

**QUALITY OF LIFE OF INDIVIDUALS SUFFERING FROM SPINAL CORD
INJURY IN NAMIBIA**

UTE SINKALA

Thesis submitted in partial fulfilment of the requirements for the degree of Master of
Arts (clinical psychology) at the University of Namibia.

Supervisor: Dr. K. Burkhardt

Co-supervisor: Professor H. Naudé

Co-supervisor: Professor J. Buitendach

January 2010

ABSTRACT

Literature has found that paraplegic as well as quadriplegic individuals are presented with a range of challenges, which are similar as well as frequent amongst them.

These include stigmatisation, discrimination, problems related to family, work and independence. Health problems such as bowel and bladder control, infections and pressure sores, as well as related psychological problems are also common (Lustig, 2005). Paralysis impacts on all areas of an individual's life, because it has physical, psychological, social, and environmental effects. Thus, it impacts on the individual's overall well-being, their level of satisfaction with life, as well as their perception of the quality of their life.

The purpose of this qualitative study was to explore the themes that represent quality of life and the meaning of quality of life, as defined by adults with paraplegia or quadriplegia. Purposive sampling was employed and seven people (3 females, 4 males; 3 persons with quadriplegia, 4 with paraplegia) participated in this study.

Semi-structured interviews, which present the participants with maximum opportunity to convey their perceptions, were utilised for data collection. The semi-structured interviews were recorded, transcribed and analysed through interpretive phenomenological analysis (IPA). IPA is prescribed as the most effective way of analysing qualitative data within exploratory psychological studies.

Based on the findings of this study, quality of life is summarised as the evaluation of

an individual's life, which is determined by the individual's health, psychological wellbeing, living environment, relationships, as well as their future outlook.

Additionally, the results indicate that quality of life, regardless of the severity of the injury is related to the following fourteen themes: aspirations, emotional wellbeing, identity, recreation, spontaneity, effort and comfort, stigma and discrimination, mobility and accessibility, relationships, resources, coping, independence, physical wellbeing, and work and money.

These findings may provide the MVA Fund and other rehabilitation institutions with information necessary to help identify most relevant professionals to assist their clients with rehabilitation. In addition, the findings may also be used in the development of programs to enhance quality of life for motor vehicle accident survivors, following severe spinal cord injuries.

TABLE OF CONTENTS

CONTENTS	PAGE
Abstract	ii
Table of contents	iv
List of tables	xi
List of figures	xii
Acknowledgements	xiii
Declarations	xiv
Chapter one: The problem and its setting	1
1.1. Background and aim of the present study	1
1.2. Statement of the problem	7
1.3. Objectives of the study	9
1.4. Significance of the study	10
1.5. Theoretical and conceptual framework	11
1.6. Structure of the thesis	13
1.7. Chapter summary	15
Chapter two: Literature review	16
2.1. Definitions of key terms and concepts	17
2.1.1. Quality of life	17
2.1.2. Life satisfaction	17

2.1.3. Disability	18
2.1.4. Adulthood	19
2.1.5. Quadriplegia	19
2.1.6. Paraplegia	19
2.2. Motor vehicle accidents	20
2.2.1. Impact of motor vehicle accidents	22
2.2.2. Consequences of motor vehicle accidents	22
2.3. Spinal cord injury	26
2.3.1. Consequences of spinal cord injury	26
2.3.1.1. Physical consequences and health complications	27
2.3.1.2. Emotional and psychological consequences	27
2.3.1.3. Social and environmental consequences	29
2.3.2. Spinal cord injury and motor vehicle accidents	30
2.3.3. Positive and negative aspects of spinal cord injury	31
2.4. Coping and disability	33
2.4.1. Stress	33
2.4.2. Disability related stress	33
2.4.3. Coping	37
2.4.3.1. Coping mechanisms	37
2.4.3.2. Coping and spinal cord injury	39
2.5. Quality of life	41
2.5.1. Theoretical models	42
2.5.1.1. Response shift and quality of life model	43
2.5.1.2. Measurement model of quality of life	48

2.5.2. Domains of quality of life	51
2.5.3. Importance of quality of life	53
2.5.4. Quality of life measures	53
2.5.4.1. Unidimensional models of measurement	55
2.5.4.2. Multidimensional models of measurement	56
2.5.5. Spinal cord injury and quality of life	58
2.5.6. Quality of life themes	61
2.6. Conclusion	68
2.7. Chapter summary	70
Chapter three: Theoretical framework	72
3.1. Maslow's theory of human motivation	73
3.1.1. Biological and physiological needs (deficiency needs)	81
3.1.2. Safety and security needs (deficiency needs)	82
3.1.3. Belongingness and love needs (deficiency needs)	83
3.1.4. Esteem needs (deficiency needs)	84
3.1.5. Cognitive needs	86
3.1.6. Aesthetic needs	87
3.1.7. Self-actualisation needs	88
3.1.8. Self-transcendence needs	89
3.1.9. Relatedness between levels of needs	89
3.1.10. Summary of Maslow's theory of human motivation	91
3.2. Person-environment fit theory	92
3.2.1. Supplies-values fit	97

3.2.2. Demands-abilities fit	98
3.2.3. Summary of person-environment fit theory	100
3.3. Defence mechanisms	101
3.3.1. Defence mechanisms related to problem-focused coping	106
3.3.2. Defence mechanisms related to emotion-focused coping	107
3.3.3. Summary of defence mechanisms	109
3.4. Chapter summary	110
Chapter four: Empirical study	112
4.1. Research Design	112
4.1.1. Stages of research	113
4.1.2. Validity	116
4.2. Participants	120
4.2.1. Population	120
4.2.2. Sampling	120
4.2.2.1. Information on the sample	121
4.2.2.2. Participant information	125
4.2.2.3. Guidelines on sampling for qualitative studies	125
4.3. Data collection	126
4.3.1. Measurement instrument	126
4.3.2. Semi-structured interviews	127
4.3.3. Guidelines on interviewing	129
4.4. Procedures	130
4.5. Data analysis	132

4.6. Report writing	134
4.7. Ethics	134
4.8. Chapter summary	136
Chapter five: Results	137
5.1. Definition of quality of life	137
5.2. Discussion of themes	140
5.2.1. Aspirations	141
5.2.2. Emotional wellbeing	145
5.2.3. Identity	149
5.2.4. Recreation	152
5.2.5. Spontaneity	154
5.2.6. Effort and comfort	156
5.2.7. Stigma and discrimination	159
5.2.8. Mobility and accessibility	162
5.2.9. Relationships	166
5.2.10. Resources	169
5.2.11. Coping	172
5.2.12. Independence	176
5.2.13. Physical wellbeing	180
5.2.14. Work and money	183
5.3. Chapter Summary	187

Chapter six: Discussion	188
6.1. Definition of quality of life	188
6.2. Quality of Life Themes	192
6.3. Discussion of the themes	195
6.3.1. Intrinsic themes	195
6.3.1.1. Aspirations	196
6.3.1.2. Emotional wellbeing	201
6.3.1.3. Identity	205
6.3.2. Summary of intrinsic factors	210
6.3.3. Extrinsic themes	211
6.3.3.1. Recreation	213
6.3.3.2. Spontaneity	214
6.3.3.3. Effort and comfort	217
6.3.3.4. Stigma and Discrimination	220
6.3.3.5. Mobility and accessibility	223
6.3.4. Summary of extrinsic themes	226
6.3.5. Support themes	227
6.3.5.1. Relationships	228
6.3.5.2. Resources	232
6.3.6. Summary of support themes	238
6.3.7. Coping	239
6.3.8. Independence	245
6.3.9. Physical wellbeing	249
6.3.10. Work and money	253

6.4. Conclusion	258
6.5. Chapter summary	259
Chapter seven: Summary of findings, recommendations and critical review	261
7.1. Main findings	261
7.1.1. Findings with regard to the definition of quality of life	261
7.1.2. Findings with regard to the quality of life themes	262
7.1.3. Findings with regard to the Namibian context	264
7.2. Shortcomings, limitations and recommendations for research	266
7.3. Recommendations to medical and rehabilitation professionals	269
7.4. Critical review of the study	271
7.5. Challenging aspects of the study	272
7.6. Benefits	272
References	277
Appendices	
A. MVA Fund: Letter requesting permission to conduct thesis research	293
B. Semi-Structured Interview Guide	297
C. Research participant: informative letter	298
D. Consent form	300

LIST OF TABLES	PAGE
Table 1: Demographic details of the participants	122
Table 2: History and personal details of the participants	123
Table 3: Definition of quality of life	139
Table 4: Aspirations	142
Table 5: Emotional wellbeing	146
Table 6: Identity	150
Table 7: Recreation	153
Table 8: Spontaneity	155
Table 9: Effort and comfort	157
Table 10: Stigma and discrimination	160
Table 11: Mobility and accessibility	163
Table 12: Relationships	167
Table 13: Resources	170
Table 14: Coping	173
Table 15: Independence	177
Table 16: Physical wellbeing	181
Table 17: Work and money	184

LIST OF FIGURES	PAGE
Figure 2.1: Response shift and quality of life model	46
Figure 3.1: Maslow's eight-level hierarchy of needs pyramid	79
Figure 4.1: Representation of the research design from stage one to four	119

ACKNOWLEDGEMENTS

First and foremost, I thank God for His grace and mercy for giving me the ability to write and complete this thesis.

I thank my supervisor, Dr. Burkhardt, for her vigilance, and the invaluable insight, support, and guidance she offered me.

I want to thank my co-supervisor, Professor Naudé, for being supportive and allowing me to draw from her wisdom.

I want to extend my gratitude to my husband, son, friends and family for their love, understanding, and encouragement.

I wish to thank the Motor Vehicle Accident Fund of Namibia (MVA Fund) for granting me access to their clients.

Lastly but most importantly, I would like to extend my gratitude to the participants of this study, for their courage and willingness to participate. Without them, this study would not have been conclusive or even possible.

DECLARATION

I, Ute Sinkala, declare hereby that this study is a true reflection of my own research, and that this work, or part thereof has not been submitted for a degree in any other institution of higher education.

No part of this thesis may be reproduced, stored in any retrieval system, or transmitted in any form, or by means (e.g. electronic, mechanical, photocopying, recording or otherwise) without the prior permission of the author, or The University of Namibia in that behalf.

I, Ute Sinkala, grant The University of Namibia the right to reproduce this thesis in whole or in part, in any manner or format, which The University of Namibia may deem fit, for any person or institution requiring it for study and research; providing that The University of Namibia shall waive this right if the whole thesis has been or is being published in a manner satisfactory to the University.

Signature Date

CHAPTER ONE

THE PROBLEM AND ITS SETTING

Chapter one comprises the review of the motivation and aim of the present study, looking at the concept of quality of life and how it is affected by spinal cord injury. This review is followed by a statement of the problem, including the research problems, and research questions. The objectives of the study, the significance of the study, as well as the theoretical and conceptual framework will also be provided. Lastly, chapter one outlines the structure of the thesis.

1.1. Background and aim of the present study

Motor vehicle accidents are among the leading causes of death in the world, including Namibia (Accident & Injury Prevention Sub Unit, 2009). For a large number of survivors, these accidents result in permanent, life changing injuries such as spinal cord injuries (Cagnetta & Cicognani, 1999). Such injuries may result in disabling paraplegia or quadriplegia, with major consequences.

Sudden-onset disability affects a wide range of life activities, such as problems with mobility, sexual function, bowel and bladder control, infections, and pressure sores. Such disability forces individuals to cope with challenges related to work, family, independence, societal reactions towards them, negative attitudes as well as

discrimination (Bishop, 2005; Chase, Cornille, & English, 2000; Dijkers, 1996; Lustig, 2005).

An individual with paraplegia or quadriplegia has to cope with changes in their social roles and interactions. In addition, they have to cope with a changed body image, find new ways of doing things, and accept increased dependence on others for the performance of familiar tasks (Dijkers, 1996). Thus, spinal cord injury requires life-long physical, psychological, social, and environmental adaptation. It impacts on every area of an individual's life and affects their quality of life by reducing opportunities for satisfaction as well as control in personally important areas of life (Bishop, 2005).

Several studies have been conducted to explore the concept of quality of life and to determine the factors that are perceived as essential in determining, defining, and assessing quality of life (Boswell, Dawson, & Heininger, 1998; Budh & Österaker, 2006; Gill & Feinstein, 1994; Hammell, 2004; Lanig, Chase, Butt, Hulse, & Johnson, 1996; Manns & Chad, 2001; Raeburn & Rootman, 1996; Renwick & Friefeld, 1996; Youngkhill & McCormick, 2006). These researchers concur that quality of life should be viewed from the subjective perspective of the individuals being assessed. In addition, they stress that comprehensive evaluation of quality of life should consider factors such as health, employment, material comforts, perceived control, social support, and social relationships.

Furthermore, Hampton (2004) also considers quality of life to be related to an individual's assessment of their satisfaction with their own life. According to Bishop (2005), life satisfaction in highly valued areas of life (such as relationships with family and friends, health, physical fitness, career, and finances) is considered to have a greater influence on the evaluation of overall quality of life, compared to areas of equal satisfaction but lesser importance. For example, a married mother might view family relationships as more valuable than a single woman who views friendship as the most important area. Accordingly, the loss of a friendship might affect the quality of life of the single woman more than it would affect that of the married woman.

Thus, for a more accurate, optimum, and meaningful assessment, researchers should utilise the subjective perceptions of people with a spinal cord injury to determine the areas in life, which have the most significant influence on their quality of life, as well as the degree of importance of these areas. Such subjective measures of quality of life also enable the researcher to explore a greater range of topics related to quality of life (Bishop, 2005; Boswell et al., 1998; Budh & Österaker, 2006; Day & Jankey, 1996; Dijkers, 1996; Fabian, 1991; Gill & Feinstein, 1994; Manns & Chad, 2001; Whiteneck, 1994).

Rehabilitation programs for individuals who are paraplegic or quadriplegic aim to improve the individual's overall quality of life. Therefore it is imperative that such programs include a comprehensive assessment of quality of life (Bishop, 2005; Hampton, 2004; Wood-Dauphinee & Kuchler, 1992). Such assessment is a

meaningful determining factor for the quality of life of people with paraplegia or quadriplegia. The measure of which may give an indication as to how successful a rehabilitation program is (Hall, Harper, & Whiteneck, 1997).

Despite the above mentioned need to incorporate measurement of quality of life in rehabilitation programs, Manns and Chad (2001) noted that, until recently developers of rehabilitation programs have mistakenly assumed that quality of life may be deduced from general measures of an individual's health or functional status.

Practitioners wrongfully accepted that an improvement in an individual's health or functional status results in a direct improvement in their quality of life. However, research has found that measures of physical health and functional status are not based on an accurate and comprehensive understanding of quality of life, thus such measures may not be used to deduce an individual's quality of life (Manns & Chad, 2001; Renwick & Friefeld, 1996; Schulz & Decker, 1985).

In order to prevent such assumptions, the present study highlights the importance of the participant's subjective views in the assessment of their quality of life. This study aims to use semi-structured questionnaires to explore the quality of life of road accident survivors, who suffered spinal cord injuries, resulting in paraplegia or quadriplegia, as well as establish the themes that determine their quality of life.

According to Barbotte, Guillemin, Chau, and Lorhandicap Group (2001), an individual's physical health, psychological state, personal beliefs, social relationships and how they relate to significant features of their environment, are all essential

contributing factors to quality of life. One of the most comprehensive definitions of quality of life has been provided by the World Health Organisation (WHO). Quality of life is defined as “an individual’s perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (WHO Quality of Life Group, as quoted in Miller, Chan, Ferrin, Lin, & Chan, 2008, p. 221).

According to the researcher’s knowledge, the majority of studies relating to quality of life, including the above mentioned studies, have been conducted in developed countries, and it is the first time that such a study will be conducted in Namibia. Compared to these developed countries, Namibia, which is a developing country, has a unique population. The World Factbook (Central Intelligence Agency [CIA], 2009) indicates that Namibia has a small population of 2.1 million, compared to developed countries such as Canada and America with a population of 33 million and 307 million respectively. Namibia also has a very low literacy rate of approximately 85 percent compared to literacy rates of 99 percent in Canada and America. There is a very high prevalence rate of and deaths due to HIV/AIDS in Namibia. At 51 years, the Namibian life expectancy is also much lower than 81 years in Canada and 78 in America. Furthermore, Namibia is a country full of diversity as indicated by the minimum of nine ethnic groups and at least 13 language groups which were identified by The World Factbook (CIA).

In addition, Namibia is a young democracy, which has only been independent for 20 years. It is still feeling the aftermath of colonialism and the apartheid regime, as the

country with the most unequal income distribution in the world (Karuuombe, 2001). The expected minimum earning for low income groups in Namibia was set at N\$ 1 676 in 2007 (Labour Resource and Research Institute [LARRI], 2008). According to the United Nations Human Development Report 2005, 34.9% of the Namibian population live on US\$1 per day and 55.8% live on US\$2 per day (United Nations Development Program [UNDP], 2005). The richest 20% of the Namibian population earn 77% of the gross domestic product (GDP) in Namibia. The bottom tier mostly consists out of black Namibians who form 87.5% of the Namibian population (CIA, 2009). The likelihood was thus high that the majority of the participants who seek assistance from the MVA Fund would fall under this low income bottom tier. The above mentioned may thus be the reason why the participants of the present study mainly consist of black individuals from such low income groups.

As mentioned previously, the researcher is not aware of previous Namibian research into quality of life. Therefore the researcher aims to use the findings from several of the above mentioned studies, particularly Bishop (2005) as well as Manns and Chad (2001), for tentative, comparative interpretation into the emerging quality of life themes. This is done in an attempt to provide specific information regarding people with paraplegia and quadriplegia in the Namibian context. The present study may serve as a baseline for future studies into quality of life in Namibia, even though these findings lack generalisability, and researchers are cautioned to avoid extrapolating findings to other populations.

The Motor Vehicle Accident Fund of Namibia (MVA Fund) manages most of the severe spinal cord injury cases that are due to road accidents in Namibia. Hence, the database of the MVA Fund was utilised to select the initial, prospective research participants. The MVA Fund is a statutory body established to design, develop, promote as well as implement motor vehicle accident and injury prevention measures in Namibia (MVA Fund, 2008). It intends to provide benefits to all people involved in accidents on the Namibian roads. The MVA Fund aims to help its clients adapt and cope successfully with their physical changes, emotional difficulties and related challenges. To ensure that their clients receive the best medical care and rehabilitation possible, the MVA fund contracts a team of experts. These include physiotherapists, occupational therapists and speech therapists to care for the functional aspects of the clients' bodies, social workers to ensure social well-being, medical doctors and nurses for the clients' physical health, and counsellors as well as psychologists who provide psychological support. These strategies are implemented as an attempt to improve the individuals' life satisfaction under difficult circumstances, including paralysis, following a motor vehicle accident. The motivation of the proposed study is thus founded on obtaining information regarding these paraplegic and quadriplegic clients' subjective quality of life.

1.2. Statement of the problem

Improving quality of life is an inherent goal for rehabilitation programs for people with disabilities such as paraplegia and quadriplegia, and examination thereof is an essential attribute of patient care. However, researchers agree that, although there

have been various attempts to define and measure quality of life accurately, defining and measuring quality of life has remained problematic (Boswell et al., 1998; Oliver, Huxley, Bridges, & Mohamad, 1996). Various researchers, including the above mentioned, have provided measures and defined quality of life, mainly in developed countries. In Namibia, to the researcher's knowledge, there is no evidence of previous research conducted to define or measure the quality of life of people with spinal cord injury.

According to Boswell et al. (1998) utilising subjective perceptions through methods such as interviews to obtain direct responses from participants concerning their quality of life adds valuable information, which may not be obtained by traditional methods such as questionnaire surveys. Based on this background, the proposed study will utilise semi-structured interviews to determine quality of life, as opposed to the traditional use of questionnaires, which focus only on the opinions of professional service providers. Future studies may aim to combine questionnaires as well as interviews in an attempt to approach the assessment of quality of life from a more comprehensive multidimensional perspective.

The present study has identified the following research problems:

- Motor vehicle accidents are frequent and often result in paraplegia or quadriplegia causing reduced physical capacity. In turn, this has physical as well as psychological implications.

- Traditionally, rehabilitation of paraplegic and quadriplegic individuals was more focused on improvement of physical health and functional status. The psychological aspects of the disability were often neglected. Research provides evidence supporting the need for subjective views in assessing quality of life and developing rehabilitation programs. Thus, a need exists for a shift in focus from more objective to increasingly subjective measures of quality of life.
- There is a lack of research into the quality of life of paraplegic and quadriplegic individuals in Namibia.

The research questions guiding this study have been formulated as follows:

- What are the most essential, contributing factors to quality of life?
- How do paraplegic and quadriplegic individuals define quality of life?
- What are the life themes that determine quality of life?
- What is the subjective level of quality of life as perceived by paraplegic and quadriplegic individuals following a spinal cord injury?

1.3. Objectives of the study

It is essential to determine the subjective quality of life of individuals with paraplegia or quadriplegia. This information may be used as groundwork to develop rehabilitation programs, which may help improve individuals' quality of life and level of life satisfaction.

The present study is guided by the following objectives:

- Identifying the factors that are most influential in affecting individuals' quality of life.
- Determining the definition of quality of life from the perspective of paraplegic and quadriplegic individuals.
- Identifying the self-perceived themes that determine quality of life.
- Examining the level of satisfaction or lack of satisfaction with the identified themes.

Once the study has been completed, the MVA Fund and other relevant stakeholders will be provided with the results from the study. These results may provide valuable information which may assist in improving their rehabilitation programs.

1.4. Significance of the study

Trauma after a spinal cord injury may result in feelings of vulnerability, insecurity, lower self-esteem, increased worry as well as pain and psychological problems such as depression and anxiety (Budh & Österaker, 2006; Cagnetta & Cicognani, 1999; Lustig, 2005). Depression, anxiety and pain affect physical, psychological and social functioning thus, one may assume that these problems have a negative impact on perceived satisfaction with important aspects in an individual's life. Therefore, it may decrease perceived quality of life.

Findings from this study may identify important themes that have an impact on and determine quality of life for individuals with paraplegia or quadriplegia. The knowledge gained may lay the groundwork, which could aid in highlighting specific areas for rehabilitation professionals to focus on, in the rehabilitation programmes aimed at improving perceived quality of life among individuals with spinal cord injuries.

In addition, these findings may assist in designing tailor made, more focused rehabilitation programs, which may lead to reduced treatment costs. Consequently, the findings might empower paraplegic and quadriplegic individuals personally, to address important aspects in their lives, improve their satisfaction in vital realms of their lives and possibly lead to an enhanced perception of overall quality of life.

1.5. Theoretical and conceptual framework

According to Orford (1992) quality of life approaches the concepts of psychological help and distress from a perspective of groups and society, it moves away from an individualistic, symptom oriented approach. Moving away from a symptom oriented approach when assessing quality of life implies that, physical symptoms of health alone may not be used as assessment criteria for wellbeing and satisfaction. Intrinsic factors of happiness, together with environmental factors, and support from people contribute to an individual's wellbeing and satisfaction with life, which in turn contribute to overall quality of life.

The proposed study recognises the complexity of human behaviour, it therefore steers away from single theory frameworks and draws from different theories to conceptualise quality of life. Firstly, Abraham Maslow's hierarchical theory of human motivation (1943), which is founded on the premise that human beings are motivated by needs to behave or act, is utilised to contextualise perceived quality of life. People are motivated by the desire to achieve or maintain various conditions or lifestyles and they engage in activities that enable them to satisfy this desire (Maslow). Sudden onset paralysis presents major challenges, which influence this desire as well as the ability to achieve goals and remain satisfied. This in turn influences the individual's level of satisfaction, and ultimately, it may affect quality of life.

Secondly, the person-environment fit theory is utilised to create an understanding of the perceptions of individuals within the context of their environment, including the daily challenges they face. The person-environment fit theory is based on the assumption that human behaviour is a function of the interaction of the individual and the environment (Livingstone, Nelson, & Barr, 1997; Orford, 1992). It is essential to incorporate this theory, as the individual with paralysis lives within an environment. Their adaptation is influenced by this environment, just as much as it is influenced by their attitude, physical abilities and limitations.

Finally, defence mechanisms are presented to promote greater understanding of individuals' actions as well as the individuals' unconscious attempts to cope with their disability (American Psychiatric Association [APA], 2005). Defence

mechanisms are unconscious psychological strategies brought into play by the individual to cope with reality and to maintain self-image (Hartmann, Kris, & Loewenstein, 1964). According to Anna Freud (1936/1937), when anxiety becomes too overwhelming, the ego unconsciously employs defence mechanisms to protect the individual. Freud further stresses that feelings of guilt, embarrassment, and shame often accompany the feelings of anxiety. Anxiety related to their future as well as guilt related to the cause of the accident are feelings that motor vehicle accident survivors often struggle with. Therefore, a discussion on defence mechanisms is viewed as vital.

1.6. Structure of the thesis

Chapter One is an introductory chapter to the thesis. The background and aim of the present study is stated. The study explores the quality of life of individuals with spinal cord injuries. The background, statement of the problem, including the research problems, and research questions are outlined.

In chapter one, the objectives of the study, the significance of the study as well as the theoretical and conceptual framework are also provided. Chapter one concludes with an outline of the structure of the thesis.

Chapter Two is a literature study in which the relevant literature and research findings on the subject of quality of life and spinal cord injury are reviewed. The key

concepts pertaining to quality of life are defined. These concepts include life satisfaction, disability, adulthood, quadriplegia and paraplegia.

Chapter three is dedicated to outlining the theoretical framework for this thesis.

Abraham Maslow's theory of human motivation is discussed as the main theoretical framework for understanding human needs as well as the individual's strive towards satisfaction of needs. The person-environment fit theory is explored as a relevant theoretical basis for understanding individuals within the context of their environment, while facing challenges related to the disability. Finally, a discussion of defence mechanisms is incorporated to foster greater understanding of individuals' actions as well as their attempts to cope with their disability.

In **chapter four**, the research methodology employed to obtain and analyse data is outlined and explained. The research design, participants and sampling, measuring instruments, research procedures, data analysis, and ethical considerations are discussed in chapter four.

In **chapter five** the results of the research study are reported. Firstly, the definition of quality of life is reported in table form. This is followed by tabular representation of the 14 themes of quality of life.

Chapter six is dedicated to discussing the results of this research study.

Chapter seven summarises the findings, discusses a critical overview on the research study as well as the limitations and benefits of the study. Recommendations are also provided in chapter seven.

1.7. Chapter summary

In chapter one, the background and aim of the present study is discussed. The statement of the problem, including the research problems, and research questions are presented. The objectives of the study, the significance of the study, the theoretical and conceptual framework, as well as structure of the thesis also are outlined.

The following chapter presents a literature review of research finding on quality of life and disability, particularly spinal cord injury resulting in paraplegia or quadriplegia.

CHAPTER TWO

LITERATURE REVIEW

The main focus of this chapter is to provide a comprehensive overview of the relevant literature and research findings on the subject of quality of life and spinal cord injury. Different concepts related to quality of life, as well as factors contributing to quality of life will be explored in order to gain a better understanding of the impact of spinal cord injury on quality of life.

In the first section of this chapter, the key concepts pertaining to quality of life are defined. These include life satisfaction, disability, adulthood, quadriplegia, and paraplegia. Following the definitions is a discussion on spinal cord injury, the consequences of sustaining such an injury, stress, as well as coping after sustaining a spinal cord injury. Thereafter, the concept quality of life will be reviewed, including the domains of quality of life, theoretical models, measurement of quality of life, and related aspects.

To the researcher's knowledge, no research has been done on the quality of life of individuals with spinal cord injury in Namibia. Therefore, the latter section of this chapter will be dedicated to a discussion on various researches done on the quality of life of individuals with spinal cord injury in other countries. Although results from studies in other countries may not be generalised and applicable to Namibia, these findings provide a sound background to base this study on.

2.1. Definitions of key terms and concepts

2.1.1. Quality of life

Quality of life is defined by Bishop (2005) as the subjective and personally derived measurement of overall well-being. Quality of life is assessed through the evaluation of satisfaction across a set of personally or clinically important domains in life.

Intrinsic to this definition, is the assumption that overall quality of life is linked to life satisfaction (Bishop). According to the WHO Quality of life Group (WHOQOL Group) (as quoted in Miller et al., 2008), the WHO defines quality of life as the “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (p. 221). Based on the WHO’s definition of quality of life, Barbotte et al. (2001) adeptly state that quality of life is a holistic concept that is influenced by several factors. An individual's physical health, psychological state, personal beliefs, social relationships and their relationship to significant features of their environment are all essential contributing factors to quality of life.

