when they would be called again to discuss their issues. In a case study of people with physical disabilities, Stewart and Bhagwanjee (1999) demonstrated the importance of self-led support groups of people with spinal cord injury in self-reliance and group participation.

Indeed, as the participants in this study said in their accounts, nobody outside this subgroup of people can claim to know their needs better than them. It would therefore be appropriate for rehabilitation professionals to facilitate formation of support groups and only come in to advise, while allowing the spinal cord injured youth to spear head all fundamental processes including health promotion strategies such as behavioural change. Furthermore the essence of health promotion is an active self-care strategy, which according to the Ottawa Charter for Health Promotion involves empowering and enabling people to increase

control over their health (Coulson, Goldstein & Ntuli, 1998). This would be more easily realized through the formation of support groups.

### **5.5 RELEVANCE TO PHYSIOTHERAPISTS AND OTHER REHABILITATION PROFESSIONALS**

Rehabilitation programs have often focused primarily on instructing individuals with spinal cord injuries in the necessary techniques of mobility and activities of daily living sometimes neglecting the broader health needs (Carpenter, 1994). Judging from the results of the present study, it is important for rehabilitation professionals including physiotherapists to broaden their services to include health promotion interventions in addition to their primary roles of improving functional independence. These health promotion interventions should include individualised programmes tailored to the spinal cord injured youth's needs such as identity and psychosocial adjustment issues, information on activities that youth with spinal cord injuries can participate in safely and information on the dangers of substance usage.

Rehabilitation professionals need to recognise that although functional independence is a worthy goal, resulting behaviours may be detrimental to the health and quality of life of youth with spinal cord injury if health promotion interventions are not put in place. Thus it is important to note that education, social support and identity adjustment among physically disabled youth with spinal cord injuries have a significant impact on the health-related behaviours that

## Discussion

they choose to engage in. They therefore need to foster positive attitudes among these youth and motivate them as well as offer relevant information to their family and friends during the rehabilitation period.

Considering the long period of time that individuals with a spinal cord injury spend with physiotherapists compared to other health professional, there exists a window of opportunity for physiotherapist to initiate individualised health promotional strategies, early in the rehabilitation programme. These health promotion strategies should be designed to address all aspects of a spinal cord injured individual's needs including self-perception psychosocial adjustment issues and health education. In addition it is important that physiotherapist and other rehabilitation professionals prepare individuals with a spinal cord injury for the attitudinal barriers that they will face once they go back to the society. With the current emphasis on primary health care in South Africa (Bhagwanjee & Stewart, 1999, White Paper on an Integrated National Disability Strategy, 1997), rehabilitation professionals should extend their services to the community by facilitating formation of support groups as some of the participant suggested.

## **CHAPTER SIX**

### **SUMMARY, CONCLUSION AND RECOMMENDATIONS**

#### **6.0 INTRODUCTION**

In this chapter a brief summary of the study is provided, conclusion and the recommendations arising from the study are proposed. The chapter ends with a presentation of the study's limitations.

#### **6.1 SUMMARY**

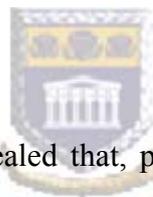
This study aimed to determine health promotion needs of physically disabled youth with spinal cord injury. The study specifically explored health-related behaviours with reference to participation in physical activity and substance usage, factors that influenced these behaviours and major issues that needed to be targeted in health promotion.

The study was carried out on the basis that there is a paucity of information of people with physical disabilities especially youth in South Africa and as such the issues of health promotion of these youth have not been sufficiently explored. In addition research in other parts of the world indicates that youth with physical disabilities are at significant risk for secondary complications such as respiratory problems, heart disease, stroke, urinary tract infections, pressure sores and emotional disorders. This according to literature could be due to the direct impact of the residual disability after a spinal cord injury or due to a choice of poor

lifestyle habits. A qualitative approach utilising face-to-face and focus group methods of data collection were used to guide the study.

The findings of this study indicate that most of the participants were indeed involved in risky health behaviours including sedentary lifestyles and substance usage such as alcohol, drugs and tobacco. A number of factors influenced participant's choice of the behaviours that they were involved in, including difficulties in identity adjustment after the injury, intrapersonal, interpersonal and environmental barriers and psychosocial difficulties associated with the adjustment to a new identity.

### **6.2 CONCLUSION**



Taken as a whole this study revealed that, participants had a number of health promotion needs mainly resulting from their health-related behaviours and the circumstances of the injury. The findings of this study indicate that participants were involved in health risk behaviours, which are associated with development of secondary conditions such as respiratory problems, heart disease, and stroke. Although a majority of participants reported being actively involved in sports prior to the injury, most of them had resorted to sedentary lifestyles after the injury. This, as the participants reported was influenced by various factors such as issues of self-identity, barriers including, intrapersonal, interpersonal and environmental issues.

As a result of the difficult process of adjusting to a “new identity” after the injury, many participants had resorted to substance usage as a coping strategy. Involvement in these health-risk behaviours indicates susceptibility to secondary conditions disease in the long term. It is clear that, health promotion strategies to encourage participation in physical activity and elimination of substance usage are needed to avoid the long-term consequences of sedentary lifestyles and substance usage in youth as they make the transition to adulthood.

### **6.3 RECOMMENDATIONS**

Based on the findings of this study, a number of recommendations are made:

- It is recommended that rehabilitation professionals expand their services to include individualised health promotion strategies in the rehabilitation programmes of physically disabled youth with spinal cord injury. In particular, physiotherapists have a window of opportunity for initiating health promotion interventions early in the rehabilitation program. These health promotion interventions need to initially, be incorporated into the treatment goals of these individuals so as to address specific needs of each individual. Once the spinal cord injured youth are discharged back into the community, follow-up workshops in the community can be organised to assist in the formation of support groups to ensure continuity of the health promotion practices.

- Social support was found to be an important resource for a choice of positive health-related behaviours. Given the importance attached to emotional support from family and friends, it is recommended that family and friends of spinal cord injured individuals are involved from the commencement of the rehabilitation process. It is further recommended that, informational support aimed at increasing awareness of the importance of physical activity, the dangers of substance usage including alcohol, tobacco and drugs be offered to the spinal cord injured youth. This information should also be availed to family and close friends for sustenance.
- The issues that were raised by the physically disabled youth with spinal cord injury in this study need to be studied further using a larger sample size. Further research is needed to enhance the understanding of the interplay of health risk factors such as the influence of psychosocial adjustment on health-related behaviours.

### **6.4 LIMITATIONS OF THE STUDY**

First this being a qualitative study, purposive sampling was used to select the participants for the study and with the kind of in-depth information required a small sample size was preferred. The findings of this study therefore cannot be generalised to all physically disabled youth with spinal cord injury.

## Conclusion and Recommendations

Secondly the use of the English language may have limited participants' expressions as opposed to if their own native language had been used. Despite these few limitations, the study revealed some interesting insights about the issues surrounding the health promotion needs of physically disabled youth with spinal cord injury in South Africa.



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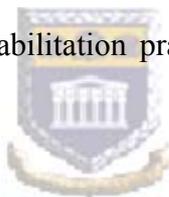
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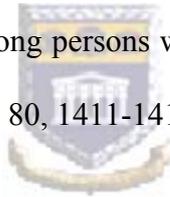
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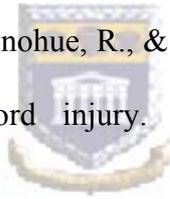
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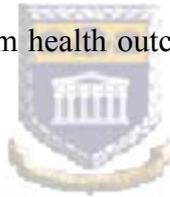
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