2.1.2. Life satisfaction

Life satisfaction is defined by Haybron (2005) as having a favourable attitude toward one’s life as a whole. It requires being satisfied, not merely thinking that things are satisfactory. Life satisfaction is a subjective measure that embodies an assessment of life as a whole based on how well personal goals match with personal achievements

(Budh & Österaker, 2006). Related to this study, losing all voluntary movement in your legs or your whole body not only compromises your physical health but also lowers an individual's life satisfaction. Thus, life satisfaction is usually compromised or lowered by spinal cord injury (Chase et al., 2000).

2.1.3. Disability

A comprehensive understanding of disability requires an overview of the concepts, impairment, disability, and handicap as distinguished by the WHO (1980).

Impairment represents any failure of function or abnormality at the organ level. It is limited to the physical, observable level of functioning such as loss of strength and range of motion. Disability is caused by limitations due to impairments, and or the lack of the ability to perform an activity in the manner or within the range considered normal based on age and gender. Disability occurs at the individual level and may be visible, or it may be cognitive. Handicap occurs at the societal level and represents a disadvantage that limits or prevents people with a disability from fulfillment of a role that is typical (WHO). Loss of ability to walk may be regarded as the impairment linked to a spinal cord injury. Requiring a wheelchair for mobility refers to the disability and handicap reflects limitations that result from the lack of accessibility to buildings or lack of ramps on sidewalk.

2.1.4. Adulthood

Adulthood is defined as the period from late teens or early twenties up until old age and death. It encompasses early adulthood (late teens to late thirties), middle adulthood (early forties to sixties), and late adulthood (sixties and seventies until death) (Santrock, 2004). In the proposed study, adulthood will refer to adults in early and middle adulthood.

2.1.5. Quadriplegia

Quadriplegia is defined as paralysis of all four limbs, usually as a result of injury to the upper part of the spine (Colman, 2006). It is also known as tetraplegia. According to Elliott and Rivera (2002) the degree of injury is described as complete or incomplete, depending on the degree of loss of either motor or sensory function or both. A complete injury causes the absolute loss of all voluntary movement below the level of injury. An incomplete injury allows for the partial retention of movement or sensation below the level of injury (Elliott & Rivera). The quadriplegic participants in this study have sustained incomplete spinal cord injuries, although only one participant has regained enough motor function to be able to walk.

2.1.6. Paraplegia

Paraplegia is defined as paralysis of the lower limbs, usually as a result of lesions in the lower or middle part of the spinal cord (Colman, 2006). Every one of the

participants in this study who are paraplegic, have sustained complete spinal cord injuries (as defined in section 2.1.5.). They have thus lost all voluntary movement below the level of injury, as indicated by (Elliott & Rivera, 2002).

The above section reflects the main concepts pertaining to this study. The following section is a review of the statistics related to motor vehicle accidents in Namibia. Subsequent paragraphs explore the impact of surviving traumatic events such as motor vehicle accidents. Furthermore, the impact of sustaining severe injuries such as spinal cord injuries, as well as its impact on the quality of life of the survivors is examined.

2.2. Motor vehicle accidents

The focus of this study is on the quality of life of the participants after sustaining spinal cord injuries in motor vehicle accidents. Thus, it is essential to consider the relevant statistics related to motor vehicle accidents in Namibia.

According to the Motor Vehicle Accident Fund of Namibia's (MVA Fund) Accident & Injury Prevention Sub Unit (2009), motor vehicle accidents are among the leading causes of death in Namibia. Furthermore, thousands of people are also injured or disabled on the Namibian roads yearly. The WHO's report on youth and road safety (as cited in Accident & Injury Prevention Sub Unit) reveals that the vast majority of deaths and injuries due to motor vehicle accidents occur in low-income and middle-income countries such as Namibia. Furthermore, economically active young people

are at greatest risk of injury or death in a motor vehicle accident. It is also evident that young males are at higher risk for road traffic fatalities as well as injuries and this has remained unabated in Namibian history (Accident & Injury Prevention Sub Unit).

The latest statistics of the MVA Fund (Accident & Injury Prevention Sub Unit, 2009) indicate that at least a total of 797 accidents were reported during the period of January up to June, 2009. In comparison with the 2008 statistics for the same period, a total of 868 accidents were recorded, which indicated a reduction in the number of accidents by 8.2% in 2009. The number of fatalities recorded during the first-six months in 2009 is 258 compared to 154 in 2008. Thus, these statistics indicate an increase in the number of fatalities by 68% even though the actual number of accidents decreased (Accident & Injury Prevention Sub Unit).

In addition, an immense increase in the number of injuries by 88% is also recorded in 2009 (1087 injuries) compared to 2008 (577 injuries) (Accident & Injury Prevention Sub Unit, 2009). Statistics also point out that most of the casualties were young people, ranging between the ages 21 to mid 30s (36%), followed by people between 31- 40 years of age (24%) (Accident & Injury Prevention Sub Unit). These statistics highlight the need to explore accident related injuries and its effects on the Namibian people. The age range of the population representing the largest number of casualties on the Namibian roads during 2008 and 2009 is comprised of adults in early and middle adulthood (Accident & Injury Prevention Sub Unit). This particular age group comprised the population from which the sample, for the present study,

was drawn.

2.2.1. Impact of motor vehicle accidents

Surviving a motor vehicle accident is a traumatic event for individuals, despite the extent of and severity of the injuries sustained. Surviving a traumatic event has an impact on various areas of the survivors' lives (Blanchard & Hickling, 1997). The more severe the injury, the more severe and longer lasting the stress response is likely to be. Moreover, it may influence the way in which an individual adapts to changes after the traumatic event. Following traumatic motor vehicle accidents, victims may experience hardships that they did not experience before the event. When the injuries sustained are severe, such as spinal cord injuries, the resulting hardships are more severe and require significantly greater adjustment than when the injuries are minor (Blanchard & Hickling).

Thus, the impact of surviving motor vehicle accidents on individuals' lives regardless of the types of injury is explored in the following section. Succeeding paragraphs explore the consequences of sustaining a spinal cord injury.

2.2.2. Consequences of motor vehicle accidents

As the statistic by the MVA Fund indicate (see section 2.2.), motor vehicle accidents happen frequently, often resulting in death, and sometimes survivors sustain severe injuries, such as spinal cord injuries. The Accident and Injury Prevention Sub Unit

(2009) also indicate that the number of fatalities has risen by 68% in the past year. Despite the overwhelming figures, in Namibia, to the researcher's knowledge, studies have not been conducted to explore the effects of surviving motor vehicle accidents on individuals and there are no statistics available on the number of accident victims who sustained spinal cord injuries.

Cagnetta and Cicognani (1999) reiterate the paucity of studies that have aimed to explore the psychological effects of surviving major motor vehicle accidents and the impact it has on the different dimensions of the survivors' lives. The few researchers who have explored this aspect have found that acute stress disorder, post-traumatic stress disorder (PTSD), generalized anxiety, panic disorder, phobic anxiety, panic reactions, depression, feelings of guilt, sleep disturbances, and psychosis are some problems that have been reported amongst survivors of motor vehicle accidents (Blanchard & Hickling, 1997; Cagnetta & Cicognani, 1999; de L. Horne, 1996; Di Gallo & Parry-Jones, 1996; Feinstein, 1996; Reynolds & Tarrier, 1996).

The National Center for PTSD (2007) reports that during and immediately after a traumatic event, many people feel overwhelmed with fear, while others feel numb or disconnected. Emotional, cognitive, physical, as well as interpersonal effects, which traumatic events have on the survivors, were identified by the National Center for PTSD. The emotional effects are shock, irritability, blame, anger, guilt, sadness, emotional numbing and helplessness. Cognitive effects include weakened concentration, poor memory, disbelief, confusion, nightmares, decreased self-esteem, self-blame, intrusive thoughts or memories, and worry. Physical effects refer to

fatigue, exhaustion, insomnia, cardiovascular strain, startle response, increased physical pain, reduced immune response, headaches, gastrointestinal upset, decreased appetite, decreased libido and vulnerability to illness. Interpersonal effects include increased relational conflict, social withdrawal, reduced relational intimacy, decreased satisfaction, externalization of blame and feeling abandoned or rejected (National Center for PTSD).

Butler, Moffic, and Turkal (1999) explored the stress reactions of individuals who have survived motor vehicle accidents. They discovered that survivors may develop significant post-traumatic stress symptoms and many others have reactions that resemble symptoms of (PTSD). Hence, research indicates that survivors may experience disabling memories and anxiety related to the traumatic event. Butler et al. also emphasise that many of these post-traumatic stress symptoms may become chronic and develop into PTSD. If there is no intervention, accident-related PTSD can have devastating effects on the survivors' quality of life (Butler et al.). For example, after surviving a motor vehicle accident, even an individual who sustained a minor injury might experience memory loss of the accidents as well as the events that led up to the accident. This individual might also feel sad, angry, have severe headaches and decreased appetite for a period of time following the accident.

The above-mentioned difficulties and reactions that resemble post-traumatic stress symptoms are to a certain extent "normal" responses to a stressful event (Cagnetta & Cicognani, 1999). The National Center for PTSD (2007) emphasises the importance of helping survivors of traumatic events such as motor vehicle accidents to recognise

the normality of most stress reactions to trauma. Shortly after a motor vehicle accident, mild to moderate stress reactions are highly prevalent amongst survivors because they are acutely aware of the grave danger they have faced. Although stress reactions may seem severe and cause distress, they generally do not become chronic problems. Most people, with minor injuries, recover fully from mild and even moderate stress reactions within six to 16 months (National Center for PTSD). However, people who have sustained severe injuries might experience stronger reactions and they may continue having stress reaction for a longer period. This might turn out to be problematic, as such responses become dysfunctional coping mechanisms when used persistently (Cagnetta & Cicognani).

Although many of the above mentioned stress reactions appear negative, it is important to highlight that individuals also show a number of positive responses after experiencing traumatic events (National Center for PTSD, 2007). According to the National Center for PTSD, these positive responses include resilience, relief and elation at surviving calamity, a sense of excitement and greater self-worth.

Furthermore changes in the way the individual views the future, feelings of self growth, learning about oneself and positive coping mechanisms are also among the positive responses that are reported (National Center for PTSD) (see section 2.5.).

According to Cagnetta and Cicognani (1999), successful recovery requires the individual to remember and accept the traumatic event, including its consequences, as a whole. The individual should also be able to view the traumatic event as a favourable turn in his or her life (Cagnetta & Cicognani). More severely injured

survivors and those with permanent disabilities may require a longer time to adjust and adapt to the post-traumatic period (Blanchard & Hickling, 1997). Severe injuries require longer adjustment period because such injuries have a greater impact on the lives of survivors and requires more significant daily adaptation (Blanchard & Hickling).

2.3. Spinal cord injury

Spinal cord injury refers to an injury to an individual's spinal cord (Colman, 2006). According to Elliott and Rivera (2002) spinal cord injury may be described as a complete or incomplete injury, depending on the degree of loss of either motor or sensory function, or both. Based on the level of injury, it may also cause what is classified as either paraplegia or quadriplegia (Elliott & Rivera) (see section 2.1.).

2.3.1. Consequences of spinal cord injury

Spinal cord injury has many effects, it affects a wide range of life activities, and requires a lifelong process of adjustment while adapting to significant physical, emotional and psychological, as well as social and environmental changes (Bishop, 2005). Although there is no known cure for paraplegia and quadriplegia brought on by a spinal cord injury, it is possible to manage its effects, thus relieve pain and discomfort, enhance functional abilities, support adjustment, and improve mental health (Dijkers, 1996).

2.3.1.1. Physical consequences and health complications

The primary challenges due to spinal cord injury are related to its physical consequences (Budh & Österaker, 2006). Based on Crewe and Krause (2002), health complications caused by spinal cord injury include problems with mobility, arm and hand strength, dexterity, bowel and bladder control, sexual function, infections, autonomic hyperreflexia, spasticity, pressure sores and pain.

Individuals with spinal cord injury often identify pain, as one of the major problems they have to deal with (Budh & Österaker, 2006). Such pain adds onto the societal and environmental challenges, which they face daily. Budh and Österaker also found that chronic pain affects occupational status, leisure and recreational activities, quality of sleep, as well as sexuality. These physical consequences result in complications related to the individual's emotional and social well-being as well as cause challenges related to their living environment. The physical impairment caused by the spinal cord injury and subsequent disability may result in constraints or complete loss of the ability to perform common tasks such as self-care and walking (Budh & Österaker).

2.3.1.2. Emotional and psychological consequences

According to Budh and Österaker (2006), there are significant indications in research that a considerably higher proportion of individuals with spinal cord injury are depressed and anxious in comparison with able-bodied individuals of a similar

background. Consequently, individuals with spinal cord injuries commit suicide two to six times more frequently than the general population. Other researchers, such as McAweeney, Forchheimer, and Tate (1996), have also explored psychological distress, following the onset of paraplegia and quadriplegia. According to them, once individuals return home, they often experience significantly more psychological distress, including a sense of isolation, compared to their psychological wellbeing during their stay in hospital or a rehabilitation centre. Consequently, they may suffer from psychological ailments such as depression (McAweeney et al.).

Budh and Österaker (2006) report that pain, depression, and anxiety are closely related, and there is increasing evidence suggesting that psychological disorders such as depression and anxiety often coexist with and may be linked to pain. Furthermore, depression, anxiety, and pain affect physical, psychological and social functioning, thus it may be assumed that spinal cord injury-related pain has a negative impact on perceived quality of life (Budh & Österaker).

The experience of a traumatic event such as a spinal cord injury is often difficult to reconcile with existing beliefs the individual has of the world as well as themselves. The “illusion of invulnerability”, the conviction that “it will not happen to me” which develops in early childhood and shields the individual from stress and anxiety is shattered (Janoff-Bulman, 1989). Feelings of vulnerability and insecurity increase and self-esteem lowers significantly (Gluhoski & Wortman, 1996). Individuals are no longer able to see themselves as safe and protected, instead they perceive the world as dangerous and threatening (Janoff- Bulman). They become restless, seeking

safety and security. This view is further supported by several other researchers, who report that most people who experience trauma, including spinal cord injury, report lower self-esteem, more worry, and psychological problems (Davis, 2001, Gluhoski & Wortman, 1996; Price, Kendall, Amsters, & Pershouse, 2004).

2.3.1.3. Social and environmental consequences

Physical limitations due to spinal cord injury and the related health complications may result in restrictions of role fulfillment as a worker, student, parent, partner, citizen and other expected roles (Dijkers, 1996; Price et al., 2004). Therefore, further complications caused by spinal cord injury are challenges related to work, family, finances, loss of independence, and societal attitudes that create barriers leading to handicap (Crewe & Krause, 2002). Often, the resulting disadvantages are due not so much to the disability, but rather due to societal reactions, negative attitudes and discrimination towards people with disabilities (Dijkers, 1996; Hammell, 2004). The individual with spinal cord injury is forced to cope with a changed body image, new ways of doing things, increased reliance on others for the performance of common tasks, as well as changes in his or her social roles and interactions (Dijkers).

McAweeney et al. (1996) conducted an investigation into the unmet independent living needs of individuals with spinal cord injury. They established that, many individuals with spinal cord injury require more social support and services after discharge, compared to the services they required in the hospital. McAweeney et al. provided several probable reasons for this increase in required services. Various

services such as attendant care and medication are readily available in the hospital, but might be difficult to obtain as soon as the individuals are discharged. Often, the paraplegic or quadriplegic individuals are less aware of the services they need in the hospital, they only become more conscious of their needs after they have been discharged. Frequently, a disruption in the continuity of care in the rehabilitation process is experienced when the individual is discharged. Subsequently, when an individual receives less, or poorer physical as well as emotional care, their level of satisfaction decreases, and ultimately, their quality of life decreases (McAweeney et al.).

It is evident that facing the physical limitations and health complications brought on by spinal cord injury, coupled with societal and environmental challenges is a laborious and emotionally taxing process for individuals with spinal cord injuries.

2.3.2. Spinal cord injury and motor vehicle accidents

The National Center for PTSD (2007) reports that surviving a traumatic motor vehicle accident, regardless of the severity of the injuries, may have emotional, cognitive, physical as well as interpersonal effects on the survivors. The responses of the victims and the effects of the motor vehicle accidents are compounded by suffering a spinal cord injury. This is because a spinal cord injury affects physical, psychological, social, and environmental dimensions of the individual's life as Bishop (2005) states. For example, an individual suffering from an emotional shock response, after a motor vehicle accident, has to deal with the added sadness and

compounded disbelief of realising that he or she has become paraplegic or quadriplegic. In addition to this shock and sadness, the individual must deal with cognitive effects, such as recurrent nightmares and a possibly decreased self-esteem. The expected responses or physical effects of surviving a motor vehicle accident, such as insomnia and cardiovascular strain may also increase significantly, as added health related complications may result due to the spinal cord injury (Crewe & Krause, 2002).

Interpersonal effects, for instance, social withdrawal and reduced relational intimacy, may be experienced by individuals with minor injuries following a motor vehicle accident (National Center for PTSD, 2007). However, these difficulties may be compounded by a spinal cord injury and these, in turn, may lead to strained relationships (Crewe & Krause, 2002). For example, problems may arise in a marriage if a motor vehicle accident renders a man paralysed and he loses the ability to have an erection.

2.3.3. Positive and negative aspects of spinal cord injury

Based on previous literature and research findings, the impact of spinal cord injury on an individual's life and subsequently on the individual's quality of life is immeasurable and largely negative. These negative effects include physical challenges (Crewe & Krause, 2002). For instance, spinal cord injury often causes chronic pain and such pain plays an important role in long-term satisfaction with life, often lowering satisfaction (Budh & Österaker, 2006). If pain lowers satisfaction, it

may negatively influence the individual's feelings and perceptions, following a spinal cord injury. The negative effects of spinal cord injury extend to emotional and cognitive difficulties (Davis, 2001; Gluhoski & Wortman, 1996; National Centre for PTSD, 2007), as well as challenges related to the individuals' interpersonal and social lives (Dijkers, 1996).

On the other hand, there are several studies providing evidence of some individuals indicating that dealing with severe trauma has had a positive effect on their lives (Calhoun & Tedeschi, 2001; National Center for PTSD, 2007). These individuals indicate that experiencing a traumatic event has increased their sense of self-confidence as well as resilience. They feel a sense of relief and elation at surviving the dangerous situation, a sense of excitement and greater self-worth. Individuals also indicate that experiencing trauma has given them an increased connectedness to others and an enhanced sense of the meaning of life (Calhoun & Tedeschi, 2001; National Center for PTSD, 2007). Furthermore, the National Center for PTSD reports that traumatic events such as a motor vehicle accident may also re-orient an individual to new priorities, goals or values.

Individuals adjust differently to the challenges posed by a spinal cord injury.

Ultimately, effective coping and successful adaptation is subjective, and determines whether the individual is able move forward in a purposeful, constructive manner and live a full and productive life (Livneh & Antonak, 1997; Vash, 1994).

2.4. Coping and disability

Stress is directly linked to coping (Lazarus & Folkman, 1984), and thus, before reviewing literature on coping, it is essential to review stress as a concept.

2.4.1. Stress

According to Lazarus and Folkman (1984) two characteristics must be present for stress to have an impact on an individual. Firstly, a given situation must be perceived as being demanding or threatening. Secondly, the individual must believe he or she lacks sufficient resources to cope with the situation (Lazarus & Folkman). According to Degraff and Schaffer (2008), the manner in which individuals perceive stress-provoking events and how they react to such events determines the impact stress has on the individuals' health. Stress might be a result of physical, psychological, and environmental factors that occur with illness, injury or disability, noise, crowding, temperature extremes, inadequate finances or living situations. Stress may also contribute to, as well as cause undesirable outcomes such as heart disease, cancer, hypertension, migraine headaches, peptic ulcers, allergies as well as adjustment problems and post-traumatic stress disorder (Degraff & Schaffer).

2.4.2. Disability related stress

In addition to normal stressors, which are faced by their able-bodied peers, people with disabilities experience disability-related problems and stress (Degraff &

Schaffer, 2008). Livneh and Sherwood (1991) are of the opinion that disability-related stress can come from perceived threats to several aspects in the individual's life. These include, life itself as well as well-being, body integrity, independence and autonomy; fulfillment of familial, social, and vocational roles; future goals and plans; and economic stability.

A traumatic event such as a motor vehicle accident is a stress provoking incident. When such a traumatic accident results in spinal cord injury, it is very challenging for the affected individual, as spinal cord injury in itself, causes enormous amounts of stress (Degraff & Schaffer, 2008). In addition to the above mentioned health complications related to stress (see section 2.4.1.), spinal cord injury also causes physical health related ailments, including bowel and bladder control, sexual function, infections, spasticity, pressure sores, and pain (Crewe & Krause, 2002). Therefore, greater amounts of stress will be induced by suffering a spinal cord injury, compared to suffering a minor injury in a motor vehicle accident.

Based on the above mentioned, it is clear that disability affects an individual's health and consequently the concern for health and related stress may have a negative impact on the individual's quality of life. According to Degraff and Schaffer (2008) disability often results in added stress to already stressful situations. For example, gynecological issues, such as fertility concerns and infections may be complicated by disability, although most women with disabilities are still able to bear children. On the other hand, men may face challenges related to low sperm count and impotence following a spinal cord injury (Degraff & Schaffer).

Pertaining to aging, Menter (1993) states that people with spinal cord injuries are not only concerned with chronological aging. They are also concerned with the amount of years that have passed since their injury. This concern is due to their reduced immune response and vulnerability to becoming sick as reported by the National Center for PTSD (2007). According to Dijkers (1996), at their healthiest, people with disability are still more prone to sickness than are able-bodied people. They frequently struggle with various acute illnesses as well as activity restrictions. These factors combined, have a compounding effect, causing major stress for many people with spinal cord injury (Degraff & Schaffer, 2008). As a result of this compounded effect, the individual with quadriplegia starts to realise significant functional limitations at 49 years of age, while those with paraplegia begin manifestations at 54 years (Menter). Thus, functional limitations manifest many years in advance of when one might assume able-bodied people face the same limitations. Limitations manifest even earlier for the quadriplegic individual, because the injury is higher up and results in the loss of more functions and has more severe harmful effects on an individual's health than does a paraplegic injury (Bauman & Spungen, 1994).

Trieschmann (1980) is of the opinion that the level of injury may also be an additional stress factor for individuals with paraplegia or quadriplegia. A higher level of injury, which results in the more severe paralysis, is associated with more complex and stressful issues. Many people with quadriplegia require daily assistance, have far more hypotension, and often live shorter lives than those with paraplegia. In addition, difficulties adjusting to spinal cord injury may lead to decreased quality of life, poor self care and costly multiple medical problems

(Trieschmann).

The complications and related stress arising from spinal cord injury are not only limited to physical health and psychological wellbeing. Dijkers (1996), states that as result of their impairments, people with disabilities are often robbed of educational, occupational and other opportunities. When spinal cord-injured individuals go back to school, tertiary education or employment, their disability, severely restrict their chances to enjoy community participation and contact with others. They often feel self-conscious and not able to enjoy activities in the same way as they did before the disability. In time, this causes significant amounts of stress, which may be the reason why statistics show that people with disabilities have less education, are more often unemployed, and have lower incomes (Dijkers).

Whiteneck et al. (2004) explored disability-related stress, its causes, affect, and impact on the individual. They believe that, for people with paraplegia and quadriplegia, daily stress may be caused by environmental barriers, which are a significant source of frustrating limitations. The main barriers include the natural environment, transportation, help at home, health care, and government policies related to disability (Whiteneck et al.). In order to deal with stressful situations that spinal cord injury presents, devising effective coping mechanisms to draw from is essential. These coping mechanisms are discussed below.

2.4.3. Coping

As indicated by the previous section, it is common for a typical day in the life of an individual with paraplegia or quadriplegia to present a long series of stressful situations, requiring a variety of coping methods or mechanisms (Degraff & Schaffer, 2008). Lazarus and Folkman (1984) define coping as “constantly changing cognitive and behavioral efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the individual” (p. 141). According to Cagnetta and Cicognani (1999), effective coping is determined by and is based on the individuals’ successes in solving everyday difficulties as well as being able to reach their goals and purposes in life.

2.4.3.1. Coping mechanisms

In essence, coping mechanisms may be categorised into problem-focused coping and emotion-focused coping (Lazarus & Folkman, 1984). Problem-focused coping involves defining the problem, generating alternative solutions, and weighing the alternatives in terms of the costs and benefits. It entails analytic processes that are aimed outward toward the individual’s environment as well as those aimed inward toward the individual's values and beliefs (Lazarus & Folkman). A form of problem-focused coping for a paraplegic individual may involve learning how to play wheelchair basketball to satisfy their desire to remain active and participate in sport. In this way, the individual is able to maintain some form of normality in life. Thus, the individual chooses to act positively instead of withdrawing from people and

refraining from activities.

In contrast, emotion-focused coping focuses on lessening emotional distress and includes strategies such as avoidance, minimalisation, distancing, selective attention, positive comparisons and deriving positive values from negative events (Lazarus & Folkman, 1984). For instance, emotion-focused coping such as self-blame is characteristically experienced by individuals who sustained a spinal cord injury in a motor vehicle accident (Delahanty et al., 1997). Moreover, self-blame is most often experienced by individuals who feel responsible for the accident and who feel that the accident could have been avoided (Delahanty et al.). A man who became paraplegic in a motor vehicle accident might blame himself for his injuries if he was the driver. These feelings affect the individual's self-confidence, self-esteem and optimism negatively.

Furthermore emotion focused coping is represented by individuals who engage in a process of reconstructing a world that makes sense after the spinal cord injury (Lustig, 2005). This reconstruction involves changes in both private thoughts and feelings related to the external world (Lustig). In an effort to cope, individuals engage in attempts to make sense of the injury and its consequences. They may try to find benefits or good things that came from the injury (Davis, 2001). Others may attempt to interpret the injury and its consequences in a way that fits in with their worldview or basic beliefs about how and why things happen. The individual may believe that the accident was God's plan, or that it just happened and is inexplicable, thus it should not be questioned (Lustig).

According to Lazarus and Folkman (1984), emotion-focused coping is often viewed as a nonproductive form of coping that does very little to actually reduce the stress, but merely increases an individual's comfort level. They agree that emotion-focused coping does not involve active steps to change the situation or lessen the stress as problem-focused coping does. Emotion-focused coping only aims to reduce the negative feelings around stress, often by distracting the people with disabilities from the emotions, thus helping them feel better.

However, Lazarus and Folkman (1984) are also of the opinion that emotion-focused coping may be a very productive and realistic way to address stressors caused by disability. Emotion-focused coping may be effective when the source of stress can neither be reduced nor resolved (Lazarus & Folkman), as is often the case for individuals with disabilities such as paraplegia or quadriplegia. The individual may try to comfort themselves, they may feel hopeless, without options, seeing that they will never walk again, regardless of how hard they try.

2.4.3.2. Coping and spinal cord injury

Cagnetta and Cicognani (1999) explored the quality of life, adaptation and coping strategies of car accident survivors who suffered permanent injuries such as paraplegia and quadriplegia. It was found that the severity of the injury, the individual's age at the time of the accident as well as the resources available for support (e.g. family, friends, doctors, self-help groups, education) are important factors that influence coping, adaptation and ultimately the restoration of quality of

life (Cagnetta & Cicognani). A previous study by Menter (1993) had already emphasised the importance of high school and tertiary education, stating that people who are educated about how their body functions stand a much better chance at coping successfully. Cagnetta and Cicognani also found that adaptation following a spinal cord injury is characterised by different emotional and behavioural reactions, perceived needs and by the adoption of specific coping strategies. Other researchers, including Degraff and Schaffer (2008) conducted a study to understand the coping response of spinal cord injured individuals against stress. They also found that in response to daily environmental, psychological and physical stressors, people with disabilities such as paraplegia or quadriplegia will employ primarily emotion-focused coping, not problem-focused coping.

Coping strategies after a spinal cord injury, regardless of time since onset, dramatically affect the adjustment and adaptation process (Degraff & Schaffer, 2008). The effectiveness or ineffectiveness of the type of coping strategies employed, may influence whether individuals' experience problems such as depression or anxiety. Within a rehabilitation setting, the adoption of certain coping strategies, such as avoidance may lead to non-compliance while other coping strategies such as active participation may lead to successful adjustment (Degraff & Schaffer). In time, with the use of effective coping strategies, people with spinal cord injuries experience a gradual recovery of self-confidence, self-esteem, optimism (which may have been impacted negatively by their disability) as well as the capacity to establish new purposes and aims (Cagnetta & Cicognani, 1999).

According to the National Center for PTSD (2007), sometimes people give indications of positive responses to traumatic events such as spinal cord injuries. These positive responses include resilience and positive coping mechanisms such as altruism (e.g., helping save or comfort others) and changes in the way individuals' view the future. Feelings of learning about their own strengths as well as growth due to the traumatic experience are also among the positive responses that are reported after successful adjustment and adaptation to spinal cord injury (National Center for PTSD).

According to Degraff and Schaffer (2008), successful adaptation acts as an important source of satisfaction and a positive motivating force which are important contributing factors to an individual's perceived quality of life. Quality of life is discussed in the subsequent paragraphs.

2.5. Quality of life

Quality of life is defined as a subjective concept that is linked to life satisfaction (see section 2.1.1). According to Brown, Bowling, and Flynn (2004), quality of life has been defined in macro (societal, objective) and micro (individual, subjective) terms. Macro terms include income, employment, housing, education, as well as living and environmental circumstances. Micro terms include perceptions of overall quality of life, individuals' experiences and values, as well as well-being, happiness and life satisfaction. Brown et al. view quality of life as multidimensional with interlinked units that affect each other. Quality of life encompasses both positive and negative

experiences as well as feelings. Individuals' values as well as their evaluations of life change over the course of time as their life, health, and experiences change. As a consequence, their perceived quality of life may also change (Brown et al.). The dynamic nature of the quality of life concept, poses great challenges for the understanding and measurement of quality of life, however a comprehensive understanding of the meaning of the concept of quality of life is essential (Boswell et al., 1998; Brown et al., 2004; Manns & Chad, 2001). Further exploration of quality of life will facilitate better understanding of the important themes that determine quality of life for individuals with spinal cord injuries.

The following sections explore the quality of life concept, its theoretical models, domains, measures and models of measurement. The impact of spinal cord injury on quality of life and the themes of quality of life amongst the spinal cord injured individuals will also be discussed.

2.5.1. Theoretical models

According to Brown et al. (2004), no definitive theoretical framework of quality of life has been developed and there is no single research framework for investigating quality of life. Models of quality of life are also not consistent, ranging from needs based approaches derived from Maslow's (1943) hierarchy of human needs (refer to chapter three), to classic models based exclusively on psychological well-being, happiness, morale, life satisfaction, social expectations or the individual's unique perceptions. Quality of life is thus a complex collection of interacting objective and

subjective dimensions (Brown et al.).

The two theoretical models that have been identified as most relevant to the present study are the response shift and quality of life model (Sprangers & Schwartz, 1999) as well as the measurement model of quality of life (Rapkin & Schwartz, 2004).

These two models are discussed in further detail.

2.5.1.1. Response shift and quality of life model

As mentioned before, an individual who is confronted with a chronic illnesses or disability is faced with severe consequences (see section 2.3.1.) and the necessity to accept their illness or disability and adapt to its consequences (Sprangers & Schwartz, 1999). According to Brown et al. (2004), consciously or unconsciously, the individual may repeatedly accommodate, adapt or adjust, to deteriorating circumstances, whether in relation to health, socio-economic or other factors, because they want to feel as good as possible about themselves.

An important mediator of the above mentioned adjustment or adaptation process is 'response shift' which is directed towards maintaining or regaining homeostasis, thus allowing the individual to feel as good as possible (Sprangers & Schwartz, 1999). Response shift involves a change in an individual's internal standards, values, as well as their conceptualisation of quality of life (Sprangers & Schwartz, 1999; Schwartz & Sprangers, 1999). Over the course of their illness, response shift takes place within the individual and these changes may be inherent to the process of

accepting their illness (Brown et al., 2004; Sprangers & Schwartz, 1999).

The origins of this response shift may be understood by examining the control theory, with its goal being homeostasis (Brown et al., 2004). Control theory argues that human behaviour is motivated by what an individual wants most at any given time (survival, love, power, freedom, or any other basic human need), not by a response to an outside stimulus (Glasser, 1985). For instance, if the individual desires love, they are willing to compromise and negotiate to satisfy their desire.

Given that response shift is recognised as a key mediator of the adjustment or adaptation process, Sprangers and Schwartz (1999) proposed a response shift and quality of life model. This model addresses how response shift may affect and help stabilise health-related quality of life, despite deteriorating or changing health status (Sprangers & Schwartz). Since response shift refers to a change in the meaning of one's self-evaluation, it may occur in any field where self-reports are required, especially in determining health-related quality of life (Howard et al., 1979), such as that of spinal cord injured individuals.

According to Sprangers and Schwartz (1999), the response shift and quality of life model has five major components. The first component is the catalyst, which refers to actual changes in the respondent's health status. The catalyst may or may not result from treatment (such as improved mobility from physiotherapy) (Sprangers & Schwartz). The second component refers to the mechanisms, which include behavioural, cognitive, and affective processes to accommodate the catalyst (e.g.

coping mechanisms, initiating social comparisons, seeking social support or engaging in spiritual practice) (Rapkin & Schwartz, 2004; Sprangers & Schwartz, 1999). The third component refers to the antecedents, which are stable or dispositional characteristics of the individual, such as sociodemographics (e.g. gender or education), personality (e.g. optimism, self-esteem, or sense of control), culture, and environment. The antecedents may influence or affect the catalyst and the mechanisms (Rapkin & Schwartz, 2004; Sprangers & Schwartz, 1999). The fourth component is response shift, which includes changes in the meaning of one's self-evaluation of quality of life (Rapkin & Schwartz) (refer to previous paragraph). The final component is perceived quality of life (Sprangers & Schwartz) (refer to section 2.1.).

According to Sprangers and Schwartz (1999), changes in an individual's health status (catalyst) may prompt behavioural, cognitive and affective processes (mechanisms) required for accommodating their illness. These mechanisms have the potential to change an individual's standards, values or conceptualisation of quality of life and this response shift will thus influence perceived quality of life. The kind of mechanisms that an individual will engage in, as well as the magnitude and type of the resulting response shift will be dependent on dispositional characteristics, which are the antecedents. Accordingly, the antecedents are assumed to have both indirect and direct effects on determining response shift (Sprangers & Schwartz). When an individual perceives a level of quality of life that is below optimal levels, they may draw from established mechanisms or initiate new mechanisms in an attempt to achieve the desired optimal level. This feedback loop is aimed at maintaining or

improving the perception of quality of life (Rapkin & Schwartz, 2004; Sprangers & Schwartz, 1999).

The subsequent figure and paragraph is used to present and explain the response shift and quality of life model by Sprangers & Schwartz (1999).

Figure 2.1. Figure representing the theoretical model of response shift and quality of life.

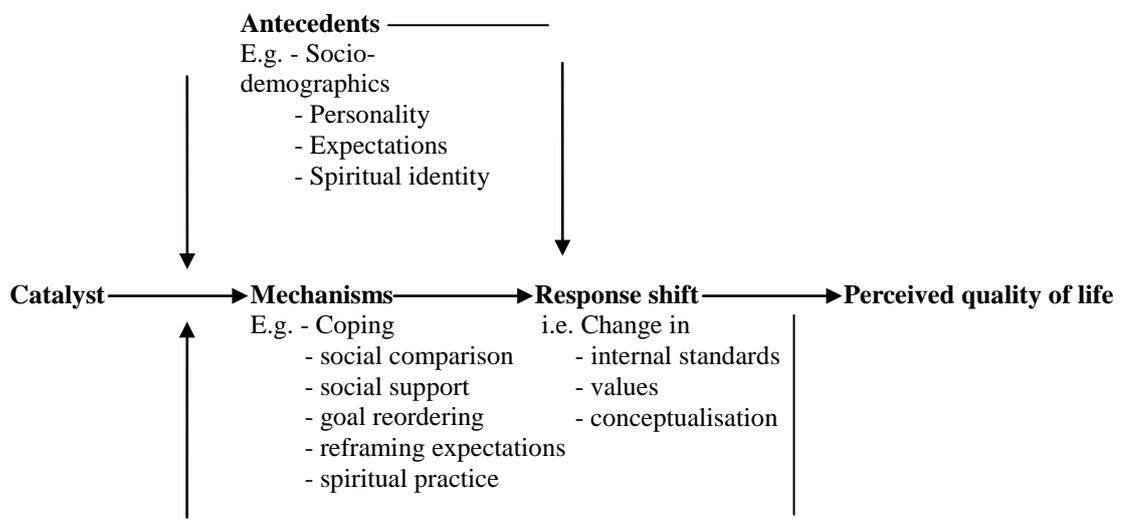


Figure 2.1. Provides an outline of the theoretical model of response shift and quality of life. It shows the interrelatedness between the five main components, referring to the catalyst, antecedents, mechanisms, response shift, and quality of life. The figure illustrates how the antecedents may influence the mechanisms employed and thus affect the type of response shift that takes place. The response shift, in turn determines the perceived quality of life. The perceived quality of life may change again as soon as the catalyst changes and the above mentioned process is repeated.

Thus, a feedback loop is sustained, which ensures that optimal quality of life levels are perceived and maintained. From “Integrating Response Shift into Health-Related Quality of Life Research: A Theoretical Model,” by M. A.G. Sprangers, and C. E. Schwartz, 1999, *Social Science and Medicine*, 48, p. 1509. Copyright 2004 by Rapkin and Schwartz. Reprinted with permission of the author.

The theoretical model, which is discussed above, is critical for ascertaining and assessing the changes in the perception of quality of life following the onset of disability or chronic illness (Sprangers & Schwartz, 1999). It may aid in understanding why individuals with chronic illnesses or disabilities sometimes report having a stable, or neither inferior, nor better quality of life than that of less severely ill or healthy individuals (Albrecht & Devlieger, 1999; Dijkers, 1996) and at times, an improved quality of life following the onset of a chronic illness or disability (Calhoun & Tedeschi, 2001; National Center for PTSD, 2007). According to Sprangers and Schwartz, this may be an indication of response shift and it plays an important yet not explicitly measured role in understanding illness and disability as well as its impact on quality of life. Integrating response shift into quality of life research may allow a better understanding of how quality of life is affected by changes in health status and it may also direct the development of reliable and valid measures for assessing changes in quality of life (Sprangers & Schwartz).

Rapkin and Schwartz (2004) recognise the significance of the response shift and quality of life model. However, they are of the opinion that, although the model is useful for understanding relationships among key concepts relevant to quality of life

assessment, it presents some problems in how information may translate from the mechanisms to response shift. The problems exist because the mechanisms (such as coping strategies) may be perceived as synonymous with aspects of response shift (such as change in values) (Rapkin & Schwartz, 2004; Schwartz & Sprangers, 1999).

Rapkin and Schwartz (2004) expanded on the response shift and quality of life model, attempting to distinguish mechanisms from response shift components. Furthermore, they aimed to differentiate response shift phenomena, as initial responses to catalysts, from those behaviours and components that help maintain the feedback loop. They also endeavour to highlight the appraisal processes of quality of life in addition to providing a measurement model for quality of life and change in quality of life (Rapkin & Schwartz). This measurement model is discussed in the subsequent section.

2.5.1.2. Measurement model of quality of life

According to Rapkin and Schwartz (2004), assessment methods of response shift provide substantial evidence that quality of life assessment involves a subjective process of appraisal. It also demonstrates that, during the appraisal process, individual differences may affect resulting quality of life scores and individuals may change their appraisal of quality of life over time.

Quality of life assessment is fundamental to many aspects of health care, thus accurate, consistent and meaningful measures of the various dimensions of quality of

life are vital (Boswell et al., 1998; Rapkin & Schwartz, 2004; Whiteneck, 1994).

Appraisal is a hidden facet in all measurement of quality of life, and all studies involving self-reported quality of life are influenced by appraisal. Consequently, a clear explanation of quality of life appraisal is fundamental. Rapkin & Schwartz suppose that, quality of life scores are dependent upon several key variables related to appraisal and when describing quality of life appraisal adequately, four distinct cognitive processes are essential.

Rapkin and Schwartz (2004) refer to the first cognitive process as frame of reference, which refers to the experiences that the individual deems relevant to their response. These depend on the meanings the individual attaches to questions (Krause & Jay, 1994), as well as demand characteristics of the testing situation (Rapkin & Schwartz). Each individual implicitly accepts that the items in the assessment refer to only certain aspects of their life. Thus, the aspects which the individual deems valid are largely determined by the individual and only partly determined by the overt item content. Items stir a range of different issues and concerns distinctive to each individual (Rapkin & Schwartz).

The second process refers to the individual's tendency to sample specific experiences within their frame of reference, before responding to the items (Rapkin & Schwartz, 2004). This sampling relies on a subjective sampling strategy, which is, at least in part, determined by the items, the broader context of the quality of life measure, as well as the assessment situation (Rapkin & Schwartz, 1999; Tourangeau, Rips, & Rasinski, 2000).

The third cognitive process involves judging each sampled experience against relevant, subjective standards of comparison (Rapkin & Schwartz, 2004). According to Allison, Locker, and Feine (1997), the individual's situation and experiences are judged against and compared to other situations as well as others' experiences. These comparisons may be based upon personal reference points, including prior functioning, lost capacities, and extreme experiences (Allison et al.).

Lastly, Rapkin and Schwartz (2004) posit that, in order to arrive at a quality of life score, individuals must apply some combinatory algorithm to summarize their evaluation of relevant experiences and formulate a response (Tourangeau et al., 2000). Individuals may combine their experiences and the significance of a particular experience might be determined only in contrast to other relevant experiences (Rapkin & Schwartz). It is essential to place added emphasis on recent patterns or unusual events. Frequently repeated or continuous difficulties may be treated as a single experience and therefore, they may receive less emphasis than they would have, had they been appraised as separate events.

According to Rapkin and Schwartz (2004), an individual's answer to any self-evaluative question depends upon the above mentioned process of appraisal. Individual differences or longitudinal changes in appraisal have an effect on how individuals respond to quality of life items. Similarly, factors that are linked to quality of life, including differences in personal circumstances, stressful events, disease progression, and interventions also depend upon the criteria individuals use

to evaluate quality of life (Rapkin & Schwartz). Changes in quality of life ratings may be due to changes in the appraisal, thus a clear understanding of quality of life appraisal is essential. According to Rapkin and Schwartz, evaluation of quality of life should include unambiguous methods and the evaluation process should integrate response shift phenomena by encompassing self-appraisal and meaning.

In the absence of a single, definitive theoretical framework for quality of life, the response shift and quality of life model (Sprangers & Schwartz, 1999) as well as the measurement model of quality of life (Rapkin & Schwartz, 2004) were used as valuable guidelines during the attempt to understand and evaluate the quality of life of spinal cord injured individuals.

2.5.2. Domains of quality of life

According to Dijkers (1996), the term, quality of life was first introduced in the 1950's. Originally, the term was used to refer to the well-being of entire populations such as the “the quality of American life”. However, in the seventies the term started being applied more frequently to individuals as well as communities, instead of merely referring to populations (Dijkers). Initially, the term quality of life was applied to individuals based on the assessment of symptoms and through the use of objective measures. Gradually, the study of quality of life moved away from individualistic, symptom-oriented views and approached the concept of psychological help and well-being from a perspective of subjective views and communities (Orford, 1992).

Three traditions of research are found within the sphere of quality of life research (Dijkers, 1996). Firstly, social indicator research deals with quality of life at the level of a society. Social indicator research focuses on what may be termed, “basic preconditions” of quality of life in a community, such as percentage of homes with running water. Secondly, there is a line of research that focuses on the individual. This second form of research involves the acquisition and loss of, “the good things in life” such as education, income, material possessions, health and community functioning. Social indicator research as well as the research dealing with the acquisition and loss of things utilised objective measures to obtain data related to quality of life. Recently, a third line of research emerged as sociologists and social psychologists shifted from objective individual-level quality of life to reporting about the subjective quality of individuals’ lives. The latest change in the study of quality of life entails investigating people's satisfaction and happiness with specific domains of their life such as career, marriage, and health as well as their opinions and feelings about their lives as a whole (Dijkers).

Since the 1980s, due to the advancements in medical sciences, there has been an increase in the survival rate among people suffering severe physical impairments including spinal cord injury (Hammell, 2004). Following this increased survival rate, greater interests have emerged among researchers for conducting investigations into the perceptions of quality of life among people with spinal cord injury.

2.5.3. Importance of quality of life

The large increase over the recent years in the number of people with chronic diseases, for example arthritis and disabling injuries such as spinal cord and brain injuries, are some of the reasons behind the emergence of quality of life as a major concern in the healthcare field (Dijkers, 1996). Fabian (1990) is convinced that quality of life is a useful means for measuring subjective well-being. Quality of life has also gained increasing importance, especially in the field of rehabilitation in the last decade. In the rehabilitation field, quality of life measures have been widely used for evaluating program outcomes, especially in respect to patients with chronic illness and disability (Fabian, 1991; O'Boyle, 1992).

2.5.4. Quality of life measures

There are several reasons why quality of life measures are increasingly being utilised within the healthcare system. Firstly, there has been an increasing awareness, that enhancing quality of life is an inherent goal for rehabilitation programs, including programs for individuals with paraplegia and quadriplegia (Fabian, 1991; Wood-Dauphinee & Kuchler, 1992). Secondly, quality of life evaluation is relevant for assessing symptoms, side effects of treatment, disease progression, satisfaction with care, quality of support services, unmet needs, and appraisal of health and health care options (Gill & Feinstein, 1994; Rapkin & Schwartz, 2004). Such assessment is an effective means to determine, whether people with paraplegia or quadriplegia experience quality in living, and whether they perceive survival to be worthwhile

(Hall et al., 1997).

Thirdly, quality of life is a representation of how good life is for an individual, related to their health, as well as their personal life (Raeburn & Rootman, 1996). Therefore, a positive change in quality of life for an individual with a spinal cord injury should be viewed as an important indicator of the effectiveness of the particular health promotion strategies that the individual is subjected to (Lanig et al., 1996). Improved quality of life is essential, not just within the rehabilitation setting but also in the individual's private life (Raeburn & Rootman). Therefore, a more accurate assessment of quality of life is crucial.

Although quality of life measures are emerging as an important focus in both rehabilitation as well as medicine, problems related to the use of quality of life assessment are still apparent (Boswell et al., 1998). Concerns exist regarding the ambiguity in the definition and a lack of clarity in the meaning of quality of life (Fabian, 1990; Hammell, 2004). In addition, Fabian stresses that, one of the fundamental limitations with using quality of life measures in rehabilitation evaluation is utilising a unidimensional model of assessment. This poses great challenges for the evaluation of subjective quality of life. However, the direct assessment of subjective quality of life has been done infrequently in rehabilitation settings (Manns & Chad, 2001) and overall, much less attention than needed has been directed to the evaluation of quality of life.

2.5.4.1. Unidimensional models of measurement

In the past quality of life was characteristically inferred from general measures of an individual's health or functional status (Renwick & Friefeld, 1996). This was generally conducted, using objective measures such as questionnaires, as opposed to more subjective measures, like interviews. Objective measures are limited, in the sense that, they fail to obtain in-depth information concerning the individuals' perceptions (Boswell et al., 1998; Whiteneck, 1994). It was assumed that improved health or functional status results in a direct improvement the individual's quality of life (Manns & Chad, 2001). For example, quality of life of a quadriplegic individual would be rated as improved as soon as the individual gains the ability to move their neck, regardless of the emotional state of the individual. However, this is not necessarily a correct assumption as measures of physical health and functional status are not based on well-developed conceptual frameworks of quality of life (Renwick & Friefeld).

Until recently, even tools for measuring quality of life of people with spinal cord injury had been adapted from measures for able-bodied individuals (Bishop, 2005; Schulz & Decker, 1985). However, without input from the people with spinal cord injury, it remains highly questionable whether tools, which are objective measures for able-bodied individuals, are able to accurately measure the true quality of life for people with disabilities (Manns & Chad, 2001). This is a major concern, especially taking into consideration what Degraff and Schaffer (2008) refer to as physical, psychological, as well as environmental factors that cause daily disability related

challenges and stress for paraplegic and quadriplegic individuals. These challenges cause stress that is unique to people with disabilities and it affects the people's subjective view of their quality of life (Degraff & Schaffer).

2.5.4.2. Multidimensional models of measurement

Multidimensional models of measuring quality of life may offer a better understanding of the impact of chronic illness as well as disability, and the process by which individuals respond to this impact (Bishop, 2005; Devins, 1994; Livneh, 2001). The validity of instruments for assessing quality of life may be improved by utilising the subjective perceptions of people with a spinal cord injury (Bishop, 2005; Boswell et al., 1998; Budh & Österaker, 2006; Day & Jankey, 1996; Dijkers, 1996; Fabian, 1991; Gill & Feinstein, 1994; Manns & Chad, 2001; Rapkin & Schwartz, 2004; Whiteneck, 1994).

Gill and Feinstein (1994) argue that the initial step in improving quality of life measurement should be the development of innovative and resourceful approaches to obtain and weigh individual responses. As indicated earlier, measuring quality of life by rating only health status may not be an accurate and reliable method as quality of life comprises the individual's perceptions, encompassing both medical and non-medical aspects of life (Manns & Chad, 2001). Comprehensive assessment of quality of life should include the assessment of factors such as health, employment, material comforts, perceived control, social support and social relationships (Younghill & McCormick, 2006).

Bishop (2005) suggests that conducting a brief, as well as multidimensional assessment of the following four domains of life, should help rehabilitation professionals to gain an understanding of individuals' experiences. The essential domains are; satisfaction, perceived control, the impact of chronic illness and disability as well as its treatment and how important each domain is to the individual (Bishop). For example, a specific paraplegic individual might value work more than family life or traveling. Thus, the impact the disability has on their level of control in their work life may have a far greater impact on their perceived quality of life compared to the impact of losing control over their ability to travel has. It is therefore essential to determine which domain is valued more and how the disability impacts on the individual's level of satisfaction in this domain (Bishop).

According to Bishop (2005), in addition to enhancing their understanding of the individual's perceptions, rehabilitation professionals may gain a comprehensive picture of the individual's overall level of adaptation. An individualised profile related to the individual's quality of life may also be gained and this profile may aid in rehabilitation planning, by providing the ability to prioritise interventions to suit individuals (Bishop). Evaluators of quality of life must thus go beyond rating scales and similar objective measures (Boswell et al., 1998). This may allow researchers to gain a better, as well as more comprehensive understanding of the various themes that contribute to quality of life, and should thus be included in the measurement of life quality (Boswell et al.)

2.5.5. Spinal cord injury and quality of life

The onset of disability such as paraplegia or quadriplegia presumably, will have an effect on quality of life, because disability affects multiple domains of an individual's life (see section 2.5.3.), and as Bishop (2005) indicates, quality of life is determined by how satisfied the individual is in multiple domains of their life. These refer to the functional, psychological as well as social domains of the individual's life. Change in one domain may reverberate to the other domains and in this way, they affect each other (Bishop).

An example may best illustrate the possible effects of spinal cord injury on individuals. For instance, a man who has recently become paraplegic may experience health complications such as breathing difficulties. Thus, he may require assistance from caregiver, diminishing his independence. He might have lost his job, which may involve physical activity that he is no longer able to perform, causing added financial stress. Additionally, he may experience difficulties in his marriage due to disability-related erectile dysfunction. Inevitably, these changes may result in decreased overall quality of life (Devins, 1994; Livneh, 2001). When attempting to define these changes in the context of a quality of life framework, the individual's response to these changes may be defined as an attempt to increase or restore quality of life (Bishop, 2005). The individual responds by utilising certain coping mechanisms in an attempt to adjust his lifestyle in order to adapt to the injuries he has suffered.

According to Dijkers (1996) impairment and disability may be minor influences on an individual's judgment of overall quality of life. Individuals with disabilities may derive satisfaction from the same aspects as non-disabled individuals, such as marriage, success and wealth. People with disabilities are not by definition less happy, less satisfied with life and less able to live productive lives than their non-disabled peers and many report experiencing a good or excellent quality of life (Albrecht & Devlieger, 1999; Dijkers, 1996). However, many people with disabilities report diminished quality of life compared to non-disabled peers, or compared to themselves prior to the onset of their disability (Dijkers). Thus, the subjective, self-assessed quality of life of individuals with disabilities is often affected by their disability. For example, as mentioned in section 2.3.1, there is no known cure for paraplegia and quadriplegia, but associated problems may be managed. Often, such treatment of chronic illness and disability has various side effects, which further impact on the individual's quality of life (Dijkers). These above mentioned factors have a major impact on the individual's emotional state. Subsequently, this impacts the way the individual perceives the world and how they perceive their quality of life.

According to Dijkers (1996), people with disability rank lower on quality of life measures, on more than just the health and disability-related concerns. Individuals with paraplegia may be able to lead normal family lives, go back to work, be happy and enjoy a good quality of life. However, they may still compare their quality of life after their disability to the way it was before the onset of their disability. Although they are able to work a full day, their quality of life and work

may be lower (Dijkers), due to, for example, backaches. This pain might force them to take frequent breaks at work, and often result in being booked off from work.

There are significant differences in the way individuals respond to the changes in their lives after a spinal cord injury. However, the difference in response is not only related to the disability type or severity (Bishop, 2005). The subjective nature of responses and the variation in the individual's response may be attributed to a complex interaction of factors inherent to the disability, the individual, and the environment (Elliott, 1994; Livneh, 2001; Livneh & Antonak, 1997). Cagnetta and Cicognani (1999) reveal that the severity of the injury, the individual's age at the time of the accident as well as the resources available for support (e.g. family, friends, doctors, self-help groups) are important factors that influence coping, adaptation and ultimately the restoration of quality of life. For example, Trieschmann (1980) believes that, a higher level of injury is associated with more complex and stressful issues related to social, psychological, physical as well as environmental factors. A higher level injury thus impacts more negatively on quality of life (Trieschmann).

Over the past two decades, several studies have been conducted with emphasis on and greater recognition of the importance of subjective perceptions in assessing quality of life and identifying determining themes of quality of life (Bach & McDaniel, 1993; Boswell et al., 1998; Duggan & Dijkers, 2001; Hammell, 2004; Manns & Chad, 2001). Subsequent paragraphs are devoted to discussing of studies that have explored the subjective views of people with spinal cord injury. The

subjective views of paraplegic and quadriplegic people were utilised to determine the themes and domains that are essential in determining their quality of life.

2.5.6. Quality of life themes

Several researchers utilised mainly subjective measurement techniques, including interviews, to identify the themes which determine and influence the quality of life of individuals with spinal cord injuries (Bach & McDaniel, 1993; Boswell et al., 1998; Duggan & Dijkers, 2001; Manns & Chad, 2001). The themes identified by these researchers may also be essential in contributing to the quality of life of able bodied individuals. However, it is the subjective views of the spinal cord injured individuals which make these themes unique and critical. Although the researchers identified different themes and discussed them separately, there are similarities which are reflected within these different themes.

Boswell et al. (1998) established that satisfaction is essential as it ultimately influences quality of life. Some of the factors found to be related to life satisfaction of individuals with physical disabilities include satisfaction with changes in family life, accepting responsibility for the injury, social support, leisure, satisfaction with personal assistance, changes in their employment status, changes in their living environment, and changes in their level of control over their lives (Chase et al., 2000; Crewe & Krause, 2002; Mehnert, Krauss, Nadler, & Boyd, 1990).

A study by Bach and McDaniel (1993) identified six determinants of quality of life

amongst individuals with spinal cord injury that are similar to able-bodied individuals. These refer to relationships, work and productivity, finances, health, having inner resources and control of one's life, and level of activity (Bach & McDaniel). They identified two additional themes, which are uniquely essential in determining the quality of life of spinal cord injured individuals. These refer to assertiveness, along with balancing dependence and independence (Bach & McDaniel).

On the other hand, Boswell et al. (1998) identified three domains of life, which primarily influence the quality of life of individuals with spinal cord injuries. These domains are attitude towards life, work opportunities, and level of resources (Boswell et al.). According to Duggan and Dijkers (2001), their research findings indicate that satisfying relationships, meaningful social roles, financial security and material assets, as well as the opportunity to pursue valued occupations (e.g. hobbies or community service) make a valuable contribution towards quality of life. In addition, personal development and values also make a significant contribution (Duggan & Dijkers).

In yet another study, Manns and Chad (2001), found that the quality of life themes are similar among quadriplegic as well as paraplegic individuals, possibly because both groups are wheelchair bound and, as a result, deal with common difficulties. They identified nine themes, which are closely linked to the themes identified by Bach and McDaniel (1993), Boswell et al. (1998), as well as Duggan and Dijkers (2001). These themes refer to physical function and independence, accessibility,

emotional well-being, stigma, spontaneity, relationships and socialisation, finances, physical well-being, and occupation (Manns & Chad).

Physical function and independence represents the individual's physical ability within his or her present limitations, referring to his or her level of injury (Manns & Chad, 2001). Similarities exist between this theme and level of activity as identified by Bach and McDaniel (1993). It encompasses the individual's ability to transfer and perform bed and wheelchair mobility as well as their independence with activities of daily living (Manns & Chad). A paraplegic individual who has a lower level of injury may have more independence than a quadriplegic individual. The paraplegic individual may be able to transfer independently from the wheelchair to other places such as the bed and are also able to use their hands (Trieschmann, 1980).

Based on the findings by Manns and Chad (2001), emotional well-being consists of two subcategories. The first category is the individual's emotional health. Emotional health represents the actual state of emotional health, which includes self-esteem, self-image, and self-confidence. The second category refers to the behaviours that the individual engages in, which may enhance or have an adverse effect on their emotional health. These behaviours are related to coping, adjustment, and outlook on life following the spinal cord injury (Manns & Chad). This theme is similar to attitude towards life, identified by Boswell et al. (1998), which is described as the factor in life that allows an individual to move forward despite obstacles. It is also the factor that can cause stagnation, consequently interfering with growth. A negative, pessimistic attitude towards life reduces life satisfaction, resulting in

lowered quality of life (Boswell et al.). This theme may also be related to the need to have inner resources and control of one's life, as well as the theme of assertiveness, as identified by Bach and McDaniel (1993). Increased assertiveness may enable the individual to move forward in life and overcome obstacles. In addition, meaningful personal values, including how spinal cord injury affects and changes these values also impacts on the individual's attitude and subsequently, their quality of life (Duggan & Dijkers, 2001).

The theme of emotional well-being is crucial (Manns & Chad, 2001). Many individuals are proud of themselves and how they have survived the difficult period following the spinal cord injury, as well as the methods of coping that they found effective (Manns & Chad). For example, a quadriplegic individual may learn how to continue working by typing with a pen in the mouth. This coping mechanism may increase the individual's self-esteem and confidence levels, as they are able to be productive with their time.

Manns and Chad (2001) refer to accessibility as a theme, which is a major contributor or inhibitor to enjoying life and having a good quality of life. This theme refers to the physical accessibility or inaccessibility of the environment (for instance, at home, work, or leisure facilities) and the effect it has on quality of life. The theme referred to as stigma, represents the perceptions that individuals with spinal cord injury have of other people's attitudes toward them. When such stigma is present or is perceived to be present, it has a negative effect on quality of life (Manns & Chad). Stigma may have an impact on the individuals' emotional well-being and

consequently affect their attitude towards life, which Boswell et al. (1998) identified as crucial in influencing quality of life. Manns and Chad also view the degree of spontaneity in daily activities, as another essential theme, which affects the quality of life of individuals with paraplegia and quadriplegia. Particularly, for quadriplegic individuals, it takes longer to do things and much more planning is needed for normal, daily activities. Consequently, lack of spontaneity has a negative impact on perceived quality of life (Manns & Chad).

Another important theme, which was identified is relationships with family, friends, and significant others (Bach & McDaniel, 1993; Duggan & Dijkers, 2001; Manns & Chad, 2001). Fostering good relationships provides an essential support system for individuals with disabilities and provides an opportunity for them to fill meaningful social roles (Duggan & Dijkers, 2001; Manns & Chad, 2001). In turn, this may increase their sense of significance. Manns and Chad suggest that several individuals with paraplegia or quadriplegia report having experienced an improvement in their relationships with family following the spinal cord injury, because they no longer take their family for granted. Through the traumatic experience and subsequent disability, many individuals recognise the importance of their relationships and learn to cultivate relationships to a greater extent (Manns & Chad).

The theme of resources cover a wide range of basic needs, including housing, clothing, medication, and food, it also encompasses other needs, such as attendant care, transportation, and financial income (Bach & McDaniel, 1993; Boswell et al., 1998; Duggan & Dijkers, 2001, Manns & Chad, 2001). Although other factors such

as attitude towards life and work opportunities are imperative in contributing to quality of life, resources are viewed as a foundation for quality of life (Boswell et al.).

Paraplegic individuals as well as quadriplegic individuals express that their financial situation has an effect on their quality of life, referring to financial security as well as material assets (Bach & McDaniel, 1993; Boswell et al., 1998; Duggan & Dijkers, 2001, Manns & Chad, 2001). Health costs, including the cost of equipment as well as services, such as home care or housekeeping, are substantial and a shortage of finances, together with the resulting concern has a negative impact on quality of life (Manns & Chad).

Physical well-being or health also has a major impact on an individual's perceived quality of life (Bach & McDaniel, 1993; Manns & Chad, 2001). Physical well-being encompasses physical health as well as the behaviours and actions that promote health or compromise health. It represents the presence or absence of physical symptoms, including physical illness, obesity, or physical injury (Manns & Chad). Pain, spasticity, urinary tract infections, and pressure sores are reported as common health problems associated with paraplegia and quadriplegia (Lustig, 2005) and have a negative effect on the quality of life. They report that, people with disability are aware that health behaviours such as eating a healthy diet, recreation, and adequate rest have a positive effect on overall quality of life. Some of these behaviours include pressure relief to avoid pressure sores and maintenance of a regular bowel and bladder regime in order to prevent infections (Manns & Chad).

Manns and Chad (2001) observed that, the themes of physical function and independence, as well as physical well-being, were found to have a more significant impact on the quality of life of individuals with quadriplegia as opposed to paraplegia (Manns & Chad). Both paraplegic and quadriplegic individuals share the view that individuals with quadriplegia face greater challenges due to more limitations, and greater restrictions to their independence. A quadriplegic injury has more severe implications for an individual's health and functionality than does a paraplegic injury (Bauman & Spungen, 1994; Noreau, Shephard, Simard, Pare, & Pomerleau, 1993). Individuals with quadriplegia have to work harder than those with paraplegia at health-promoting behaviors such as maintaining a healthy body weight.

Having the opportunity to pursue valued occupations, to contribute and create through an occupation as well as related activities is fundamental in influencing quality of life (Bach & McDaniel, 1993; Boswell et al., 1998; Duggan & Dijkers, 2001, Manns & Chad, 2001). These researchers also agree that not being able to return to work after sustaining a spinal cord injury has a negative impact on the individuals' quality of life. Working enables the individual to exercise independence, thus balancing dependence and independence (Bach & McDaniel) is also reflected in this theme. This theme of occupation includes more than only paid employment. It refers to work as a means of personal fulfillment and occupying the individual's time. It also implies that volunteer work, school, as well as housework are essential for quality of life (Manns & Chad). Many people with disabilities enjoy using their experiences to motivate and help others who are facing similar difficulties.

An additional, important element to employment is energy expenditure, referring to the amount of time which is consumed by the disability while the individual attempts to maintain professional obligations (Boswell et al, 1998). Manns and Chad (2001) also found that, energy expenditure for daily tasks increases as soon as people become disabled, regardless of the type of disability. For example, when an individual returns to work, after suffering a spinal cord injury, the time and effort spent preparing for work and getting to and from work is often experienced as enormous.

Even though energy expenditure increases for both paraplegic and quadriplegic individuals, the quadriplegic individual typically spends more energy performing activities of daily living (Janssen, Van Oers, Van Der Woude, & Hollander, 1994). The amount of energy expenditure varies, however it may have a negative impact on both the paraplegic as well as the quadriplegic individuals' lives, particularly regarding physical function, level of activity as well as work and productivity (Bach & McDaniel, 1993; Manns & Chad, 2001). It is not possible to predict the degree of impact, as it is subjective and only the participants can truly evaluate it. However, the impact may be felt over various domains of life and it ultimately affects quality of life (Bach & McDaniel, 1993; Manns & Chad, 2001).

2.6. Conclusion

Research findings suggest that, spinal cord injury affects a wide range of life activities such as health, social relationships, and environmental interactions. Thus, it

requires a lifelong process of adapting to significant physical, psychological, social, and environmental changes. People with disabilities experience disability-related problems and stress in addition to normal daily stresses. This requires the adoption of coping mechanisms to reduce stress. The emotion-focused coping mechanisms that are employed most frequently, often serve to only distract people from their emotions, and help them feel better, instead of reducing the actual stress.

Quality of life is a multidimensional construct with a complex collection of interacting objective and subjective dimensions (Brown et al., 2004). There is no definitive single theoretical model for quality of life. The models range from models based on Maslow's hierarchy of needs to models based on psychological well-being, happiness, life satisfaction, social expectations or the individual's unique perceptions (Brown et al., 2004).

Assessment of quality of life, utilising objective measures, indicates that, on average, people with disabilities have a lower quality of life than non-disabled people.

However, researchers have pointed out that, these differences based on objective measures, are not a true reflection of the subjective quality of life of people with disabilities. Thus, researchers agree that, the assessment of quality of life should include subjective views of the individuals whose quality of life is being assessed (Bishop, 2005; Boswell et al., 1998; Budh & Österaker, 2006; Day & Jankey, 1996; Dijkers, 1996; Fabian, 1991; Gill & Feinstein, 1994; Manns & Chad, 2001; Whiteneck, 1994). These views may be obtained through subjective measures such as interviews.

Researchers have identified several factors ranging from personal aspects including independence to functionality of the body, employment, and resources as important determinants of quality of life (Bach & McDaniel, 1993; Boswell et al., 1998; Duggan & Dijkers, 2001; Hammell, 2004; Manns & Chad, 2001). Based on previous research findings, it is evident that quality of life is not determined by a single factor. A complex relationship exists between personal aspects and the domains in life. Each domain, on its own, is insufficient to improve an individual's quality of life. It is rather the interaction of relationships, social roles, and resources that form themes, which contribute to the quality of life for an individual with a spinal cord injury (Bach & McDaniel, 1993; Boswell et al., 1998; Duggan & Dijkers, 2001; Hammell, 2004; Manns & Chad, 2001).

2.7. Chapter summary

In chapter two the relevant literature and research findings on the subject of quality of life and spinal cord injury were reviewed. Definitions were provided for the concepts of life satisfaction, disability, adulthood, quadriplegia, and paraplegia. Spinal cord injury, including its consequences related to stress and coping, was discussed. This was followed by a discussion on the broad field of quality of life, including the domains of quality of life, theoretical models, and measurement of quality of life.

In the next chapter, Maslow's theory of human motivation will be discussed as the broad theoretical framework. The person-environment fit theory will also be

discussed, and defence mechanisms will be incorporated for a better understanding of perceived quality of life and coping with disability.

CHAPTER THREE

THEORETICAL FRAMEWORK

In this chapter an overview of the theoretical outline for the study is presented.

According to Brown et al. (2004) quality of life models utilise a range of indicators during the appraisal of quality of life. These include objective indicators (external, structural features and characteristics) and subjective indicators (involves values and perceptions). The essential aspects incorporated in these quality of life models include satisfaction of human needs, psychological aspects, health, physical functioning, social aspects, and the environment (Brown et al.). Taking the above mentioned aspects into consideration, Maslow's hierarchical theory of human motivation is identified as essential and relevant to this study. The individual's strive towards self-actualisation as well as their subjective satisfaction with the extent to which their needs have been met is an important determinant of perceived quality of life (Brown et al.).

The person-environment fit theory is also explored as a relevant theoretical basis for understanding the perceptions of individuals related to the environmental challenges they face daily. This theory may aid in the conceptualisation of social aspects as well as the environment, which are influenced by social support and activities, including societal, environmental, and neighbourhood resources (Brown et al., 2004). Finally, a discussion of defence mechanisms is incorporated, as a means to foster greater understanding of individuals' actions as well as their attempts to cope with their

disability. Defence mechanisms are related to personality and the largely unconscious handling of internal conflict. Psychological aspects such as personality (including personal growth, cognitive competence, adaptability, perceived independence, optimism, self-esteem, sense of control, independence) also influence quality of life (Brown et al., 2004; Rapkin & Schwartz, 2004; Sprangers & Schwartz, 1999).

3.1. Maslow's theory of human motivation

Abraham H. Maslow (1908 –1970) developed a theory referred to as the human motivation theory (Koltko-Rivera, 2006). Maslow's theory is part of humanistic psychology. It emerged in response to existing theories such as psychoanalysis and behaviourism, which shared a deterministic, mechanistic, pessimistic and absolute conception of the individual (Buss, 1979/1986). For instance, psychoanalysis emphasised a nature of destruction, negation, and despair associated with individuals. Maslow intended to focus on the positive aspects of human nature and his view of human nature focussed on construction, affirmation, and hope (Buss).

Maslow posited that human needs may be arranged in a hierarchy and every human behaviour or action is an attempt to satisfy these needs (Maslow, 1943). The human motivation theory is vital in the study of quality of life, given that satisfaction and happiness play an important contributing role to quality of life. According to Hörnquist (1982) human needs may be viewed as the foundations for quality of life,

hence quality of life may be defined in terms of human needs and the satisfactory fulfilment of those needs.

Initially, Maslow (1943) identified five basic levels of needs, arranged in ascending order on the hierarchy, from the most basic, primitive needs on the lowest level to the highest level needs at the top of the hierarchy (Koltko-Rivera, 2006). Stated according to the hierarchy, these basic needs are: biological and physiological needs, safety needs, belongingness and love needs, esteem needs and self actualisation needs. Basic needs are “instinctoid” and may thus be equated to instincts in animals (Simons, Irwin, & Drinnien, 1987). These instinctive needs are essential for human survival, require urgent gratification and are crucial for physical as well as emotional wellbeing. The five basic needs may be grouped into deficiency needs and growth needs (Reisinger, 2009).

There is a clear distinction between deficiency needs and growth needs. Deficiency needs refer to the first four levels on the hierarchy of needs, and growth needs refer to the fifth level of the basic needs (Meyer, Moore, & Viljoen, 2003). Deficiency needs merely focus on the satisfaction of needs such as the need for food or safety. On the other hand, the growth oriented needs allow the individual to go beyond needs altogether and achieve fulfilment or maximum growth (Rowan, 1999).

According to Maslow and Lowery (as cited in Reisinger, 2009), Maslow subsequently identified two other growth needs below self actualisation as well as one higher level of growth needs above self actualisation (see figure 3.1). Therefore,

the growth needs are comprised of cognitive needs, aesthetic needs, self-actualisation needs and transcendence needs (Reisinger). In total, 8 levels of needs that motivate people to act have been identified. The higher level needs are essential for influence and personal development (Maslow, 1943).

In addition, Maslow pointed out that, whether it is behaviour to consume or to do, all behaviour should be seen as a pathway through which many needs can be expressed or satisfied simultaneously. Thus, every act has more than one motivation and is able to satisfy more than one need (Maslow, 1943). The above statement is based on the view that, human needs are never fully satisfied, they are recurrent and people are continuously motivated and striving to satisfy their needs. Therefore, Maslow refers to sufficient satisfaction of needs (1970), as he maintained that it is very difficult for humans to achieve complete satisfaction. For instance, the four most basic needs occur recurrently, an individual might experience hunger, feel threatened or lonely many times in life, even if these needs have been satisfied at a prior time.

Maslow (1943) also posited that, when an individual is experiencing grave deprivation in the basic levels of needs, each level of needs is “prepotent” to the next higher level. Thus, until sufficient satisfaction is obtained, the needs will surface and require gratification according to the hierarchy. Therefore, the emergence of one need usually rests on the satisfaction of a prior need, no need can be seen in isolation, and every need is related to the satisfaction, or dissatisfaction of prior needs (Maslow).

The above mentioned is especially true within the deficiency needs; when grave deficiency is experienced at a lower level need, that need must be met before moving to the next higher level (Huitt, 2004). For example, physiological and biological needs must receive sufficient satisfaction before security and safety needs surface (Mathes, 1981). According to Maslow (1970), the individual who is experiencing grave deprivation and is driven by a deficiency need experiences uncomfortable tension and can think of nothing else, they are obsessed merely with the need they are experiencing.

Furthermore, the individual may tend to think, sleep and obsess about that need only and all their capacities are put into satisfaction of that particular need, at the expense of all else. They are dominated by this need will tend to define life itself in terms of this need. This individual's whole philosophy of the future also tends to change and their view of the future is that they will be happy if they are never deprived of that need again (Maslow, 1943, 1970).

The gratification of deficiency needs results in a decrease in tension, therefore an individual who is driven by these needs' sole objective is to evade unpleasant circumstances and to survive (Meyer et al., 2003). Such motivation does not allow room for growth in order to attain the individual's full potential. Neither does it lead to complete happiness and satisfaction. For instance, an individual who becomes paraplegic after a motor vehicle accident may be left with fear. They might be driven by a need to feel safe and secure. Thus, other higher level needs might be pushed to the back and the individual's main focus will be on the satisfaction of the basic

second level need of safety. An individual is ready to act upon the growth needs only after the deficiency needs are sufficiently satisfied on a regular basis (Huitt, 2004). The individual will then continue striving to attain maximum growth, which may only be attained if all the needs have been fulfilled (Meyer et al.).

Researchers such as Huitt (2004) and Reisinger (2009), further explored Maslow's theory of human motivation. According to Huitt, an individual who does not experience grave deprivation in any of the deficiency needs, is able to satisfy the deficiency needs as crises come up, because (as mentioned above), although individuals strive for maximum growth, needs are never fully satisfied, they reoccur depending on circumstances. If deficiency needs are sufficiently satisfied, the individual may no longer be aware of this need and they may focus on satisfying higher level needs again. If at some future time a deficiency is detected, the individual will act to remove the deficiency (Huitt). Thus, satisfaction of needs is not a linear process, it involves ascend and descend. Ascent refers to rising to higher levels and descent refers to moving down to satisfy lower level needs (Rowan, 1999).

Although, every individual acts to satisfy deficiency needs prior to acting on growth needs, Reisinger (2009) adds that individuals differ in the order in which they attempt to satisfy their needs. When certain needs are fulfilled, on the hierarchy that level is of low concern. The individual concentrates on satisfying other needs, which are of higher priority, in the hierarchy. The order of satisfaction remains according to the hierarchy, no level is ever neglected. For example, some individuals may be more

concerned with satisfying level four (esteem) needs after level two (safety) needs have been satisfied. They may not concentrate on level three (belongingness and love) needs, as those are satisfied. Individuals may also express multiple needs at the same time (Reisinger), such as a paraplegic, more concerned about self-catheterising and whether to use a colostomy or not (level one). They may also be concerned with adaptation, safety and security in their home after discharge (level two).

Furthermore, their concerns may include how to deal intimate relationships and social acceptance (level three). Simultaneously, they may be concerned about progress and acknowledgment at work.

The subsequent figure and paragraph is used to explain the hierarchy of needs according to Maslow's theory of human motivation.

Figure 3.1. Pyramid representing the eight-level hierarchy of human needs model based on Maslow's theory of human motivation.

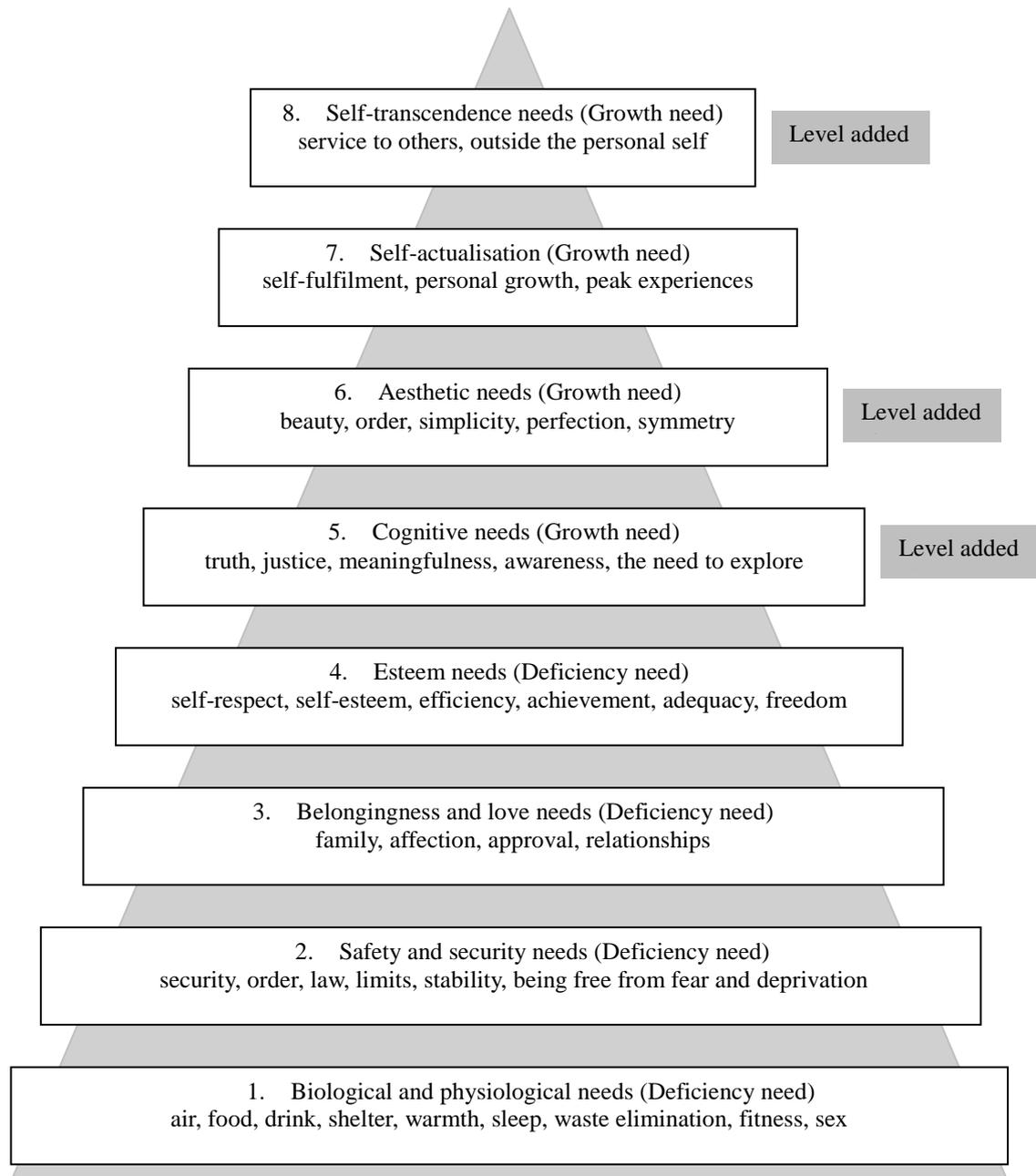


Figure 3.1. Maslow's eight-level hierarchy of needs pyramid. Initially, Maslow developed a five-level hierarchy of needs model comprised only of the five basic needs. It consisted of biological and physiological needs, safety and security needs, belongingness and love needs, esteem needs, and self-actualisation needs. The model

was later adapted and now comprises eight levels of needs. The following three were added after model was adapted; cognitive needs, aesthetic needs, and self-transcendence needs. The hierarchy of needs comprises eight levels of needs, four deficiency needs and four growth needs (see figure 3.1). From *International Tourism: Cultures and Behaviour* (p. 274), by Y. Reisinger, 2009, Oxford: Butterworth-Heinemann. Copyright 2009 by Elsevier Ltd.

As can be seen in figure 3.1 the hierarchy of needs is represented on a pyramid with level one at the bottom and level eight at the top. The first four levels refer to the deficiency needs. Level one represents the biological and physiological needs, which are followed by the safety and security needs on level two. The third level refers to the belongingness and love needs, which are followed by the esteem needs on level four.

Level five, which represents the first level of the growth needs, refers to the cognitive needs. These needs were added to the hierarchy at a later stage, after the model was adapted. Level six refers to aesthetic needs, also added following the adaptation. Level seven refers to self-actualisation needs and level eight refers to self-transcendence needs, which are at the top of the hierarchy and were also added after the adaptation of the model.

A more detailed discussion of the eight levels of Maslow's hierarchy of needs follows.

3.1.1. Biological and physiological needs (deficiency needs)

Biological and physiological needs include elementary needs such as the need for air, food, drink, shelter, warmth, sleep, waste elimination, fitness, and sex (Reisinger, 2009). Although sex is identified as a biological need, sexual behaviour is partly determined by other needs such as the need for love and affection, which are on the third level of the hierarchy (Maslow, 1943). These deficiency needs are what Maslow identified as the starting point for human motivation theory and are the most urgent of all human needs (Meyer et al., 2003). If these needs are not gratified, they dominate all other needs and cause a great deal of stress, anxiety and tension for the individual who is experiencing the deficiency (Meyer et al.).

Physiological needs are the strongest needs people experience. An individual who is deprived of multiple needs such food, safety, love and esteem, would be motivated to gratify the physiological needs first (Maslow, 1943; Simons, et al., 1987). For instance, an individual who becomes quadriplegic following a motor vehicle accident may experience deprivation of most of his basic needs as they may be unable to drink and eat by themselves. They may experience health complications, which may be accompanied by relationship, social and work difficulties. However, the individual will foremost focus on satisfying the physiological needs in order to survive.

Once the biological and physiological needs are reasonably satisfied on a regular basis, a new set of needs emerge. The second level refers to safety and security

needs.

3.1.2. Safety and security needs (deficiency needs)

Safety needs include the need for protection from elements, security, order, law, limits, stability and being free from fear and deprivation (Reisinger, 2009). Maslow (1943) is of the opinion that an individual who is motivated by a need for safety will be preoccupied with the search for safety. Safety seeking will be a strong determinant of their current world view and future outlook (Maslow).

Maslow (1943) believed that, a healthy adult's safety needs are largely satisfied. They feel fairly safe from extreme temperatures, attacks from animals, accidents as well as criminals. However, even in the absence of the above mentioned physical threats to wellbeing, threats to safety still exist. An individual's search for a job or the desire for an insurance policy reflects this need for satisfy and security (Maslow).

It is vital to consider the context in which the individual lives and this may basically determine the level of safety they feel. For example, Namibia is a country with a high crime rate, which may threaten individuals' safety and security needs, as people fear being mugged or burgled. Even though a great part of the country is desert land, the Caprivi region is prone to floods and the people, who live in this region, might also feel threatened. Thus, different situations may threaten people's safety and security needs.

At times, quadriplegics may have caretakers who ensure that their daily needs are met. However, once their physiological needs are met, they may be driven by a need for safety and security. This is due to the loss of the ability to do things for themselves. For instance, lack of mobility makes it difficult to escape from dangerous situations. This need also exists in wanting to experience the familiar rather than the unfamiliar (Maslow, 1943). For example, quadriplegic individual's desire for life as it was prior to the spinal cord injury as well as fear of the unknown life ahead.

Once the safety and security needs are reasonably satisfied on a regular basis, the belongingness and love needs emerge as the third level of basic needs.

3.1.3. Belongingness and love needs (deficiency needs)

Belongingness and love needs manifest as the desire to be part of a work group, the desire to have a family, affection, approval and relationships (Reisinger, 2009). The prevailing needs at this level are to receive love, give love, as well as have relationships with people (Meyer et al., 2003). Intimacy includes romantic relationships which may lead to the satisfaction of sexual needs.

As mentioned earlier, sex is identified as biological and physiological need, however sexual behaviour has multiple determinants and the need for sex is an important factor of the love and belongingness need (Maslow, 1943; Meyer et al., 2003). Sex is also determined by needs such as the desire for giving and receiving love (Maslow).

Love is not synonymous with sex, many people who yearn for sex may also be yearning to give and receive love, to belong to somebody as well as to prevent loneliness. A lack of intimacy may result in isolation and loneliness (Maslow).

A paralysed, bedridden individual may have lost friends due to their disability. They may feel more intense than ever before the absence of friends, a partner, or family and children. They may strive with great intensity to attain love and acceptance. Not only do they desire to belong, there is also a yearning for identification with a home or neighbourhood (Maslow, 1970).

As soon as the belongingness and love needs are reasonably satisfied on a regular basis, the fourth level of needs emerge. This level refers to the esteem needs which are the highest level of deficiency needs.

3.1.4. Esteem needs (deficiency needs)

Esteem needs include the need for self-esteem, as well as the esteem an individual derives from others (Simons et al., 1987). Maslow (1943) recognises that people have a desire or a need for a stable, firmly based, high evaluation of themselves, as well as self-respect and self-esteem. In addition, firmly grounded self-esteem is based on real capacity, achievement, respect, and affirmation from others. Such recognition ensures that the individual derives esteem from other people (Maslow).

Maslow classifies self-esteem needs into two types of needs. Firstly, needs based on

the individual's achievements such as a sense of efficiency, capability, achievement, confidence, personal strength, adequacy, independence and freedom (Maslow, 1943, 1970). Paraplegia and quadriplegia challenges an individual's sense of independence, as well as their identity. Secondly, the needs related to the esteem from others, particularly, a desire for reputation and prestige. This includes honour, importance, social standing, recognition, attention, appreciation of competence and dignity (Maslow, 1943, 1970). Research has proven that disability has adverse impact on the perception non-disabled people have of disabled-people.

Manns and Chad (2001) report, the paraplegic or quadriplegic individual believes that they are often perceived as being physically deformed, unattractive, and mentally challenged. This view impacts on the individual's self-esteem needs. They may strive harder to fulfil esteem needs following a disability. Satisfaction of esteem needs leads to feelings of competence, confidence, feeling needed and useful (Meyer et al., 2003). If unfulfilled or unsatisfied, esteem needs lead to feelings of rejection, inferiority, weakness and helplessness (Meyer et al.).

As soon as esteem needs are reasonably satisfied on a regular basis, a new set of needs emerge. The cognitive needs emerge as the fifth level of needs. Contrary to the previous four levels of needs, which referred to deficiency needs, cognitive needs refer to the first level of growth needs.

3.1.5. Cognitive needs

The first level of growth needs comprises of cognitive needs, which refers to the need for knowledge and understanding. Cognitive needs encompass the need for truth, justice, meaningfulness, awareness, and the need to explore (Meyer et al., 2003; Reisinger, 2009). In the broader sense, people are able to satisfy some of their cognitive needs at work. Any disability that impairs an individual's capacity to work, robs them of their ability to satisfy these cognitive needs. The impairment of being paralysed impedes on the satisfaction of growth needs, even though they may have been satisfied before.

People often exhibit a need for information as they wish to understand their own personal experiences, their environment and themselves (Sharf, 1997). They may use their religion or beliefs to find purpose and justice in events; others may be more inclined to search for information pertaining to their condition. The need for information is a cognitive need which may be expressed by disabled individuals as they search for reasons why they are in this situation.

This search for meaning may be used as a coping mechanism. Once you attain a certain level of understanding, growth takes place and the individual is able to elevate to the next level, seeking to satisfy aesthetic needs.

3.1.6. Aesthetic needs

Aesthetic needs refer to the need for beauty, order, simplicity, perfection and symmetry (Meyer et al., 2003; Huitt, 2004). These needs may be expressed in the individual's desire for artistic expression, such as painting or dancing. The individual with a disability may express this need through their desire to enjoy the things they enjoyed prior to becoming disabled, such as travelling, appreciating nature, and taking part in outdoor activities.

According to Martin and Joomis (2007) aesthetic needs refer to the quality of being creatively beautiful, or artistically pleasing, to live an easy, comfortable life, and to achieve perfection in the way things are done. It may also refer to the individual's need to express themselves in pleasing ways, such as decorating their house, washing and waxing their car or taking care of other belongings, and keeping up with the latest styles in clothing (Martin & Joomis). Disability may introduce atypical ways to appreciate and fulfil aesthetic needs.

A certain degree of fulfilment, satisfaction and, balance are essential to graduate to a higher level of self-actualisation (Huitt, 2004). The challenge of being paralysed may put strain on finding fulfilment and symmetry in life.

3.1.7. Self-actualisation needs

Self-actualisation refers to the individual's desire to do that which the individual believes they were born to do (Meyer et al., 2003). According to Simons et al. (1987), the need for self-actualisation is often expressed in a sense of restlessness, feeling on edge, tense, as if the individual is lacking something. When an individual is hungry, unsafe, unloved or lacking self-esteem it is easy to know why they are restless. However, it is not always clear why they are restless when they have a need for self-actualisation (Simons et al.).

On this level, individuals strive to realise personal potential, they strive towards self-fulfilment, personal growth and peak experiences (Maslow, 1943, 1970). Self-actualisation may only be achieved once the deficiency needs are being met on a regular basis (Meyer et al., 2003). Individuals who are striving towards self-actualisation may exhibit aspirations reflecting their maximum potential, either personally, financially or career wise. For a paraplegic or quadriplegic individual, the challenges brought on by their disability may often outweigh the mechanisms utilised to meet these challenges. Subsequently, it may be difficult for the individual to successfully meet the deficiency needs, thus also self actualisation.

Following self-actualisation, there exist only one higher level of needs and they refer to self-transcendence needs.

3.1.8. Self-transcendence needs

Self-transcendence needs refer to the individual's desire to connect to something beyond the ego or to help others find self-fulfilment and realize their potential (Huitt, 2004). At the level of self-transcendence, to a great extent, the individual puts their own needs aside. The individual chooses to be of service to others, some higher force or cause which they regard as important and outside the personal self (Koltko-Rivera, 2006).

Self-transcendence may involve helping others, advocating for human rights, anti-discrimination, universal religion and ethics (Reisinger, 2009). As people become more self-actualised and self-transcendent, they develop more wisdom and automatically know how to react to as well as how to behave in a wide variety of situations (Huitt, 2004). Self-transcendence may be seen as the ultimate level of growth and satisfaction which people strive to attain.

3.1.9. Relatedness between levels of needs

According to Maslow (1970), when an individual experiences grave deprivation in a deficiency need, they are unable to move on to the next level until that need is sufficiently satisfied. Therefore, the emergence of one need usually rests on the satisfaction of a prior need, no need can be seen in isolation, and every need is related to the satisfaction, or dissatisfaction of prior needs (Maslow, 1943). However, because the complete satisfaction of needs is a very difficult or virtually impossible

prospect, needs reoccur, even if they had been satisfied earlier (Maslow, 1970).

Thus, Huit (2004) and Rowan (1999) are of the opinion that needs are not always gratified in strict agreement with the hierarchy. From time to time, higher level needs may motivate behaviour in the absence of the satisfaction of lower level needs. Thus, satisfaction of needs is not a linear process. An individual who is striving to meet esteem needs may simultaneously find themselves struggling to meet safety and security needs (see figure 3.1). This might occur because sudden onset disability may threaten the individual's feelings of safety and security. Nonetheless, the general believe according to Maslow (1970) is that such cases are rare and generally, the hierarchy applies.

According to Maslow, self-actualisation and self-transcendence are the optimal levels of functioning (as cited in Meyer et al., 2003). Meyer et al. emphasise that individuals strive for self-actualisation and self-transcendence, as it encourages them to discover and fulfil their maximum potential. However, self-actualisation and self-transcendence are generally difficult to attain due to factors such as lack of self-knowledge and obstructions, including fear of taking risks and experimenting.

A few more examples which prevent individuals from attaining maximum potential include the individuals' failure to acknowledging their own talents, avoiding responsibility, and fear of overestimating their own abilities and thus avoiding any attempt at doing anything (Meyer et al., 2003). A lack of integration within the individual, which could be due to cultural stereotypes that define what men and

women should or should not do are further contributors that prevent self-actualisation and self-transcendence.

3.1.10. Summary of Maslow's theory of human motivation

People are driven by at least five basic levels of intrinsic needs and three higher-order needs. In total, eight levels of needs act as the motivation for most behaviour, consumption behaviour as well as actions taken. People are thus motivated by a desire to achieve, attain or basically to satisfy their needs. The basic needs are biological and physiological, safety and security, belongingness and love, esteem, cognitive, aesthetic, self-actualisation and self-transcendence needs. The lower, four levels of needs are deficiency needs and the top four levels are growth needs.

These needs are arranged in a hierarchy from the most primitive biological and physiological needs at the very bottom, to the highest self-transcendence needs at the top of the hierarchy. These hierarchical needs, primarily the deficiency needs, are dependent upon one another. The satisfaction of one level of needs leads to the emergence of the following level of needs. An unsatisfied need monopolises consciousness until it is satisfied on a regular basis and only then will the individual become aware of the next level of needs.

People generally strive towards self-actualisation and self-transcendence; however people in general are at all times partially satisfied as well as partially unsatisfied. Therefore humans always have needs that they attempt to satisfy. Threats to the

possibility of attaining specific needs, such as a threat to the safety of an individual, result in a hampering of growth towards self actualisation in an individual.

Maslow's theory of human motivation provides a valuable framework for conceptualising human needs as well as the individuals' strive towards satisfaction, self-actualisation and self-transcendence. However, it does not suffice to view the individual in isolation. It is essential to consider the individual in the context of their environment. Thus, the subsequent section is devoted to discussing the person-environment fit theory. The person-environment fit theory places the individual in a context and examines the impact the environment has on the individual and their satisfaction.

3.2. Person-environment fit theory

Research has revealed that the amount of involvement with which people engage in their activities impacts on the outcome of those activities. In addition, the environment in which the individual operates also has an influence on the possible outcome of the interactions (Amiot, Vallerand, & Blanchard, 2006). Characteristics of the individual, the environment, as well as the manner in which the individual and the environment interact are important factors that contribute to the individuals' satisfaction with themselves and their environment.

The interaction between the individual and the environment has previously been summarised by various researchers as "person-environment fit" (French, Rodgers, &

Cobb, 1974; Kulka, Klingel, & Mann, 1980) or “goodness of fit” (Lerner, 1983).

Goodness of fit has been interpreted as a process involving interaction between the individual and the environment leading to attitudes, behaviours and adjustment (Kurosawa, 1995). Thus person-environment fit and goodness of fit share the theoretical orientation of focussing on the interaction between the individual and the environment. Throughout this paper, the concept person-environment fit theory will be utilised. This theory is based on the assumption that human behaviour is a function of the interaction of the individual and the environment (Orford, 1992).

Commonly, person-environment fit theory and most related research has been conducted in work settings, however, as a process theory, it may be applied not only to work settings, but also to different life domains, such as work, family, and leisure (Harrison, 1978). Theoretically, person-environment fit is a central concept that is assumed to be multidimensional and influence a wide variety of psychological phenomena, ranging from satisfaction to personality consistency (Roberts & Robins, 2004).

Person-environment fit embodies the premise that attitudes, behaviours, and other individual-level outcomes result not from the individual or environment separately, but rather from the relationship between the two (Lewin, 1951; Murray, 1938; Pervin, 1989). Environmental factors may include products and technology; the natural environment, including human-made changes to the environment; social support and relationships; attitudes; and the availability of services, systems, as well as policies (Tomey & Sowers, 2009). This combined influence of individual and

environmental factors on each other in turn influences outcomes such as success or failure in the individuals' efforts (Livingstone et al., 1997). These efforts may include failed or successful adaptation to and coping with disability.

The term "fit" refers to the degree of similarity or compatibility between individual characteristics and situational characteristics (Livingstone et al., 1997). Relevant individual characteristics include values and abilities, while relevant environmental characteristics include supplies and demands (French, Caplan, & Harrison, 1982). It is the discrepancy between personal characteristics, and environmental supplies and demands that may create additional problems, beyond those resulting from the environment or personal characteristics alone (Kahana, Lovegreen, Kahana, & Kahana, 2003). Within the paraplegic and quadriplegic community, individual characteristics may refer to coping mechanisms employed and an individual's functional abilities such as the ability to push a manual wheelchair. Environmental characteristics may refer to the availability of ramps to improve accessibility to buildings.

Fit is determined by examining the relationship between the individual's values and abilities and the environmental components (French et al., 1982) (see sections 3.2.1 and 3.2.2). Exploring the relationship between personal characteristics and the environmental components has been found to be a useful way of predicting strain such as job or workload dissatisfaction (French et al., 1982; Harrison, 1978).

Determining fit may also be a valuable means of assessing and improving quality of life of individuals in various other settings, including quality of life of individuals with paraplegia or quadriplegia. Lack of person-environment fit is conceptualised as an important source of chronic stress that is likely to elicit adverse health, low life satisfaction and consequently lead to poor quality of life (Kahana et al., 2003).

The individual with a disability such as paraplegia or quadriplegia may no longer fit comfortably into the environment they lived in before their disability. Alterations may need to be made to their environment in order for the individual to live comfortably. For example, once the individual becomes wheelchair bound, their environment must be altered to become wheelchair friendly. Their car might have to be modified so they are able to drive around by themselves. Furniture might have to be rearranged to make more room in their home in order to accommodate their wheelchair. Alterations such as the placement of ramps to increase the accessibility to buildings within the individual's environment may also be required. These alterations may contribute to improving the individual's independence and consequently improve their quality of life.

However, adjustments must also involve attitude and behaviour changes to ensure a match between the individual and the environment. For instance, in addition to modifying their car, the individual must make an effort and actively attempt to overcome their concerns, anxiety and worry related to driving themselves around. Only with a change of attitude will they be able to adapt successfully after the onset of their disability. Furthermore, it is likely that a certain degree of discrepancy may

exist between psychological needs and environmental demands (Okubo, Kurosawa, & Kato, 2007). Such discrepancy could motivate the individual to behave in certain ways. The behaviour of the individual may affect the interaction between them and the environment, which in turn will influence the outcome of adjustment, following the onset of their disability.

It is suggested that poor fit between an individual and their environment, due to the above mentioned discrepancy, may motivate them to choose certain types of behaviour (Okubo et al., 2007). For example an individual with paraplegia or quadriplegia may be in an environment that is fully adapted and equipped for their optimum functioning, however depression may prevent the individual from enjoying a good quality of life. Thus, depression may result in behaviours such as withdrawal which is a non-productive, largely negative, and ineffective form of coping. It has increasingly become apparent that the individual does not exist in isolation; they live in an environment, and form part of a system. This environment has an influence on the individual's feelings and actions, just as much as the individual has an effect on their environment. People are more satisfied if they are able to interact comfortably with their environment.

The environment must meet the individual's needs and the individual must be able to manipulate their environment to a certain degree. The degree of interaction determines whether there is a fit or a match between the individual and the environment. Thus, it is essential to examine this context of the person within their environment. Person-environment fit encompasses two distinct versions of fit,

supplies-values fit and demands-abilities fit (Edwards, 1996). These two versions of person-environment fit are discussed in subsequent sections.

3.2.1. Supplies-values fit

The supplies-values fit refers to the match between an individual's values (also referred to as motives) and the environmental supplies available to fulfil those values (Edwards, 1996). According to French et al. (1982) values include the need to achieve, gain power, money, have opportunities to achieve, as well as support from people. Supplies refer to the amount, frequency, and quality of environmental attributes that may fulfil the individual's values. Supplies can be regarded as either objective or subjective (French et al.).

Thus, the features in the environment as well as the individual's perception of these environmental features are essential. They impact on the individual's behaviour as well as emotions. Strain only occurs if the individual's subjective view is that the supplies will not meet their values (Edwards, 1996). For example, the individual may believe that being confined to a wheelchair hampers their ability to take part in outdoor activities such as hunting. This might affect their adaptation process negatively, regardless of the information about options available. The individual may be convinced that the environmental supplies are unable to meet their need for outdoor activities and achievement. They may find it difficult to change their perception. Thus, they may not be able to devise effective coping mechanisms to deal with their disability.

According to Edwards (1996) the cognitive comparison of the individual's needs and desires against the perceived environment or the events experienced by the individual is the underlying process of the supplies-values fit model. Thus, supplies-values fit involves an individual's evaluation of their environment based on personal values (Edwards & Cooper, 1990). As such, strain increases when supplies fall short of values (Cummings & Cooper, 1979; French et al. 1982; Schuler, 1982). For example, following a motor vehicle accident, an individual may have a desire to return to work as a bricklayer. However, they may have become paraplegic and will thus be unable to fulfil their desire. In this instance, the desired work environment is not conducive and the individual's values, which include aspirations as a bricklayer, remain unsatisfied. Thus, the individual experiences strain (stress).

3.2.2. Demands-abilities fit

Various researchers have explained the concept of demands-abilities fit. According to French et al. (1982), it examines the extent to which an individual's abilities meet the demands of their environment. Edwards (1996) refers to it as the match between environmental demands and an individual's abilities.

The individual's abilities include the skills, knowledge, time, and energy the individual draws upon to meet environmental demands (Edwards, 1996).

Environmental demands refer to quantitative and qualitative requirements placed on the individual and can be objective (e.g. length of work day) or socially constructed (e.g. group norms, role expectations) (Edwards). How the individuals' abilities and

the environmental demands influence, and have an effect on people with spinal cord injury, may be illustrated in a couple of examples.

An individual with paraplegia or quadriplegia may not be able to work the same length of hours as they were able to work before the disability. The individual might perceive this as a misfit between their abilities and the environmental demands. They might translate it as failure to cope, as they are not able to fit into their life as it was prior to the disability. In order for the individual, to cope effectively, adjustments must be made to the environmental demands as well as the individuals' abilities. For example, the demands placed on the individual to work long hours may be adjusted, so that they can work more flexi hours or shorter hours, with which he may be able to cope better. Better hours may lead to improved satisfaction for the individual, who may be able to enjoy a better quality of life.

If personal characteristics and abilities as well as environmental factors and demands do not match, it signifies a misfit between the individual's abilities and the environmental demands. This signified misfit may lead to negative outcomes such as lower satisfaction, lower performance, higher strain, and unhappiness, and lowered quality of life (Livingstone et al., 1997; Orford, 1992). Furthermore, the individual's perceptions of themselves and their environment are also important contributing factors to satisfaction, performance, strain, and happiness (Orford). Thus, when exploring an individual's quality of life, it is essential to consider the individual within the context of their environment as well as how the individual values and abilities match the demands of the environment.

3.2.3. Summary of person-environment fit theory

The person environment fit theory is the basic premise underlying theories in various domains of organizational behaviour, such as job satisfaction and the quality of work life (Edwards, 1996). However, this theory may be applicable to diverse life situations such as the study of quality of life in various settings other than work environments. These life situations include rehabilitation and adaptation of people with disabilities, seeing that the person-environment fit theory assumes the interaction of the individual with the environment has a major impact on human behaviour as well as the outcome of such behaviour (Orford, 1992). The influence of individual and environmental factors on each other in turn influences outcomes such as success or failure including successful adaptation to and coping with disability. These outcomes depend on the fit between the individual and environmental characteristics (Livingstone et al., 1997).

Fit refers to the match between the environmental factors and the individual characteristics. The person-environment fit theory encompasses two separate versions of fit. The supplies-values fit refers to the match between an individual's values and the environmental supplies available to fulfil those values (Edwards, 1996). Demands-abilities fit examines the degree to which an individual's abilities meet the environmental demands (French et al., 1982). The better the fit, the more desirable the outcome, and the greater the misfit, the less desirable the outcome.

For the paraplegic and quadriplegic population, their adaptation and coping depends

largely on their immediate environment. Adaptation and coping also depends on their interaction with their environment, to the same degree that it depends on their health and their personal attributes. Thus, enjoying a good quality of life is influenced by and largely depends on a fit between the individual and their environment. Both paraplegia and quadriplegia are debilitating conditions, which present many challenges for an individual. Disability requires physical, emotional as well as environmental changes, which are extremely stressful and anxiety provoking. In order to deal with the challenges, individuals must develop ways of coping with their disability. The subsequent section presents various defence mechanisms. An understanding of defence mechanisms conceptualises the individual's attempts to cope with their disability and related challenges.

3.3. Defence mechanisms

Individuals with disabilities are faced with challenges unique to them. These challenges affect almost every area of their lives, as it has emotional, as well as physical implications (Crewe & Krause, 2002; Degraff & Schaffer, 2008). This results in higher or compounded levels of anxiety and stress which surpass levels faced by able-bodied people (Degraff & Schaffer). If an individual does not devise effective strategies to manage the stress in their life, their physical health and emotional wellbeing may deteriorate. Poor health may cause unhappiness, lowered satisfaction and eventually, poor quality of life. Quality of life will be lowered, as it is affected by an individual's level of satisfaction in many different domains of life (Bishop, 2005). According to Brown et al. (2004), consciously or unconsciously,

individuals may accommodate, adapt or adjust to deteriorating circumstances because they want to feel as good as possible about themselves.

The process of adaptation may be aided by coping mechanisms, which are a means to defend the individual against challenging situations (Degraff & Schaffer, 2008), as well as defence mechanisms. Defence mechanisms are means by which the unconscious mind helps individuals deal with anxiety-inducing events or trauma that the conscious, rational part of the self is unable to resolve sufficiently on its own (Vaillant, Bond, & Vaillant, 1986). Consciously, the individual may be unable to deal with the traumatic event, possibly based on a lack of rational coping strategies, due to weak ego strength, or simply because the problem is not rationally soluble (Vaillant et al.).

According to Plutchik, Kellerman, and Conte (1979), defence mechanisms and coping strategies rely on different theoretical backgrounds and describe distinct psychological processes. The distinction is related to coping mechanisms being conscious, intentional processes compared to the defence mechanisms which are unconscious, unintentional processes (Plutchik et al.). However, contrary to these distinctions, the two notions of defence mechanisms and coping strategies are defined as similar in the Diagnostic and Statistical Manual (DSM IV) (APA, 2005).

According to Degraff and Schaffer (2008) people approach these challenges in many different ways; each individual may consciously develop their own coping strategy and employ coping mechanisms that suits them. Some coping mechanisms are more

successful than others. When coping mechanisms fail, the individual may experience greater amounts of stress and anxiety (Degraff & Schaffer, 2008) and the ego may start employing defence mechanisms (Vaillant et al., 1986). Researchers presume that anxiety, including disability related anxiety, may be lessened by employing defence mechanisms (Carlson, 1990; Gillett, 1994; Meyer et al., 2003; Westen, 1999).

According to Gillett (1994), theorists agree that the repeated “successful” use of a defence mechanisms results in a progressive reduction in the degree of the anxiety. Successful reduction does not imply complete elimination of anxiety, thus some degree of anxiety still remains (Gillett, 1994). However, when defence mechanisms are employed successfully, at least temporarily, anxiety is reduced to a point that it is no longer perceived as threatening to the individual. Therefore understanding the use of defence mechanisms is essential in attempting to comprehend the individual’s efforts to cope with their disability.

Psychoanalytic theory, as well as psychodynamic theories, indicates that aggressive drives within the individual often come into conflict with the prohibitions of the individual’s moral values. It results in the development of intrapsychic conflict and defence mechanisms are activated in order to avoid anxiety (Carlson, 1990; Meyer et al., 2003). Therefore, defence mechanisms may be defined as a range of largely unconscious processes by which people protect themselves from awareness of their undesired and feared impulses as well as thoughts and feelings (Meyer et al., 2003; Vaillant et al., 1986). These impulses may include anger and suicidal thoughts

following a spinal cord injury, which could be due to anxiety and depression.

Defence mechanisms serve the function of reducing anxiety or reinforcing pleasurable emotions (Carlson, 1990; Meyer et al., 2003). Furthermore, they allow the individual to distance themselves from full awareness of unpleasant thoughts, feelings and desires (Carlson, 1990; Vaillant et al., 1986). According to Vaillant et al., there are positive, more adaptive as well as negative, less adaptive defence mechanisms. Although, defence mechanisms may seem to make situations more tolerable, initially, they often result in matters going unresolved. For an individual with paraplegia, unpleasant thoughts could involve facing the reality of not being able to walk or the implications of having no sensation in their sexual organs. Defence mechanisms such as denial (which is negative) or acceptance (which is positive) might thus be employed in order to deal with these unpleasant thoughts.

According to Meyer et al. (2003) defence mechanisms mainly operate unconsciously and their primary function is to prevent anxiety provoking material from surfacing. For this reason, individuals are mostly unaware of their use of defence mechanisms for coping. Thus, on a conscious level, individuals basically have a largely distorted and unreal image of themselves and their environment (Meyer et al.).

Although defence mechanisms operate mainly unconsciously, Westen (1999) promulgates that the use of defence mechanisms is not necessarily a sign of maladjustment or a psychological disorder. Westen also points out that some degree of defensive distortion may be useful, such as the tendency for people to see

themselves more positively than is warranted by reality. For example, an individual with quadriplegia could engage in self-talk to keep themselves positive and focus on the pleasant things in life. Such defences only become damaging when they hamper normal functioning or development instead of promoting it (Westen). Psychoanalytic and psychodynamic theories postulate that people rarely use only one type of defence mechanism. Individuals often defend themselves against anxiety by employing a variety of defence mechanisms simultaneously. Thus, there is significant degree of overlap between the defence mechanisms (Meyer et al., 2003).

For better understanding of the way in which individuals utilise defence mechanisms, attention is paid to examining a number of defence mechanisms. As mentioned earlier, defence mechanisms enable individuals to deal with anxiety that remains following failed attempts to deal with situations consciously through coping strategies (Vaillant et al., 1986). For example, using rational problem solving as a coping mechanism may be an effective form of problem-focussed coping. However, Vaillant et al. are of the opinion that, if the active coping fails, and the individual starts overemphasising the role of rationality (to the exclusion of emotionality, spirituality, aesthetic responses and so on), they may be suffering from overuse of intellectualisation as a defence mechanism. Many defence mechanisms involve a compulsive overuse of a single ego state (Vaillant et al., 1986). From a clinical perspective, defence mechanisms assist in dealing with anxiety, thus the discussion of defence mechanisms is linked to coping mechanisms.

The coping mechanisms that have been identified by Lazarus and Folkman (1984)

include problem focused coping such as acting out and spending time with the family. Emotion-focused coping such as denial, withdrawal, avoidance and minimalisation are identified as the coping mechanisms that are employed most extensively by people with disabilities. As is evident, there appears to be an overlap between the coping strategies identified and the defence mechanisms identified in the literature, particularly within the DSM IV (APA, 2005; Lazarus & Folkman, 1984; Vaillant et al., 1986). Thus, the subsequent section is devoted to a discussion of several defence mechanisms.

3.3.1. Defence mechanisms related to problem-focused coping

Problem-focused coping involves defining the problem, creating optional solutions, and weighing the alternatives before making a final decision (Lazarus & Folkman, 1984). This type of coping is a conscious ego function, thus not a defence mechanism (Vaillant et al., 1986). It refers to an individual's attempt to deal with emotional conflict and internal or external stressors by actions rather than reflections or feelings (APA, 2005). The individual who copes through acting out may take active steps to change themselves as well as their surroundings after the onset of a disability. On the other hand, acting out may be employed without consciously deciding on it. Thus, as an impulsive action, it may be classified as a defence mechanism. For the purposes of this study acting out is regarded as a positive defence mechanism and is associated with problem-focussed coping, leading to positive outcomes.

Acting out refers to many different ways of taking active steps towards change. For example, an individual with paraplegia may modify their car in order to improve their independence, instead of focusing on feeling restricted by not being able to drive themselves around. The defence mechanism of self-observation (APA, 2005) may also be associated with problem-focused coping. The individual deals with emotional conflict and stress by reflecting on their own thoughts, feelings, motivation, and behaviour. After reflecting, they attempt to respond appropriately (APA).

3.3.2. Defence mechanisms related to emotion-focused coping

Lazarus and Folkman (1984) have determined that emotion-focused coping mechanisms are most commonly employed by people with disabilities. Emotion-focused coping focuses on lessening emotional distress. It does not involve taking active steps to reduce the stress, but merely increases an individual's comfort level (Lazarus & Folkman, 1984). The defence mechanisms, which may be identified as largely emotion focussed appear to be less adaptive and include affiliation, altruism, autistic fantasy, denial, help-rejecting complaining, humour, intellectualisation, passive-aggression, and rationalisation (APA, 2005; Vaillant et al., 1986).

Affiliation refers to the individual's way of dealing with conflict or stressors by turning to others for help or support. It involves sharing problems with others without blaming others for their problems (APA, 2005). Such support is essential for people who struggle with paraplegia or quadriplegia. Altruism refers to an

individual's attempt to deal with conflict or stress by dedicating themselves to meeting the needs of others (APA, 2005; Vaillant et al., 1986). The individual experiences gratification through the responses of others whom they have helped. Autistic fantasy refers to the way in which certain individuals deal with conflict or stress by extreme daydreaming. The daydreaming might be used as a replacement for human relationships, more effective action, or problem solving (APA). Often, individuals who are paraplegic or quadriplegic may spend extensive amounts of time daydreaming (T. Cloete, personal communication, July 8, 2009).

Denial is one of the most commonly used types of defence mechanisms and one of the least adaptive, most harmful form of defences (Vaillant et al., 1986). It refers to the individual's refusing to acknowledge some painful aspect of external reality or subjective experience that would be apparent to others and refers to actual loss of reality contact (APA, 2005; Vaillant et al., 1986). The defence mechanism referred to as help-rejecting complaining involves protesting or making repetitious requests for help (APA). However, this complaining may be a means to disguise covert feelings of hostility or reproach toward others. The individual may express these feelings of hostility or reproach by rejecting suggestions, advice, or help offered. Individuals who feel hopeless after a spinal cord injury may sometimes resort to this type of coping (APA). When humour is employed as a coping mechanism, emotional conflict and stress is dealt with by emphasising the absurd, amusing or ironic aspects of the conflict or stress (APA, 2005; Vaillant et al., 1986). Humour may be classified as a form of defence that is adaptive and positive to a large extend (Vaillant et al.).

During intellectualisation, the individual deals with conflict or stressors by the extreme use of abstract thinking or generalising to control or minimise disturbing feelings associated with the emotions or the stressor (APA, 2005; Vaillant et al., 1986). Intellectualisation is also one of the most common defence mechanisms employed as individuals try to make sense of their disability and it may be an adaptive form of defence (Vaillant et al.). The defence mechanism of passive aggression is exhibited through indirect and unassertive expression of aggression towards others. There is a facade of overt compliance present that masks covert resistance, resentment, or hostility (APA). This type of defence mechanisms may prove to be harmful (Vaillant et al.). For example, anger concerning a motor vehicle accident may be suppressed and contribute towards passive aggression.

Rationalisation is employed when emotional conflict or stress is dealt with through concealing the true motivations for the individual's own thoughts, actions or feelings (APA, 2005). Thoughts, actions and feelings are concealed through the elaboration of reassuring or self-serving but incorrect explanations (APA). Rationalisation may also be due to a search for answers.

3.3.3. Summary of defence mechanisms

Defence mechanisms refer to a range of semi-conscious and unconscious processes by which people attempt to protect themselves from undesired and feared impulses. Even though defences are mainly unconscious, they are used as coping mechanisms to help people deal with challenges such as those brought on by a disability. Defence

mechanisms serve to reduce anxiety and induce pleasant feelings. To some extent, the use of defence mechanisms may be helpful and effective. However when overused, defences may become damaging by hampering normal functioning or development.

There are numerous types of defence mechanisms that have been identified by psychoanalytic theory as well as psychodynamic theories. However not all defence mechanisms were discussed in this chapter. Emphasis was put on defence mechanisms related to problem-focused coping and emotion-focused coping. The defence mechanisms that are discussed in this chapter include acting out, self-observation, affiliation, altruism, autistic fantasy, denial, help-rejecting complaining, humour, intellectualisation, passive-aggression, and rationalisation.

3.4. Chapter summary

In chapter three, Abraham Maslow's theory of human motivation is explored and discussed as the fundamental theoretical framework for the study. Maslow's human motivation theory is vital to the understanding of human motivation, behaviour, and satisfaction, which ultimately influences quality of life. The person-environment fit theory is also drawn upon to contextualise how the individual interacts with their environment following a disability. This is essential as people exist within a context and any physical changes on their body affect how they interact with their environment. In addition, person environment interaction also contributes to feelings of happiness and satisfactions, which influences quality of life. Lastly, defence

mechanisms are discussed for a clearer understanding of the means individuals employ in order to cope with their disability.

The methodology used to gather and analyse data for the research is outlined as well as discussed in the following chapter. The research design, participants and sampling, measuring instruments, research procedures, data analysis and ethical considerations will be discussed.

CHAPTER FOUR

EMPIRICAL STUDY

This chapter outlines and discusses the methodology employed to obtain and analyse the data. The primary aim of this study was to explore the quality of life of road accident survivors who suffered spinal cord injuries, resulting in paraplegia and quadriplegia on the Namibian roads. The required knowledge was gained through obtaining subjective views of paraplegic and quadriplegic individuals regarding the important components that contribute to their quality of life. For the purpose of shedding more light on the above mentioned aim, the research design, participants and sampling, measuring instruments, research procedures, data analysis, and ethical considerations are discussed in this chapter.

3.1. Research Design

The researcher aimed to investigate subjective views of participants, regarding areas of their lives, unfamiliar to the researcher. The investigation was carried out in the absence of a working hypothesis. No attempt was made to test, prove or disprove assumptions, solve a practical problem or to explain a specific phenomenon. Colman (2006) refers to such studies as exploratory studies. Exploratory studies are open, flexible and inductive ways of obtaining subjective information from participants (Terre Blanche, Durrheim, & Painter, 2006). An interpretive phenomenological analysis (IPA) method of data analysis was employed to gather data for this

exploratory study. IPA aims to conduct a detailed exploration of how individuals make sense of their personal and social world. Personal experiences as well as perceptions of an object or event are considered crucial for IPA (Smith & Osborn, 2006). IPA is pre-eminently suited to explore subjects within health, social, and clinical psychology (Smith & Eatough, 2007; Smith & Osborn, 2006).

3.1.1. Stages of research

The research was conducted in the following four stages; firstly, consent; secondly, data collection; thirdly, data analysis; and lastly, report writing. Throughout the first three stages administrative matters were continuously dealt with. The third stage, data analysis, consisted of three steps. These steps include; step one, translation of transcripts; step two, manual analysis with IPA; and step three, electronic data analysis with ATLAS.Ti. Due to the fluid nature of IPA, the stages overlapped occasionally.

During the first stage of acquiring consent, the Motor Vehicle Accident Fund of Namibia (MVA Fund) was contacted with a request to grant permission to approach some of their clients for participation in the study (see Appendix A). Once permission was granted, prospective participants were contacted telephonically. Appointments were scheduled as soon as verbal consent was obtained from the participants.

Stage two, data collection, was performed using semi-structured interviews (see

Appendix B). These semi-structured interviews were conducted at times, as well as places, which were most suitable for the participants. Verbal consent was obtained from the participants and each participant signed two copies of a consent form (see Appendix D) prior to the semi-structured interviews being conducted. One copy was retained by the researcher and the other given to the participant for their record.

The semi-structured interviews lasted between 45 minutes to 80 minutes. As a result of unforeseen health complications, one participant's appointment was interrupted. The appointment was rescheduled, thus the interview with that particular participant was conducted over two consecutive days. During the semi-structured interviews, the researcher made written notes where necessary and all the semi-structured interviews were recorded. Although eight semi-structured interviews were carried out, only seven were utilised for this study. The eighth transcript was eliminated as the particular individual did not sustain his injuries in a motor vehicle accident.

Amongst the seven semi-structured interviews utilised; four were conducted in English, two in Afrikaans and one in Damara-Nama, since the researcher is fluent in these three languages. As the researcher is equally fluent in all three languages employed during the semi-structured interviews, the service of a professional translator was not required. It is crucial to mention that, due to the researcher's inability to speak Oshiwambo, there exists a limitation to the research. It is a possibility that the two Oshiwambo speaking participants, who were interviewed in English, may have felt limited, and unable to express themselves as openly, as they might have done, in their home language. The process of translation was assisted and

reviewed by an independent third party with an honours degree in psychology as well as a post graduate diploma in translation. This individual is trained in SDL Trados, which is one of the market leading computer assisted translation software packages (SDL Trados, 2009). All the semi-structured interviews were translated loosely, yet special care was exercised to ensure that the gist of the conversation constructs remained equivalent. The semi-structured interviews were conducted between May and July 2009.

Stage three, data analysis was conducted in three steps. These steps are; step one, translation of transcripts; step two, manual analysis with IPA; and step three, electronic data analysis with ATLAS.Ti. Once the semi-structured interviews had been collected, step one of data analysis entailed transcribing the semi-structured interviews word for word, as well as translating four transcripts into English (see above paragraph for more detail). The second step involved using IPA, as recommended by Smith and Eatough (2007) and Smith and Osborn (2006), to familiarise the researcher with the transcripts as well as to identify the most prominent themes. Lastly, during step three of data analysis, the transcribed semi-structured interviews were entered into ATLAS.Ti. This is a computer based package that aids in managing and analysing research with qualitative data (Muhr & Friese, 2004). The transcripts were analysed as recommended by Muhr and Friese, and the final themes were selected.

Stage four, which was the final stage of this research, involved report writing. The listed themes were translated into a narrative account to provide a report on the

results of the study. During this phase, care was taken to distinguish between the researcher's interpretation of the passages and the participants' actual words. Certain passages are loaded with more than one theme. Thus, it was imperative that the researcher was able to recognise this and distinguish between themes. Interpretative analysis of data is fluid, in the sense that there are not clear distinctions between the stages, hence one stage may overlap with another and the researcher often moved back and forth between transcripts (Smith & Eatough, 2007; Smith & Osborn, 2006).

3.1.2. Validity

A core requirement of a good research study, whether qualitative or quantitative is ensuring that the results are valid, congruent, as well as comprehensive (Terre Blanche et al., 2006). According to Smith and Osborn (2006) qualitative research addresses the concern of validity in three ways. Firstly, validity is addressed through sensitivity, secondly, through commitment, rigour, transparency, and coherence. Thirdly, validity is addressed through ensuring impact and importance. In addition to validity, congruence and comprehensiveness are identified as essential principles for qualitative research (Terre Blanche et al.).

Guaranteeing validity through sensitivity has a specific outcome. Smith and Eatough (2007), postulate that sensitivity refers to clarifying the context of theory and the social context of the relationship between the researcher and the participants. For example, a researcher must explicitly state if there had been any previous contact, and the nature of the contact between the researcher and the participants. This is

important as it indicates the background, history and context of the semi-structured interviews. Smith and Eatough also link sensitivity to clarifying the understanding created by previous researchers who utilised related methods or analysed related topics. In order to guarantee sensitivity, the researcher clarifies the nature and context of previous contact with the participants, as well as the benefits of such previous contact in this report (see section 4.4.1). In addition, the researcher conducted a literature review on the topic of quality of life, particularly paying attention to spinal cord injured individuals.

To guarantee validity through commitment, rigour, transparency, and coherence, it's essential to define these terms. Commitment entails demonstrating prolonged engagement with the research topic and rigour refers to the completeness of data collection as well as data analysis. Transparency points to ensuring data collection, as well as analysis are detailed. Coherence ensures that the research question fits the method of analysis (Smith & Eatough, 2007). In order to guarantee the above mentioned, the researcher collected data, using semi-structured interviews, which Smith and Eatough as well as Smith and Osborn (2006) recommended, as the most appropriate data collection method for studies of this nature. Furthermore, the researcher also conducted IPA, which is a very detailed form of data analysis (see section 4.6).

To maintain validity through impact and importance implies that the study has a theoretical, practical or socio-cultural impact (Smith & Osborn, 2006). Through writing a theoretical framework, the researcher ensured that the study has a sound

theoretical basis (see chapter three) and the study is also contextualised to fit Namibia (see chapter two, six and seven).

In addition to validity, congruence and comprehensiveness are essential principles that qualitative researchers should maintain (Terre Blanche et al., 2006). Congruence refers to ensuring that no part of the final account contradicts another and that the answer to the research question is conveyed in an intelligible manner.

Comprehensiveness maintains that the explanations provided are a complete representation of the social context or the psychodynamics (Terre Blanche et al.). By adhering to the research ethics (see section 4.8), the researcher attempted to achieve congruence and comprehensiveness.

Throughout the research process, the researcher strived to ensure that validity, congruence and comprehensiveness were maintained and this was used as a framework for the research.

Figure 4.1 represents the research design, including the processes of gathering data and analysing data.

Figure 4.1. Representation of the research design from stage one to stage four.

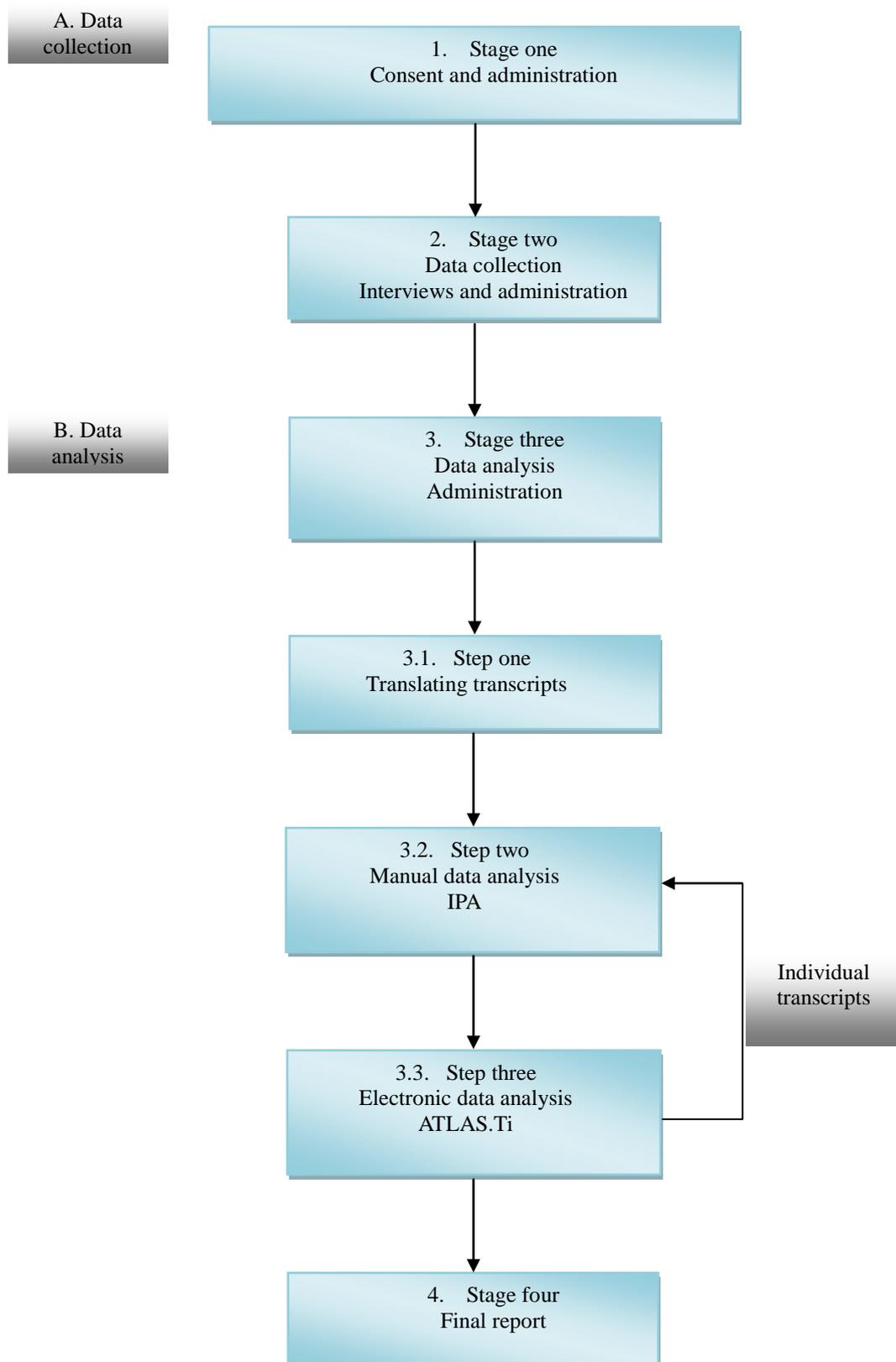


Figure 4.1. Provides an outline of the research design. It shows that the research process consisted of four stages. Stage one entailed, obtaining consent from the MVA Fund as well as the participants. Stage two involved collecting data through semi-structured interviews. Data analysis represents stage three, which was divided into three steps. Step one involved translation, step two, manual analysis and step three, electronic analysis. Finally, a narrative account of the findings was written up in stage four. Figure 4.1 also represents the fluidity of the research process and that administration spread over the first three stages.

3.2. Participants

3.2.1. Population

The population consisted out of paraplegic and quadriplegic people, who had been involved in motor vehicle accidents. The participants were selected through identifying an initial participant and using that individual as a referral base to other individuals. The final selection of participants was done based on their willingness to participate in the study.

3.2.2. Sampling

The participants were selected through purposive sampling. Purposive sampling refers to the method of selecting cases, not just based on availability and willingness to participate, but cases typical of the population under study are selected (Terre

Blanche et al., 2006). This sample was selected specifically from a list of male and female adults with a spinal cord injury who were involved in motor vehicle accidents between one and eight years prior to 2009. The participants were fluent in either one of three languages; English, Afrikaans or Damara-Nama and they were interviewed in their language of preference.

The purpose of IPA is to obtain an in-depth understanding of the participants. Therefore, it is not useful to think in terms of random or representative sampling, but rather in terms of finding a small group for whom the research question will be meaningful (Smith & Osborn, 2006). Guidelines designed by Smith and Osborn suggest five or six as a reasonable sample size for a student project utilising IPA. Therefore, a small sample, consisting of eight individuals, was selected for this study, but only seven transcripts were utilised.

3.2.2.1. Information on the sample

Pseudonyms were provided to protect the identity of the participants. The majority of the participants entrusted the choice of pseudonyms to the researcher, thus the researcher chose to refer to the participants as participant 1 up to participant 7. The numbers that were allocated to the participants were determined by the order in which the participants' transcripts were entered into ATLAS.Ti, which was done randomly.

Demographic details and a brief background of the participants are presented in the

following 2 tables.

Table 1 presents the demographic details of the participants.

Table 1.

Demographic Details of the Participants

Participants	Sex	Age	Residence	Employment
P1	Female	38	Otjiwarongo	Unemployed
P2	Male	30	Windhoek	Self-employed
P3	Male	26	Otjiwarongo	Self-employed
P4	Male	24	Oshakati	Unemployed
P5	Male	28	Oshakati	Unemployed
P6	Female	21	Outjo	Unemployed
P7	Female	45	Windhoek	Unemployed

Note. P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5, P6 = Participant 6, P7 = Participant 7. Participants are presented in the far left column, followed by their gender. The participants' ages, residency as well as employment status is also presented in table 1.

The final research sample consisted out of seven participants, four males (P2, P3, P4 and P5) and three females (P1, P6 and P7). P4 and P5 both live in Oshakati. P3 and P1 live in Otjiwarongo. P2 currently resides in Berseba, although he lived in Windhoek prior to the accident. P6 used to live in Rosh Pinah prior to the accident,

but she currently resides in Outjo, while P7 lives in Windhoek. The residence of the participants is essential as it indicates that the sample is representative of people living in the different regions in Namibia. Only two participants displayed entrepreneurship interests and have attempted to generate income through running small business ventures as is presented in Table 1.

Table 2 presents the historical information as well as personal details of the participants.

Table 2.

History and Personal Details of the Participants

Participants	Married	Children	Injury	Year of injury	Ethnicity
P1	Widowed	Yes	Quadriplegia	2008	Ndebele
P2	No	None	Paraplegia	2008	Nama
P3	No	None	Quadriplegia	2005	Damara
P4	No	None	Quadriplegia	2007	Oshiwambo
P5	No	None	Paraplegia	2001	Oshiwambo
P6	No	None	Paraplegia	2008	Coloured
P7	Yes	Yes	Paraplegia	2008	Ojtitherero

Note. P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5, P6 = Participant 6, P7 = Participant 7. Participants are presented in the far left column, followed by their marital status and whether they have

children or not. The type of injury sustained as well as the year in which the participants were injured is also presented. Finally, the participants' ethnicity is presented in the right hand column of Table 2. The categories provided for ethnicity were not allocated by the researcher; they reflect the participants' own words. Thus, these categories are not allocated with derogatory connotations and are free of judgement.

As is evident in Table 1, P7 is married, P1 is widowed and these two participants are the only individuals who have children. The remaining participants are not married and do not have children. Namibia is a country with a very diverse population. The World Factbook (CIA, 2009) indicates that there are a minimum of nine ethnic groups and at least 13 language groups in Namibia. As a result of purposive sampling (see section 4.3.2), which was employed, as well as the above mentioned diversity, the researcher had little control over which ethnic groups are represented in the study. P4 and P5 belong to the Oshiwambo ethnic group and P3 belongs to the Damara ethnic group. P2 belongs to the Nama ethnic group, while P6 belongs to the coloured ethnic group. P1 is a Zimbabwean lady who belongs to the Ndebele ethnic group and P7 belongs to the Herero ethnic group. Four out of the seven participants were injured a year prior to the semi-structured interviews, while P5, who has been paraplegic for the longest period, was injured eight years ago. The remaining two participants, P4 and P3, were injured two and four years respectively, prior to the semi-structured interviews.

3.2.2.2. Participant information

The participants' history has an influence on their perceptions and the researcher's previous contact with the participants (refer to section 4.4.) enabled the researcher to obtain greater insight into the participants' circumstances. This insight and understanding permits the richness of the findings to emerge in the discussion (refer to chapter 6) of the research results. However, certain information regarding the participants was omitted from this report, due to ethical consideration, although the omitted information is viewed as vital and would contribute to a better understanding of the researcher's interpretations. Omitting this information protects the participants' identity as well as their personal information, which ensures that the research report is presented in an ethically sound manner. Furthermore, by doing this, the researcher honours the participant's trust in the research process.

3.2.2.3. Guidelines on sampling for qualitative studies

Based on guidelines by (Terre Blanche et al., 2006) there are important characteristics that should be present in the participants of qualitative research studies. Based on the qualitative nature of this study, these guidelines were found to be of relevance and were valuable in assisting the researcher to select the research sample. The researcher thus looked for the presence of the following characteristics in all the participants.

- Each participant must have had a personal experience of the topic being

researched. For the purposes of this study, the topic was spinal cord injury. Thus, all the participants should have sustained a spinal cord injury and be either paraplegic or quadriplegic as a result of the spinal cord injury.

- Participants must have the ability to describe their experiences in detail.
- Each participant must demonstrate an open attitude as opposed to a defensive attitude.
- Participants must show genuine interest in participating and they should believe that participating will have some value for them.

The researcher strived to ensure that every one of the research participants possess the above mentioned characteristics, to ensure that the information obtained from them is valid and useful as research data.

3.3. Data collection

3.3.1. Measurement instrument

As the topic that was being researched is of a sensitive nature, semi-structured interviews were employed as the measurement instrument. Terre Blanche et al. (2006) recommend interviewing for collecting in-depth data during research. Particularly, open ended, semi-structured interviews are viewed as an effective qualitative means of gathering information. In addition, this type of interviewing is deemed the exemplary means of data collection for IPA studies.

IPA views the participants as the experiential experts and allows the participants' maximum opportunity to tell their own stories (Smith & Eatough, 2007). The participants largely direct the semi-structured interviews and are allowed to introduce novel issues that the researcher may not have thought of exploring, but may be of relevance to the research area. This type of interview allows the researcher to develop an interview guide (see Appendix B), which enables the researcher to focus on a list of key topics and subtopics (Terre Blanche et al., 2006).

The interview schedule developed by Manns and Chad (2001) was adapted and utilised for the semi-structured interviews in this research. It allowed the researcher to explore aspects that were important to the participant's lives before and after the spinal cord injury and how the spinal cord injury may or may not have affected these aspects. The interview schedule also enabled the researcher to explore the participants' degree of life satisfaction, as well as their definition of the term quality of life.

3.3.2. Semi-structured interviews

During data collection, semi-structured interviews were utilised as a measurement instrument. In order to enhance understanding of the purpose and how this instrument is utilised, the following section will explore semi-structured interviews in more detail.

Smith and Osborn (2006) summarise the advantages of semi-structured interviews as

facilitating rapport with participants, allowing a greater flexibility of coverage, and producing very rich data. This is achieved through allowing the participants certain leverage to direct the semi-structured interviews into novel areas (Smith & Osborn, 2006). The researcher had previous contact through counselling sessions with some of the participants, thus the researcher had rapport with these participants. This allowed the researcher to have greater understanding of the participants' accounts. To ensure that rapport was established with the rest of the participants, the initial contact with these participants was spent building relationships as well as becoming acquainted with the participants and their pasts. Rapport may be used to achieve entry into a participants' world, as well as to negotiate more evenly balanced power dynamics between researcher and research participant (Gaglio, Nelson, & King, 2006).

The researcher proceeded to discuss the research only after ensuring the participants were comfortable and trust had been established. This was deemed necessary due to the sensitivity of the topic. Particularly in settings within health and social sciences, when carrying out qualitative research, researchers must have rapport with the participants (Gaglio et al., 2006). Furthermore, Gaglio et al. state that it is possible to build rapport through setting clear expectations for a researcher as well as the participants about what they might expect from research. It is also important to interact with the participants in person as opposed to using e-mails or telephones.

A few disadvantages related to semi-structured interviews have been identified. Most importantly, it is believed that semi-structured interviews reduce the control the

researcher has over the semi-structured interviews. The semi-structured interviews take longer to carry out as well as to analyse and the semi-structured interviews are also more difficult to analyse (Smith & Osborn, 2006).

3.3.3. Guidelines on interviewing

Although the researcher is guided by an interview schedule, Smith and Eatough (2007), acknowledge that a semi-structured interview is largely directed by the participants. The researcher ought to allow the participant to introduce novel ideas, however, they should prevent losing control of the interview. The researcher may therefore employ techniques to ensure that they obtain the relevant information from the participants, within a limited amount of time.

To prevent losing control during the semi-structured interviews, the researcher made an effort to comply with the guidelines on interviewing as set out by Smith and Osborn (2006).

- The researcher made an effort not to be rushed or to rush the participant. The participants were given sufficient time to reflect and to respond after each question.
- The researcher used minimal probes such as: “How did you feel? Can you tell me more?” This was done in an effort to encourage the participants to elaborate on thoughts and feelings.
- The researcher made an effort to ask only one question at a time and to clarify

aspects if the participants did not understand.

- The researcher monitored the participants' nonverbal responses during the interview to establish the possible effect the interview might have on the participants. This was helpful in order to recognise when to probe and when to refrain.

The semi-structured interviews were recorded and transcribed. The transcriptions were prepared at a semantic level. This requires writing down all the words that were spoken, including false starts and significant pauses as well as laughs, sighs and other important features of the interview. This form of transcription was followed based on the recommendation by Smith and Osborn (2006) for transcribing semi-structured interviews for IPA. The transcriptions were then translated loosely.

3.4. Procedures

The MVA fund was approached and permission was requested to conduct the research by contacting clients on their database. Once consent was granted, the prospective participants of the study were identified. They were approached and verbal information about the research as well as an informative letter (see Appendix C) was provided to them. Once verbal consent was obtained, a formal appointment was made for the semi-structured interviews. The semi-structured interviews were conducted individually, in a quiet setting of each participant's choice. Before commencement of the interview, each participant was requested to sign two copies of a consent form (see Appendix D). One of which was kept by the researcher, and

the other given to the participant. One quadriplegic participant was unable to sign the consent form and he gave consent by allowing someone else to sign on his behalf.

Prior to the semi-structured interviews, the researcher scheduled a meeting with each participant and spent time building rapport with the participants. During the semi-structured interviews an attempt was made to ensure comfort and feelings of ease for the participants. As mentioned previously, the researcher is fluent in English, Afrikaans and Damara-Nama. Thus, it is possible that the two, Oshiwambo speaking participants, who were interviewed in English may have been disadvantaged as they may not have been able to express themselves as candidly as possible. The researcher did attempt to ensure that all questions and concepts were stated as clearly as possible. The interview time varied between 45 minutes and 80 minutes. The participants were free to use pseudonyms of their choice. However, the majority requested that the researcher decide on the pseudonyms, thus they are referred to as participant 1 up to participant 7. Four participants were interviewed in Windhoek. Two were interviewed in the rehabilitation centre, one, at the researcher's office and the fourth participant was interviewed at her home. The three remaining participants were interviewed in Otjiwarongo, two at their homes and the third one at the researcher's family home.

The semi-structured interviews were recorded, as this gave the researcher the advantage of keeping full record of the entire interview without being distracted by careful and detailed note taking. Attention was paid to reassure the participants and to ascertain that they are open and honest. This reassurance was essential as Terre

Blanche et al. (2006) mention that research participants have a tendency to perform for the recorder, resulting in skewed results. The semi-structured interviews were transcribed verbatim and translated, where necessary. This process allowed the researcher to familiarise herself in-depth with the transcripts. The interviewing and transcribing was followed by qualitative data analysis.

3.5. Data analysis

Smith and Eatough (2007) and Smith and Osborn (2006) agree that IPA is not a prescriptive approach to data analysis. It provides a set of guidelines, which can be adapted by the researcher in light of the research aims. Meaning is central to interpretive analysis. The aim is to understand the complexity of the meaning, not the frequency. Thus, the researcher engages in an interpretive relationship with the transcript (Smith & Eatough, 2007; Smith & Osborn, 2006).

Data analysis commenced after the data was collected through semi-structured interviews. Data analysis was conducted in three steps. Step one involved translating the semi-structured interviews. The researcher translated the semi-structured interviews and the translations were verified by an independent third party. The independent third party has an honours degree in psychology as well as a post graduate diploma in translation. She is trained in SDL Trados, which is among the market leading computer assisted translation software packages (SDL Trados, 2009). All the semi-structured interviews were translated freely, yet care was ensure that the essence of the conversation constructs were not lost.

Step two involved using IPA, which is recommended by Smith and Eatough (2007), as well as Smith and Osborn (2006) to familiarise the researcher with the transcripts and to identify the most prominent themes. The researcher read the transcripts several times as recommended by Smith and Osborn, in order to become familiar with the accounts. No attempt was made to select or omit certain passages and the researcher took note of the richness of the information and contradictions in what the participants said. The researcher made comments on the significant aspects that were mentioned by the participants. The comments included attempts at summarising or paraphrasing, associations or connections between different comments as well as preliminary interpretations (Smith & Osborn). The transcripts were read through once again and the initial notes were used to write down emerging themes. Smith and Osborn emphasise the need to be able to find expressions at this stage of the analysis that allow theoretical connections within and across cases, without losing the essence of what is being said. This process allows the researcher to turn the initial notes into concise phrases that capture the crucial quality of what was said in the semi-structured interviews (Smith & Osborn).

Once the researcher was familiar with the transcripts and had manually identified prominent themes, the researcher moved on to the third step of data analysis. During the third step, ATLAS.Ti, a computer based package that aids in managing and analysing research with qualitative data (Muhr & Friese, 2004), was used to cluster, verify and find the frequency of the themes. The transcripts were entered into ATLAS.Ti and the interpretive process of searching for themes was repeated using the guidelines of ATLAS.Ti. The emerging themes, as well as the frequency thereof,

were listed and the researcher explored possible connections between the themes. Themes that were found to be linked were clustered together and a final table of “superordinate” themes from all the transcripts was constructed as advised by Smith and Osborn (2006). This was done through a very challenging process of prioritising and deciding which themes to keep and which to cut. The above mentioned was also done according to the guidelines of Smith and Eatough (2007), as well as Smith and Osborn (2006).

3.6. Report writing

The researcher used the final themes to do a write-up and final statement outlining the meanings that are inherent in the participants’ experiences. Thereby, the researcher compiled a list of domains that the participants perceive as essential in determining their quality of life. A total of 14 themes emerged as significant contributing factors to quality of life.

To ensure that the interpretations were done correctly, the data was verified by the researcher, the supervisor, as well as the co-supervisor. An independent master student in psychology also verified the final data.

3.7. Ethics

Conduct throughout the research procedures was in accordance with ethical guidelines as put forward by the American Psychological Association (APA) (2002).

The results of the study are available to all participants at their request. The results are also available to MVA Fund in a confidential manner. Concerns regarding ethics during the study were addressed in the following manner.

- Informed consent

Prospective participants who were approached were provided with a verbal explanation of the aims and the purposes of the research. Participation was voluntary and all participants were provided with two copies of a consent form (see Appendix D), which they were requested to sign upon agreement of participation. The content of the form was also explained verbally. The consent form relates to issues of confidentiality, nonmalificence and beneficence, which are explained below.

- Confidentiality

The participants were assured that all obtained information will be treated confidentially and the recordings are stored in a safe place. Only the researcher knows the true identity of the participants, as the participants had the freedom to make use of pseudonyms of their choice. However, upon the participants' request, the researcher allocated pseudonyms.

- Nonmalificence and beneficence

Participation was voluntary and to ensure nonmalificence, participants were free to withdraw from the research at any point. The participants are free to contact the researcher if they want further information or if they want to see the final research product. Findings from the research will be beneficial to the participants, as it will

raise awareness about their quality of life. The results of this research study will be made available to the MVA Fund and may provide the MVA Fund with a better understanding of their clients' quality of life. The results may also be used to implement improved rehabilitation programs for paraplegic and quadriplegic clients of the MVA Fund. Ultimately, the research results will be used to fulfill the principle of beneficence as stated by APA (2002) that all research conducted should strive to benefit those with whom the research is conducted.

3.8. Chapter summary

Throughout this chapter, the methodology that was employed with regard to how this study was conducted is outlined. The chapter commenced with an introduction of the qualitative nature of the study followed by an outline of the research design. The population as well as the final sample and the semi-structured interviews as a measurement tool were discussed. This was followed by the detailed description of the research procedures that were adhered to and the data analysis that was conducted. The chapter was concluded with an outline of the research ethics that were taken into consideration throughout the conduct of the study.

The results with regards to the themes that emerged are reported in chapter five and these themes as well as the connection of the themes are discussed in chapter six.

CHAPTER FIVE

RESULTS

In chapter five the results of the study, based on the qualitative data analysis, are reported. Firstly, a definition of the term quality of life as perceived by the participants' is presented. The definition is followed by an outline of the 14 themes of quality of life that were identified. These themes are presented in the order in which they are grouped in the discussion of results (see chapter 6). When presenting quotations, the questions posed by the researcher are omitted and only the participants' words are emphasised.

Several quotations are loaded with more than one theme, thus those are presented more than once. Perceptions related to these important themes of quality of life are presented, every theme unique to each participant and their circumstances.

Consequently, the themes are a sum of all the themes identified by participants. As can be seen throughout this chapter, several themes were only identified by a few participants and others themes by all the participants.

5.1. Definition of quality of life

The participants' were asked the question: "What do you understand by the term, quality of life?" Their responses were interpreted to compile a collective definition of quality of life. Thus, this definition of quality of life is presented as it was defined

by the participants.

The participants' understanding of the term quality of life is presented in Table 3.

Table 3*Definition of Quality of Life*

Participants	Quotes	Codes
P1	<p>“It’s like, the life that you are living. Maybe the difference between the quality of the life that you were living before the accident and the quality of life of the life that you are living after the accident . . .”</p>	1:1[29:31]
P2	<p>“It’s now the way I understand neh? That’s now the condition in which you, mm, go into life... The things that are still lying ahead and things that I have already left behind. That . . . that’s how I understand it. Ok . . . The phases will be different neh? Because now I am mos in a wheelchair. Before I was not, so the circumstances are different. There are two sides. The most important neh, is . . . I have, a person must actually realise neh, that in this time how the things that you lost in the past and how the sweet life that you still have to go enjoy in the time that still lies ahead. Actually even if it’s not as sweet. The life that you live now must be at a place or stage that you can also be satisfied.”</p>	2:191[11:26]
P5	<p>“Quality of life is how a person should stay in his life, yah. As well as, I as a person I like to do what I want.”</p>	5:1[9:11]

Table 3 (continued)

Participants	Quotes	Codes
P6	“If you, the way I understand it is, like in. the way I understand, it is for me, what makes life around you comfortable and all those things. I would say friends and family are the most important things in a person’s life.”	6:180[18:20]
P7	“Quality of life... I understand, uhm, if you are happy in your life. . . And . . . What else is being affected by the accident...”	10:1[36:40]

Note. P1 = Participant 1, P2 = Participant 2, P5 = Participant 5, P6 = Participant 6, P7 = Participant 7. Participants’ phrases are presented as quotes in the left-hand column, while the right-hand column presents codes that represent the locations of quotations within transcripts.

Table 3 presents the definition of the term quality of life as perceived by the participants.

5.2. Discussion of themes

Interpretive phenomenological analysis yielded 14 themes that represent quality of life for the participants. These themes are presented in the order in which they presented in the discussion of results (see chapter 6). They are as follows aspirations:

emotional wellbeing, identity, recreation, spontaneity, effort and comfort, stigma and discrimination, mobility and accessibility, relationships and resources, coping, independence, physical wellbeing, and work and money. The themes are further categorised into intrinsic themes, extrinsic themes, and support, which will be discussed in detail in chapter six.

5.2.1. Aspirations

The theme of aspirations is represented by the participants' desire to set goals and strive towards achieving these goals. Aspirations encompass the participants' dreams and hopes for the future as well as their past achievements which they are proud of.

Extracts from several transcripts representing the participants' aspirations are provided in Table 4.

Table 4*Aspirations*

Participants	Quotes	Codes
P2	<p>“Mm, so what has been affected is. You know I used to put such a big thought into agriculture. You know, I always thought that one day, I would one day have my own cattle and stuff and be my own boss. My desire was to be a farmer, having my own kraal, my own livestock. You know this one has my mark on it. So that’s the type of vision or desire I had for my life.”</p>	2:112[670:674]
P3	<p>“I was thinking one day I should be a hydraulic mechanic. Yes... So that I can one day go to Russia or wherever. So my dream has been cut off. Yes. Yes, but I’m having new dreams... If one day I should get the power and I know I shall get it ... from any direction ... then I shall start another program or another career... That one, it is just about social work, the people who were giving me love where I’m needing more support.”</p>	3:20[127:132]

Table 4 (continued)

Participants	Quotes	Codes
P4	<p>“It is just to have my, my family... And my cows... Ya, so that I can enjoy my land and family.”</p> <p>“Yes, I was at the Olympic in Oshikango I was come first. I was winning my T-shirt and short and cup and the ... the what, the ... what do you call that one? The (pause) ... I was winning many things there (pause) Yah, I was the winner. Yes, there were many people.”</p>	<p>4:4[40:45]</p> <p>4:164[428:438]</p>
P5	<p>“At the, ok, at the past (pause) could even just decide to go and ... to have my own house. Yah and ... and a wife also (giggle) but now ... I can't do it maybe, I think so ...”</p>	5:23[188:190]
P6	<p>“You understand and from there, I had other plans. From there I would have later worked on the mine itself.”</p>	6:22[271:275]

Table 4 (continued)

Participants	Quotes	Codes
P6	<p>“...things that can affect my future. You understand?</p> <p>(pause) Radio DJ, I already know radio’s that are looking for people and you know all those things...</p> <p>Yes and another thing is, I feel, why I am saying, it didn’t really affect me so much is. If I maybe did not get hurt in the accident then maybe I would have still be working. Yes then I wouldn’t have. But now maybe I can actively pursue my dreams. I don’t work at this moment.</p>	6:179[890:900]

Note. P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5, P6 = Participant 6. Participants’ phrases are presented as quotes in the left-hand column. The right-hand column presents codes indicative of the locations of quotations representing aspirations within transcripts.

As is evident in table 4, each participant expressed unique desires. Thus, the theme of aspirations is diverse. It ranges from a desire to own property, and have a family of their own (by marrying and having children) to aspiring to study, build a career, and help people who are in need. In addition, aspirations also represent past achievements of which participants expressed pride.

5.2.2. Emotional wellbeing

Emotional wellbeing refers to the emotions that are experienced by the participants and how these emotions are related to the way they experience life. Based on the findings, participants commonly experience emotions such as anger, frustration, loneliness and hopelessness. These emotions are closely linked to feelings of hopelessness and loss of control. Emotional wellbeing and a sense of control are identified as important contributing factors to quality of life.

Table 5 presents extracts that are indicative of participants' emotional wellbeing which affects their quality of life.

Table 5*Emotional Wellbeing*

Participants	Quotes	Codes
P1	“That the urologist should see. So I was so scared, but I said I won’t go back. (laugh)”	1:54[352:352]
P2	“But, you know sending people. Actually ... the shame ... (pause) how can I say this? Mmm. You also feel embarrassed.”	2:39[187:188]
	“Mm, so actually your life has been cut in half. Even half of it. Even the thing that you can do, you can’t do. Something you could do. And you can even see exactly. This thing is something that I can do, mm ... Even if you really want to try, mm, you want to do”	2:32[174:176]
	“Mm, so now when I got home, since I started staying at home. Well, there is loneliness and sadness. You feel these things. You become a little bit angry. But then again, actually getting angry doesn’t help. What will that do? That’s how I take it. And then I, maybe getting angry, getting angry and then I just stay as if I am not angry.”	2:151[955:958]

Table 5 (continued)

Participants	Quotes	Codes
P3	<p>“ like, like now just a, the rolling stone. What somebody gives me I must take, what somebody gives me, I must eat, what somebody gives me, I must eat, when somebody talks to me, I must answer it. Just like that. Anybody talks I talks I talk ... I just do it.”</p>	3:100[729:734]
P4	<p>“But it’s not, you have to do it, but the heart is not good... Mm ... It’s not good, but you have to, to agree with the life.”</p> <p>“Oh, i just shivering very much. I just shiver and I am very afraid. Shivering and my mind is messes up. And too much dreams. Dreams that I am in accident and I can’t run away, I can’t move, up to now that afraidness is not leave me. At first I was even afraid of riding in the wheelchair, but no that is better. I am just think that maybe one day the afraid will also go, be better.”</p>	4:51[385:385] 4:125[734:738]
P5	<p>“M e is safe only that I can walk where there is many people. The place where there is many people. Then it’s safe to me.”</p>	5:49[433:435]

Table 5 (continued)

Participants	Quotes	Codes
P6	“I, I, I don’t know. I told someone the other day, how will I be able to accept if I am always reminded that I am in this situation?”	6:7[114:115]
	“... and in those times I again come back to the emotional stuff where I say God why? You understand, why now why? And then I get depressed because of all those things.	6:54[515:516]
P7	“It makes me feel..... I’m very disappointed.”	10:21[210:210]

Note. P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5, P6 = Participant 6, P7 = Participant 7. Participants’ phrases are presented as quotes in the left-hand column. The right-hand column presents codes indicative of the locations of quotations representing emotional wellbeing.

Table 5 presents the theme of emotional wellbeing, which reflects the emotions participants experience on a regular basis. A variety of emotions expressed by participants include sadness, disappointment and anger. These emotions often add to feelings of hopelessness due to loss of control over the participants’ bodily functions. It further leads to an emotional loss of control.

5.2.3. Identity

The theme identity refers to the participants self-perceptions. A sense of identity is viewed by the participants as an important contributing factor to quality of life. This theme encompasses the participants' view of themselves before they became disabled. It also presents the way in which that view has been challenged and changed by the spinal cord injury. Identity comprises of self-perception, self-concept, self-esteem and self-confidence.

Table 6 presents phrases that represent the participants' expressions of identity.

Table 6*Identity*

Participants	Quotes	Codes
P1	“Yes, I am no longer a mother.”	1:36[258:258]
	“I can . . . just . . . because I was complaining that my stomach is big. It was not big before. I was even asking the physiotherapist. She was saying maybe the muscles are so lose”	1:64[399:400]
	“What am I going to do? Because what I am now physically.”	1:78[479:479]
P2	“I cannot, mm ... like a parasite, I just have to wait from others.”	2:28[170:170]
	“My self worth ... yes, that has been cut in that way.”	2:87[467:467]
P3	“Yes, that I was suppose to be and come at ... where, where ... my dignity, my dignity should stand, but ...”	3:2[22:23]
	“Like I am needing something, like a small baby.”	3:45[280:280]
P5	“ I say now I am just..., life now is, ...I am just a patient”	5:8[86:86]

Table 6 (continued)

Participants	Quotes	Codes
P6	“Yes, I, I, I became people shy I was, I, in the beginning I you know, I had a good self-image self-esteem, but now, nowadays I have a low self-esteem.”	6:35[390:391]
	“Yes, I, I, I became people shy I was, I, in the beginning I you know, I had a good self-image self-esteem, but now, nowadays I have a low self-esteem.”	6:35[390:391]
	“From the billionaire to the, to the beggar. ...That’s how I feel.”	6:88[1010:1014]
	“You understand? Yah, we can’t, on a passport photo neh, yah, you just see the head, you don’t see the other stuff. ...that’s how I want to be seen. ...If someone asks me, I, I just want to be seen like a passport photo. Tanja ... do you understand? That ... no, not for the beautiful face. Just Tanja. Not with the wheelchair and the what and the what, you understand?”	6:113[1235:1246]

Note. P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P5 = Participant 5, P6 = Participant 6. The left-hand column presents quotes which reflect the participants’ identity. The right-hand column presents codes indicative of the

locations of quotations representing identity.

Based on table 6, it is evident that, some of the participants view themselves differently to the way they perceived themselves before they became disabled. A number of participants went as far as comparing themselves to a baby. Several participants also expressed that they have somehow lost their beauty as a result of the disability; others mentioned becoming withdrawn and shy. One participant reported having lost his dignity, and yet another compared himself to a parasite.

5.2.4. Recreation

Enjoying recreational activities such as sports is recognised as an essential factor that adds to a person's quality of life. A few participants stressed the importance of being able to enjoy life, having fun as well as being able to engage in calming activities in order to relax.

Table 7 presents the extracts from transcripts that are representative of the theme of recreation.

Table 7*Recreation*

Participants	Quotes	Codes
P1	<p>“And you can, you should have something that you can make your ... like go to church or some sport that makes you happy. ... Yes, that you go out having fun or you relax your mind chatting or something.”</p> <p>“Mm, to town I used to go walk and do window shopping.”</p>	<p>1:11[72:75]</p> <p>1:31[234:234]</p>
P5	<p>“To play, mm, to play sports, to communicate with friends and to read... Mmm... I play... Basketball. ... Yes...”</p>	5:3[42:47]
P6	<p>“You know I was always curious and people would say, stop being so curious but I just wanted to hear everything. I wanted to just talk to people and stuff. It’s very nice for me.”</p>	6:32[355:356]
P7	<p>“And sometimes, I also go outside and so, especially weekends ... It is mos comfortable, then we sit there in front of the veranda, and if I get tired, then they bring me in again.”</p>	10:64[949:961]

Note. P1 = Participant 1, P5 = Participant 5, P6 = Participant 6, and P7 = Participant 7. The left-hand column presents quotes which reflect the participants’ expression of

recreational activities that they enjoy. The right-hand column presents codes indicative of the locations of quotations representing the theme of recreation.

Table 5.5 represents the theme of recreation. Participants' view of recreation is represented by engaging in physical activities, particularly sports, or taking a walk, spending time with people, reading, and relaxing.

5.2.5. Spontaneity

The theme of spontaneity refers to making uncalculated, impulsive decisions. Participants expressed that due to the disability, daily activities require much more planning. This limits the possibilities for them to do things at the spur of the moment.

Table 8 represents the phrases that express the participants' desire for spontaneity.

Table 8*Spontaneity*

Participants	Quotes	Codes
P2	“ I cannot just get up and look for a job just like that”	2:27[169:169]
	“Mm, and even, mm, the things you used to do. The things you used to do. You know when you were whole, you were whole. When someone walks past, you could just get up and go.”	2:88[469:470]
P4	“You have to say ag, the shade is going on that side, let me move. Then you have to follow the shade. ...For when I have to feel that even maybe you want to go to somebody for instance Ute, you say, ag ... I want to go ...Ute, for instance maybe I know your place... Ah, I have to go and I get here.”	4:73[580:588]
P6	“Because I have to think of all these things before I can make decisions. ...In the beginning it was easy to just get in the car or to just get a taxi, but now I have to think, wow, this and this, and this and this.”	6:97[1113:1118]

Note. P2 = Participant 2, P4 = Participant 4, and P6 = Participant 6. The left-hand column presents quotes which reflect the participants' expression of their lack of spontaneity and how that affects them. The right-hand column presents codes indicative of the locations of quotations representing the theme of spontaneity.

Table 8 indicates that the theme of spontaneity revolves around the participants' desire to be able to do the things they want to do when they want. The participants expressed negative feelings towards having to meticulously plan everything, including a supposedly easy action, such as catching a taxi into town, since becoming disabled.

5.2.6. Effort and comfort

Majority of the participants conveyed a need to live effortlessly and comfortably as an important factor of quality of life. This theme refers to the way participants' experience their daily life. Simple tasks such as cooking or taking a bath, that able-bodied individuals may take for granted, require more effort and may at times be experienced as uncomfortable as well as difficult.

Table 9 includes extracts from the transcripts that represent the theme of effort and comfort.

Table 9*Effort and Comfort*

Participants	Quotes	Codes
P1	“It’s really, because I spend one hour, she spend one hour with me bathing, after, she apply lotion on me, she dress me. ...Takes long time to do for a big person like me.”	1:92[571:574]
P2	“Now, actually the comfort, the lack of comfort also gives me or causes lots of sadness and pain. It’s a big problem if you live in uncomfortable circumstances, because then things are very difficult for you to do. If there is comfort where you are living, then you can do things. “You know there are no rubbish bins and things like that. Black plastic bags are the rubbish bins.”	2:133[832:835] 2:193[863:865]
P4	“ Yes, it’s difficult and there is no electrical, whatever at night, they want to turn you, there is not light in the room, there is darkness. They have to take some...some... mmm, parafien only...”	4:23[192:193]
P5	“At the village is more sand to walk in, even with the wheelchair. ...and the ... they even the wood to cook. Wood ...Yah on the fire ... is ... water are from wells and no electricity.”	5:28[248:252]

Table 9 (continued)

Participants	Quotes	Codes
P6	“I mean if I go somewhere, I have to think of my catheterizing times and all that. I have to think of all the times and, so it’s very difficult.”	6:68[651:652]
	“You know little things affect you very much. You might possibly think that it’s small but at the end of the day it’s big.”	6:92[1074:1075]
P7	“It is very difficult these days. After the accident happened.”	10:87[1377:1385]

Note. P1 = Participant 1, P2 = Participant 2, P4 = Participant 4, P5 = Participant 5, P6 = Participant 6, and P7 = Participant 7. The left-hand column presents quotes which reflect the effort it takes participants to do daily activities, their desire for comfort, and how the lack of comfort affects them. The right-hand column presents codes indicative of the locations of quotations representing the theme of effort and comfort.

Table 9 clearly indicates that the theme of effort and comfort does not only extend to daily tasks, such as cooking or taking a bath, it also includes the effort required to use a wheelchair. Other than that, it has to do with how the lack of comfort in an individual’s living environment can have an effect on the individual.

5.2.7. Stigma and discrimination

The theme of stigma and discrimination refers to the participants' perception of how the external world perceives disability as well as the way able-bodied individuals react to disability. Stigmatisation in the form of comments made or discrimination in the form of services withheld on account of the disability has an impact on an individual's quality of life.

Table 10 is a representation of the participants' view of stigma and discrimination.

Table 10 (continued)

Participants	Quotes	Codes
P3	<p>“Yes, yes. People just think. Maybe because of the wheelchair I am just stupid ... I’m dull, I’m what and ... what.... yes, because I’m also short in the wheelchair... I’m not having the same length.”</p>	3:57[364:370]
P4	<p>“Having a disability, it is not very good, it’s not important to stay with the people who are able to do their things. ... Ya, some they are friendly, some they are not. ...Some they have to say some things which are not important to you. ... You, it makes you to feel badly.”</p>	4:20[164:169]
P6	<p>“How people treat us. Uhm, I mean, sometimes you go to town and people look, people always look, people will always and forever look. But then you get those who look and say something. ...Or you get those that feel and look so uncomfortable around you. You are already uncomfortable. You understand? Now they make you even more uncomfortable. And not just that. body language, and ..., uhm, face expressions. Small things, you know, it matters.”</p>	6:109[1207:1222]

Note. P1 = Participant 1, P3 = Participant 3, P4 = Participant 4, and P6 = Participant 6. The left-hand column presents quotes which reflect the participants' thoughts regarding stigma and discrimination, as well as how it affects them. The right-hand column presents codes indicative of the locations of quotations representing the theme of stigma and discrimination.

Table 10 reflects the participants' thoughts related to stigma and discrimination. Participants are concerned about and affected by stigma and discrimination. Table 10 reveals that the participants' perceptions about how they are viewed by others determine the degree to which stigma and discrimination affects the participants.

5.2.8. Mobility and accessibility

The theme of mobility and accessibility refers to the participants' need to be mobile as well as their need to access places, buildings and other facilities without feeling restricted. They believe that their quality of life is affected by feelings of restriction. Not being able to move around freely due to restrictions imposed by a wheelchair, or being bedridden is an essential component of this theme and is just as imperative as the limited accessibility to buildings and other facilities.

Table 11 presents the theme of mobility and accessibility as expressed by the participants.

Table 11 (continued)

Participants	Quotes	Codes
P4	“Like I used to travel a lot. Ruacana, the waterfall, Epupa. I was there. I visit many places. It was nice.”	4:95[723:724]
P5	“For now I am not going outside for many places as I was mmm”	5:9[81:81]
P6	“. . . , let me say because I am in this situation and I wake up every day and I remember, ai, I can’t get out of bed. See, that reminds me again.”	6:183[72:73]
	“. . . , let me say because I am in this situation and I wake up every day and I remember, ai I can’t get out of bed. See, that reminds me again.”	6:183[72:73]
	“and, and, uhm, the ramps are very important to us, because ... and, and, and ... yah, the ramps are very important because we, we want to go everywhere and we want to go where we want... But then we can’t because there are stairs and it makes it very difficult for us.”	6:123[1367:1373]

Table 11 (continued)

Participants	Quotes	Codes
P6	<p>“And, if can’t easily find a toilet that that is wheelchair friendly... Big enough to go into... You know, I recently said, the service stations, I have never travelled on the road and found, I am sorry if I am wrong, I have never seen a toilet at a service station that is big... Enough... I have never seen it. How can I use the toilet if it is not big enough for me to go into? What should I do on the road, also want to, on the road go to a service and I also want to use the toilet, but I can’t.”</p>	6:126[1391:1406]
P7	<p>“If my, if my husband and the kids go buy groceries I just go, but then I just sit in the ... car. Then you also don’t see what is happening, happening in the surroundings.”</p>	10:61[910:914]

Note. P1 = Participant 1, P2 = Participant 2, P4 = Participant 4, P5 = Participant 5, P6 = Participant 6, and P7 = Participant 7. The left-hand column presents quotes which reflect the participants’ thoughts regarding mobility and accessibility, as well as how the disability affects their sense of mobility and accessibility. The right-hand column presents codes indicative of the locations of quotations representing the theme of mobility and accessibility.

Table 11 indicates that the participants view the restriction of their mobility as a major contributing factor to the way they perceive their quality of life. Mobility and accessibility encompass concerns regarding moving around comfortably in a wheelchair, being able to go to town and find parking, as well as being able to go inside shops in shopping malls.

5.2.9. Relationships

The theme of relationships refers to the value participants place on having intimate bonds others. It also refers to the strength participants draw from significant others in their life and how such support is a valuable component in improving one's life.

Relationships refer to relationships with family, friends, spouses, as well as romantic or work related relationships.

Table 12 represents the relationships that were presented as most important by the participants.

Table 12*Relationships*

Participants	Quotes	Codes
P2	<p>“You maybe if now you had a girlfriend she could or would do things for you. Some things she would have done for you, because even that would have been a big help. But then again now I am without a girlfriend and now you know all these things that I am doing by myself is stuff she would have done.”</p> <p>“Even the relationship about friends. Yes, some took their love that they gave me back... No, they took it back. Yes ... Those who have a human mind stay with me, but many ... they abandoned me.”</p>	<p>2:110[636:639]</p> <p>3:125[97:103]</p>
P4	<p>“The things which is important to me? It is just to have my, my family.”</p> <p>I feel sad. . . Because we study with her. We are together in the same village, but she have to make me like that. Maybe she is happy for me to be disability.</p>	<p>4:3[38:38]</p> <p>4:177[944:949]</p>
P5	<p>“After she, she, she see me like this, she is ... go. She leave me.”</p>	<p>5:70[618:620]</p>

Table 12 (continued)

Participants	Quotes	Codes
P6	“I would say friends and family are the most important things in a person’s life.”	6:2[19:20]
	“And I experienced it. And I am sitting here because of peer pressure you understand.”	6:75[786:786]
P7	“Yes, it has uhm, uhm, actually touched them a lot, ... like, now, especially my son, if I now start getting sick, or if he hears I’m sick, then he doesn’t even want to come visit me at the hospital. ... He doesn’t even want to come in the room, then he goes and sits there behind and Cries...”	10:51[784:794]
	“Yes, there is big difference, because like now, my husband just moves alone, and, and, and then (silence), like in if he, like I said now if he now goes somewhere, and he wants to take me with, then I can’t, then he can’t take me with. ...move around, yah. Mm, after the accident.”	10:78[1194:1210]

Note. P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5, P6 = Participant 6, and P7 = Participant 7. The left-hand column presents quotes which reflect the participants’ expressions related to relationships. It is evident that

friendships and family are essential. The right-hand column presents codes indicative of the locations of quotations representing the theme of relationships.

Table 12 depicts the relationships that are most essential to the research participants. It is evident that the most important relationships include family and friends.

5.2.10. Resources

The theme of resources refers to the much needed medical and physical support. Such support may included support from nurses, physiotherapists and caregivers who assist the individual to improve, not just their health, but also their overall satisfaction with their life. Furthermore, resources encompass the equipment, medication and other medical supplies needed to enhance the participants' health or the lack of which may negatively affect their health.

Table 13 refers to resources which the participants' identified as essential.

Table 13*Resources*

Participants	Quotes	Codes
P1	<p>“Because like you need to travel. You need even to ... like now, there are some kind of dresses I should wear. Maybe I can wear and dress myself.”</p> <p>“the muscles from before. She is also exercising them. The physio told me some of the exercises to do to help.”</p>	<p>1:88[556:557]</p> <p>1:100[402:403]</p>
P3	<p>“Yes, I didn’t even have a passport of the hospital... Now I have it ...”</p>	<p>3:54[335:337]</p>
P4	<p>“Yah I need, the electronic wheelchair, an electronic one. So I can push for myself.”</p> <p>”...and we we’ll need some people who are, like the counselling, make your heart better that you are not the one.”</p> <p>“For everyday.... The things which is needed in the everyday. You just need water? You just need shelter and (pause) something...,something to listen like the radio and watching TV, what happens inside and outside. . .”</p>	<p>4:126[136:136]</p> <p>4:30[230:231]</p> <p>4:176[57:60]</p>

Table 13 (continued)

Participants	Quotes	Codes
P5	“Yes sometimes I will need someone to cook, to wash my clothes... But I think I can stay with someone.”	5:77[388:389]
P6	“Put a ramp, then nobody has to help me.”	6:133[1478:147]
P7	“Yes, there is medication that I drink, I get for spinal cord uhm, uhm, medication ... Then I get now, uhm, after, after the accident, mmm, I also got an epilepsy, so I’m still using that medicine. Yah, no, this year.”	10:96[545:554]

Note. P1 = Participant 1, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5, P6 = Participant 6, and P7 = Participant 7. The left-hand column presents quotes which reflect the participants’ thoughts related to their need for resources. The right-hand column presents codes indicative of the locations of quotations representing the theme of resources.

Table 13 clearly presents the type of resources that the participants view as essential in their day to day lives. These resources include medication, human resources such as nurses and an assistant to help at home, as well as a hospital passport amongst other resources.

5.2.11. Coping

The theme of coping refers to the participants' attempts to deal with and make sense of the challenges they face in life. Each participant employs their own variety of coping methods.

Table 14 represents the phrases from the transcripts that represent the participants' attempts to cope with challenges they face.

Table 14*Coping*

Participants	Quotes	Codes
P1	<p>“Yes, my whole image was affected, and there’s nothing I can do even if I say I don’t like it. Nothing I can do to change it.”</p> <p>“Ideas and stuff, or, or, and idea with solutions. Not just, why don’t you do this. While I, I just what you tell me needs capital and I don’t have that capital.”</p>	<p>1:66[413:413]</p> <p>1:82[495:496]</p>
P2	<p>“I can do things, a few things. I can do many things still.”</p> <p>“Mm, but that is rare, because in that location where I stay, I was very helpful with people ... Mm, at the time when I was walking. That’s why when something, say someone maybe told their child to do something and that child is being disrespectful towards the parent, then the person will say, og, if Willem was still walking, I would not suffer like this. Even now as I was being fetched to come here...”</p> <p>“I can do things, a few things. I can do many things still.”</p>	<p>2:20[132:132]</p> <p>2:145[916:920]</p> <p>2:20[132:132]</p>

Table 14 (continued)

Participants	Quotes	Code
P3	<p>“...and I’m just staying at home because I got just, uhm, I got more needs than that is normal.”</p> <p>“They operate me. And it took a long time to get better. Mm, but I’m giving the time. You see I might be patient, but then I think where is my willingness to live with, must I wait, be patient. How can I be patient? I must be willing”</p> <p>“But as the time goes, now, I am trying my best to do it myself. ...If I’m also lying in the bed in the middle of the night while I am not having anything, I’m always take a nap or sleep. I’m exercising, while I’m alone I don’t stop. Yes.”</p>	<p>3:32[202:203]</p> <p>3:48[299:304]</p> <p>3:96[685:694]</p>
P4	<p>“something to listen like the radio and watching TV, what happens inside and outside”</p> <p>“In the hospital are so, we are, we are many with disability. We stay together, we have to encourage ourself... Because sometime, you are feeling badly about the disability, but if there is so many... someone to encourage you...”</p>	<p>4:6[59:60]</p> <p>4:153[147:152]</p>

Table 14 (continued)

Participants	Quotes	Codes
P4	<p>“and we we’ll need some people who are, like the counselling, make your heart better that you are not the one... Mm, and they will help, some of the people to help you.”</p>	4:30[230:233]
P5	<p>“Now I can take it as it is. Cause I know not what can I do, what...”</p> <p>“Just ... we are many and ... that’s why we are chose to do some sport like basketball. Yah it’s only that we can do ... I can go to shops also to ”</p>	5:14[104:106] 5:85[288:289]
P6	<p>“I always think why, why this? But maybe God thought, ok girl you’ve dance enough, now chill... (laugh) I have to now sit down for a bit because I dance too much.”</p>	6:159[241:246]
P7	<p>“Yes, give it to the Lord, He will manage me, He will, every, every day when I wake up I see a, a change after praying”</p> <p>“Yes, you will just get used to it, it only depends from your heart... Look, if you, how can I say, there are mos people mos now with soft hearts that can’t take the punch and so, ...so I can still take the punch.”</p>	10:24[234:235] 10:75[1113:1122]

Note. P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5, P6 = Participant 6, and P7 = Participant 7. The left-hand column presents quotes which reflect the participants' efforts to cope with their disability. The right-hand column presents codes indicative of the locations of quotations representing the theme of coping.

Table 14 indicates that coping is represented by activities that emphasise keeping one-self occupied. These activities may include, being helpful to others, praying, questioning the reasons why the disability occurred, exercising, and listening to the radio, among other coping activities.

5.2.12. Independence

Independence refers to the ability to be able to do things without help, to be able to live alone, or live with minimal assistance. The degree of independence is affected by the participants physical functionality, such as the ability to get on and off a wheelchair without assistance, or not or being able to grasp a cup in the hand. The participants express that a lack of independence definitely has a negative effect on their quality of life.

Table 15 presents extracts from the transcripts that represent the participants' expression of their desire for independence.

Table 15*Independence*

Participants	Quotes	Codes
P1	<p>“Without someone saying why did you touch this or why does this place look like this. To have your own source of living. To do your own things without anyone interfering. . .”</p> <p>“It’s (inaudible). So, privacy is not good. Everything you want even if I want to go to town. I can’t go alone. I can’t do my private thing. I have to say pick this for me, you don’t have privacy... Everything I want to do. You need assistance”</p>	<p>1:9[57:59]</p> <p>1:50[328:330]</p>
P2	<p>“Yes, it also, now that I am, mm, actually in a wheelchair. It also affected my freedom, mm. I, mm, I can actually not do anything like I used to.”</p>	2:12[99:100]
P3	<p>“...and I’m just, and I’m just staying at home because I got just, uhm, I got more needs than that is normal.”</p>	3:31[202:203]
P4	<p>“ Because, I’m washing, I’m feeding, everything I need someone to do for me. Whatever I’m drink, I need water. Whatever I am do and want to I need someone to come and put me on the wheelchair. Everything.”</p>	4:8[89:91]

Table 15 (continued)

Participants	Quotes	Codes
P4	<p>“It’s, it’s changed my life like I am not able to, unable to follow my business again. Like at the first I have to go on the Friday before the weekend. I am buying all the things for the whole week.”</p>	4:90[689:691]
	<p>“It affect me more things to do, but it is because now I’m just, I’m just talking but I can’t do... It... I’m just talking but I am just on the same place. I am no go for to do this and this.”</p>	4:103[777:782]
	<p>“My stomach . . . , like a colostomy, mmm. Ah, it is just... like. They do not put me colostomy. Me, I just want colostomy, but they not put me colostomy. It’s not good.”</p>	4:36[250:251]
P5	<p>“It’s only that now there are many things that I can’t do. Than in the past, the past.”</p>	5:20[162:163]
	<p>“Yah but it’s difficult to have someone help you every time... But, if, if I am in house... Yes sometimes I will need someone to cook, to wash my clothes... But I think I can stay with someone.”</p>	5:42[384:389]

Table 15 (continued)

Participants	Quotes	Codes
P6	<p>“You know, because I don’t want the most important is for me..... I don’t want to be dependent on another person, I want as much as possible to be as independent as possible.”</p> <p>“You know, because I don’t want the most important is for me..... I don’t want to be dependent on another person, I want as much as possible to be as independent as possible.”</p>	<p>6:70[701:703]</p> <p>6:70[701:703]</p>
P7	<p>“Or I can’t also go to the children’s meetings at school. ...If the parents are called to come and look at the kids school books. Then it has to be (Name) or the dad if he’s off from work”</p> <p>“No, I can’t... Only the upper part I can turn myself, . . .But the legs, the legs I’m being helped. Mm, must be helped, mm. The part from my butt, from the butt... Until here (pointing downwards) I must be helped...”</p>	<p>10:20[182:190]</p> <p>10:94[343:355]</p>

Note. P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5, P6 = Participant 6, and P7 = Participant 7. The left-hand column presents quotes which reflect the participants’ need for independence. The right-hand

column presents codes indicative of the locations of quotations representing the theme of independence.

Table 15 indicates that the theme of independence represents the participants' desire to live independently. Their desire to be able to perform tasks such as cooking, eating, bathing, and travelling is also clearly depicted in Table 15. This theme also reflects the negative feelings that the candidates express regarding the need to have someone assist them all the time.

5.2.13. Physical wellbeing

The theme of physical wellbeing refers to the participants' physical health, particularly the aspects of health that have an impact on the participants' ability to enjoy life. The measures they engage in to promote and ensure their own health as well as factors that hamper or negatively affect their health and wellbeing also forms part of physical wellbeing.

Table 16 provides quotations presenting the participants' physical health as well as attempts to improve and maintain their health.

Table 16*Physical wellbeing*

Participants	Quotes	Codes
P1	“Spasms. They are too much.”	1:19[133:133]
P2	“Because, we were given instructions. If this happens, do that and when you sit in wheelchair, even this that we sit. You can’t just sit. You must move around because the blood gets blocked and that’s what causes bedsores and stuff.”	2:90 [480:482]
	“...with that burning feeling. Oh, that burning feeling, it feels a lot like it burns in (inaudible) it feels to me that is actually a big problem for me.”	2:102[560:561]
P3	“Then I must ... wait for the ... a few days. Then I must the pain. And mostly the pain it cause me the ... (show whole body).... yes, if I, if I, if I pain too much and the, the stomach is forever pressing, and if I pain too much then that’s the time I must go to the toilet.”	3:59[393:399]
P4	“It’s having the smoke, the... the what, what do we call that one? Ya, the smoke, it’s not good to us! We are breathing difficult. If you breathe in, in.”	4:24[197:198]
P5	“It’s only that now, the problem I have is only this, the the pressure sores”	5:16[118:118]

Table 16 (continued)

Participants	Quotes	Codes
P6	<p>“Uhm, the thing is. Difficulty breathing sometimes, dizziness, every morning I get dizzy. Akrinor is a pill I take every morning so that I don’t feel dizzy. Basically low blood pressure. Yes say that rather.”</p>	6:8[155:157]
	<p>“... every morning for the rest of my life I have to take half a tablet of disprin ... for blood clotting, to keep my blood flowing, because of ... we mos don’t move around too much, then it could clot. So for the rest of my life I have to every morning drink a disprin, half of it... Well I never ever used to drink pills, now I have to, everyday.”</p>	6:137[1522:153]
P7	<p>“Then I get a headache. Stiff headache. And then, then, the blood pressure is very high. It gets pressed because of the urine.”</p>	10:38[423:431]
	<p>“Yes, there is medication that I drink, I get for spinal cord uhm, uhm, medication . . . Then I get now, uhm, after, after the accident, mmm, I also got an epilepsy, so I’m still using that medicine.. . Yah, no, this year.”</p>	10:96[545:554]

Note. P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5, P6 = Participant 6, and P7 = Participant 7. The left-hand column presents quotes which reflect the participants' physical wellbeing. The right-hand column presents codes indicative of the locations of quotations representing the theme of physical wellbeing.

Table 16 indicates that the theme of physical wellbeing represents the participants struggle with ailments such as urinary tract infections, low blood pressure, headaches, dizziness, pain, pressure sores and muscle spasms which occur frequently. It also includes their attempts at dealing with and minimising these ailments.

5.2.14. Work and money

The participants regard paid employment as an important contributing factor to making life meaningful. Thus, losing the ability to work productively has an impact on quality of life. The theme work and money encompasses the need for paid employment as well as the ability to be industrious. This theme also encompasses the need for money

Table 17 presents the participants perceptions regarding their loss of the ability to work and earn money as well as their need for money.

Table 17*Work and money*

Participants	Quotes	Codes
P1	<p>“Cause of, if you have, because money, money, money is because the cost of living is so high so you need money to do whatever you want in life.”</p> <p>“Mm, that I enjoy in life ... It’s like I enjoy to work for my children. I enjoy to have a job. To get my money and do my own things.”</p>	<p>1:2[37:38]</p> <p>1:27[186:187]</p>
P2	<p>“You must now, even if, even if you don’t have work, you must do something so that you at least say (pause) so you can say at least in my life I did this to get by and I went this far...”</p> <p>“Even then they, they asked me to look after the house. Mm, you know, if I see the house is being broken into then even if I can’t do anything, I can do something.”</p>	<p>2:5[44:47]</p> <p>2:154[973:974]</p>
P3	<p>“With, to work for yourself for your dignity ... as a life, as a process of life.”</p>	<p>3:5[44:44]</p>

Table 17 (continued)

Participants	Quotes	Codes
P3	“(sigh) Yes, my medication is sometimes I need medication and then I don’t have so much cash ...then I must order from MVA and then they must say no wait and what, no we must see the doctor, who is expensive, which medication? And always the cheap thing.”	3:72[533:537]
P4	“Most important is just to help my mother and father and to work some things which is needed by the nation (pause) uhmm, what...”	4:1[24:25]
P5	“Oh, I enjoyed my work... My work as a taxi driver”	5:5[62:64]
P6	“... I always believed, what you do, you are seen for what you do, you understand? You know, cause I always, I, I, I started small, I started at a lodge and at the end of the day people saw me and then I started working there at the mine a supervisor.”	6:12[264:267]
	“I had just recently started buying things for myself. I bought my microwave. I would have soon bought myself a fridge. Everything was just so right for me, you won’t believe it, it was wonderful. I had my boyfriend, I had the best work.”	6:182[984:993]

Table 17 (continued)

Participants	Quotes	Codes
P7	<p>“Yes, the expenses, they, uhm, it gets to (Name) and my husband, when I worked, then everything, actually, my salary was more than theirs, ...so, and I mos, I did, let me say, I did the, the, the, the covered, like the house, electricity and that I covered myself, and X and my husband the food, and they paid the lose bills.”</p>	10:80[1231:1235]
	<p>“Yes, the expenses, they, uhm, it gets to (Name) and my husband, when I worked, then everything, actually, my salary was more than theirs, ...so, and I mos, I did, let me say, I did the, the, the, the covered, like the house, electricity and that I covered myself, and X and my husband the food, and they paid the lose bills.”</p>	10:80[1231:1235]

Note. P1 = Participant 1, P2 = Participant 2, P3 = Participant 3, P4 = Participant 4, P5 = Participant 5, P6 = Participant 6, and P7 = Participant 7. The left-hand column of the table presents quotes which reflect the participants’ need for work and money. The right-hand column presents codes indicative of the locations of quotations representing the theme of work and money.

From table 17, it becomes evident that all the participants place very high value on

employment and earning money. Money is seen as an essential source for sustenance as well as to support other family members. Work also gives the participants a sense of meaning and purpose. Table 17 also shows that participants require money regardless of whether they earned it through work or if it was given to them.

5.3. Chapter Summary

In this chapter, the results related to the 14 themes of quality of life were reported. The themes include aspirations, coping, effort and comfort, emotional wellbeing, identity, independence, mobility and accessibility, physical wellbeing, recreation, relationships, resources, spontaneity, stigma and discrimination as well as work and money.

In the next chapter the results will be discussed.

CHAPTER SIX

DISCUSSION

Chapter six is devoted to discussing the results of the IPA. The discussion of the results is focussed on defining and explaining the themes which participants view as most significant in determining their quality of life. The discussion begins with the researcher's interpretation of the participants' perception and definition of quality of life. This definition is followed by an explanation of the 14 themes representing quality of life.

For purposes of discussion, ten themes were ascribed to categories referred to as intrinsic, extrinsic, and support, therefore, they will be discussed accordingly. The remaining four themes, which did not fit into these categories, are discussed individually. The order of discussion of the themes will be as follows: three intrinsic themes, five extrinsic themes, two support themes, and lastly, the four individually discussed themes. The themes are not arranged according to a specific order, they are discussed randomly.

6.1. Definition of quality of life

When asked to define quality of life, many of the participants were unable to provide a clear definition. For most of them, it was the first time they had heard of the concept, quality of life. However, when asked to explain their perception of quality

of life, most of the participants, including those who could not give a definition, linked quality of life to feelings of happiness (see Table 3, code 10:1[36:40]).

Participants also compared their current situation and happiness with the way their life was prior to their accidents. This finding is similar to the research report by Lustig (2005). Lustig reported that a redefinition of the meaning of life as well as the things that are important in life takes place after the onset of disability. This process of redefinition involves changes in both private thoughts and feelings related to the external world. In line with this finding, P1 clearly expressed such a comparative view during her interview. According to her, when attempting to define quality of life, an individual should consider the way life is now, compared to the way it was prior to the onset of their disability (see Table 3, code 1:1[29:31]).

According to P2, quality of life changes over time and is influenced by satisfaction. He expressed that quality of life is impacted by an individual's past experiences and current situation in life. Furthermore, P2 emphasised that satisfaction is an important component of quality of life (see Table 3, code 2:191[11:26]). Based on this opinion, it is evident that P2's view of quality of life reflects similarities with research findings by Boswell et al. (1998). They characterised quality of life as developmental, based on the perception that it changes throughout life, as priorities change. Due to the developmental nature of quality of life, individuals incessantly have the opportunity to improve it. This tendency to strive for improvement in life was also identified by Maslow. According to Maslow (1943), people instinctively attempt to improve their lives, particularly, relating to their perception of themselves

as well as their goals and aspirations. In line with Maslow's theoretical viewpoint, P2 realises the importance of having a positive outlook, being content and striving to improve his life, even in the midst of difficulty. This may be translated into a persistent attempt to improve his quality of life.

Both P2 and P5 pronounced that quality of life is a subjective construct. P5 is convinced that only he knows what quality of life means to him and it involves being able to engage in activities that pleases him (see Table 3, quote 5:106[6:15]). This interpretation of quality of life is in agreement with the view of Day and Jankey (1996). According to them, the perceptions of individuals who are being assessed are essential in the ultimate definition and representation of their quality of life.

In addition to the above mentioned opinions, P6 expressed an alternative view of quality of life (see Table 3, quote 6:178[11:31]). According to her, paying attention to small things that people often take for granted, feeling comfortable and valuing relationships are important aspects regarding the meaning of quality of life. Thus, P6's definition of quality of life is largely determined by social and emotional aspects.

According to the researcher's knowledge, no previous studies have been conducted in Namibia to explore the quality of life of individuals with spinal cord injuries. The majority of the studies that have been reviewed as background for this study were conducted in developed countries. Thus, vast differences, which are related to the economic, social, ethnic, and cultural backgrounds, exist between the participants of

this study and the participants of studies conducted in other countries. However, there are similarities in their perception of quality of life. For example, they share the view that quality of life is a subjective construct, which changes over time as it is affected by changing life-circumstances. Such life-circumstances may include compromised health, living environment, employment, comforts, perceived control, social support and relationships, the onset of disability, as well as traumatic events such as motor vehicle accidents (Boswell et al., 1998; Manns & Chad, 2001; Youngkhill & McCormick, 2006). These life-circumstances and the manner in which individuals react to them are affected by an individual's past and they have an influence on the individual's emotions and future outlook (Boswell et al., 1998; Manns & Chad, 2001). The accounts of the participants in previous studies, as well as the present study also give evidence to support this notion that life-circumstances have a great influence on quality of life. They share the view that quality of life is linked to factors of happiness, satisfaction with life, support from people as well as being comfortable with life. These factors may also be classified as changing life-circumstances. At this stage, it is imperative to highlight that, although similarities are pointed out between the perceptions of the participants of the present study and participants of previous studies, this study is not intended for comparative purposes.

In summary, it may be pointed out that the participants of the present study view quality of life similarly to the manner in which Youngkhill and McCormick (2006) conceptualise quality of life, as a subjective assessment of people's current and future life circumstances. Furthermore, based on the present research findings it may be concluded that the participants' define quality of life as follows: Quality of life is a

developmental, subjective evaluation of an individual's life, which is determined by an individual's health, psychological wellbeing, living environment, relationships, as well as their future outlook.

6.2. Quality of Life Themes

Based on the above mentioned definition of quality of life, specifically, it's subjective nature; it is evident that quality of life is a broad concept. Consequently, a vast number of factors exist that may have an influence on the participants' quality of life. These influential factors, including physical and psychological health, social relationships, and finances, were revealed during the semi-structured interviews. It became apparent that each participant's experience of their motor vehicle accident as well as their disability is unique. However, striking similarities exist between the participants' accounts of the way the accident has affected their health, their daily activities, their outlook on life, and their satisfaction with life. These similarities as well as differences were analysed to determine the factors that are most important to each individual and how it affects their quality of life.

Initial data analysis involved sorting the information according to apparent similarities in the accounts of the participants, in order to identify emerging themes. It became apparent that some themes are similar to themes which were identified in previous studies. In this regard, it is imperative to point out that this is an exploratory study and it is the first time a study such as this is conducted in Namibia. Therefore, even though there is congruence with themes from previous findings, it is essential

that all the findings (themes) be included in the report. Also considering that these findings may serve as a baseline for future studies, several themes were named after similar themes in previous studies. Other themes were identified as new and named according to the relevant and most prominent issues. This data analysis revealed 14 themes, which the participants of the present study regard as essential in determining and influencing their quality of life. Furthermore, attention was paid to the WHO's definition of quality of life. It implies that, individuals' perceptions of their position in life is important and their views should be regarded in the context of the culture and value systems as well as their goals, expectations and concerns (WHOQOL Group, as cited in Miller et al., 2008). "This wide-ranging concept is affected by people's social relationships, physical health, psychological state, level of independence, and by their relationship to salient features of their environment" (Barbotte et al., 2001, p. 1048). Keeping in mind, these social relationships, physical health, psychological state, level of independence, and relationship to the environment, the researcher attempted to group the 14 themes. Ten themes were categorised into intrinsic, extrinsic and support themes. The remaining four themes, which did not fit into these three categories, were treated as individual themes.

Primarily, three themes were identified as themes which are associated with the individual's psychological state. These themes are categorised under intrinsic themes and they include aspirations, emotional wellbeing, and identity. Five themes were identified as extrinsic themes, which are associated with the individual's emotions as influenced by observable factors within their environment. Extrinsic themes refer to the individual's relationship with and interactions with their environment. The five

themes which are classified as extrinsic themes encompass recreation, spontaneity, effort and comfort, stigma and discrimination, as well as mobility and accessibility.

In addition to the individual's personal, psychological factors, and their interaction with their environment, individuals rely significantly, not only on themselves, but on support from people as well as other resources. Therefore, two themes were identified as themes which refer to the essential aspect of support. The two themes which are classified as support themes are relationships and resources. Four themes did not fit the three allocated categories. These themes, which are not grouped, will be discussed individually. They include coping, independence, physical wellbeing, and work and money. Furthermore, data analysis revealed that, these four individual themes, are perhaps the most crucial and influential themes of quality of life, based on the emphasis the participants placed on them. To a certain extent, even though each theme is separate, at times, there is substantial of overlap between the themes, as nearly all the themes have an influence on each other.

Maslow's theory of human motivation is vital in the study of quality of life, given that satisfaction and happiness play an important contributing role to quality of life. Thus, the 14 quality of life themes are linked to Abraham Maslow's human motivation theory. Individuals with disabilities are driven by a desire to satisfy needs that might have arisen with the onset of their disability. The satisfaction of a need enables an individual to grow and move on to pursue the satisfaction of a higher level need (Huitt, 2004). In addition, the system in which the individual exists, including their physical environments, their support system also affects what the

individual does and how they feel (Amiot et al., 2006; French et al., 1982; Kulka et al., 1980; Orford, 1992). Thus the person-environment fit theory is also linked to this discussion of quality of life.

6.3. Discussion of the themes

6.3.1. Intrinsic themes

The themes of aspirations, emotional wellbeing and identity are associated with the individual's psychological wellbeing. Therefore, these three are referred to as intrinsic themes. Intrinsic themes refer to the participants' perception of themselves. They are intrapersonal themes which are largely independent of external influences. However, it is essential to realise that all of the 14 themes of quality of life are interlinked and none of the themes may be seen in complete isolation. Thus, the external environment also has some degree of influence on the individuals' perception of themselves. This understanding is in line with the theoretical view of the person-environment fit theory. This theory is built on the premise that attitudes, behaviours, emotions, and other day to day occurrences in an individual's life result, not from the individual or environment separately, but rather from the relationship between the two (Lewin, 1951; Murray, 1938; Pervin, 1989).

The first intrinsic theme under discussion is aspirations.

6.3.1.1. Aspirations

Setting goals and striving towards achieving these goals was identified as important by the majority of the participants. Being driven by the need to achieve motivates an individual, enhances the way they experience life and may improve their quality of life. The theme of aspirations refers to an individual's desire to reach personal heights, whether personally, in relationships as well as an individual's desire to advance their career. Thus, it encompasses the search for knowledge, meaningfulness, and exploration which may refer to the individual's attempt to satisfy their cognitive needs (Maslow, 1943, 1970). Furthermore, it refers to the individuals attempt to satisfy, what Maslow identified as, their need for self-actualisation, which involves striving to realise personal potential, self-fulfilment, personal growth, and peak experience.

For many of the participants' expression of aspirations, to a certain degree, involves work and money, as well as achieving specific goals such as building a career. For example, P3 expressed his desire to pursue his dream of becoming a hydraulics mechanic, mainly to enable him to support his family. P2 reflected on his desire to become a farmer, to own a farm and livestock.

The individuals' pasts and environment, including the availability of financial resources have an effect on their actions and feelings; consequently, it affects their future aspirations. These past experiences may be referred to as their life-circumstances (Boswell et al., 1998; Manns & Chad, 2001; Youngkhill &

McCormick, 2006). For instance, this basic focus of their aspirations being equated to having a job and money could be linked to their background as low-income workers. In 2007, the minimum wage for the Namibian worker was set at N\$ 1676 per month (LARRI, 2008). Prior to their disability, some of the participants worked jobs where they earned a wage of N\$3 per hour, at times, even less than that. The shortage of, or lack of finances may be referred to as environmental supplies and demands, while the individuals' lack of skills and education may be referred to as values and abilities according to the person-environment fit theory (French et al., 1982; Kahana et al., 2003). None of the participants have tertiary education and they only possess the skills they acquired in their previous jobs. For most of them, their previous jobs involved physical work, and now, they are not able to return to work.

With a lack of skills and education, all participants, excluding P6, express concern for their future. Thus, the participants' aspirations reflect their perceptions and background of wanting to own property and financial security, as opposed to just having a job. They desire better income and improved life-circumstances, and for P3, the disability seems to have robbed him of his future education and career plans. Becoming a hydraulics mechanic reflected his desire to become self-actualised, his strive to realise personal potential, self-fulfillment, personal growth, and peak experience, as stated by Maslow (1970). In addition, the desire to work and earn money, as well as the desire to build a career may reflect a need for safety and security. This reflects a basic, level two need, according to the hierarchy of needs, based on Maslow's theory of human motivation.

The level of needs exhibited by the individuals prior to their disability, has a major influence on their current aspirations. For example, the participants who were striving to fulfil basic love and belongingness needs prior to the accident may find that their belongingness and love needs are threatened much more following the onset of disability. Therefore, these participants, experience an intense search to satisfy these needs. Their future outlook is also preoccupied with ensuring belongingness and love needs. Such preoccupation with specific needs is in line with the preoccupation with deficiency needs, as stated by Maslow (1970).

For instance, the theme of aspirations reflects P5's future dreams and hopes. However, it is not represented by a search for cognitive needs or self actualisation. P5 feels that his environment (supplies), referring to the hospital and the people available to assist him daily, do not adequately meet his needs. However, he does not possess the physical strength (abilities) required to live on his own. Prior to his accident, he had a girlfriend, but she left him after the onset of his disability. He also expressed that, due to his disability he does not have the physical features and confidence he believes are required to nurture and maintain a romantic relationship. According to the person-environment fit theory, this represents a mismatch between P5's skills, abilities as well as needs and his environment's supplies and demands. Mismatch may result in stress that is likely to bring about adverse health, low life satisfaction and consequently lead to poor quality of life (Kahana et al., 2003). Thus, his aspirations reflect a need for belongingness and love, which was also his main desire prior to the onset of his disability. P5's aspirations also reflect a desire for safety and security as the disability has rendered him hospitalised for close to eight

years. Thus, he desires the safety and comfort of his own home and a family to satisfy his need for belongingness and love (see Table 4, code 5:23[188:190]).

The aspirations of participants, who are from more middle-income backgrounds seems to differ from participants from low-income backgrounds', whose aspirations involve more basic level needs, such as safety and security. Participants who are from more privileged backgrounds, whose basic needs were satisfied regularly, are able to aspire towards self-actualisation and self-transcendence. After the onset of disability, such individuals may still be motivated by the need for self-actualisation. However, they might descend and become preoccupied with satisfying a lower level need such as safety and security, which is under threat after the onset of disability, even though that need might have been satisfied before (Huitt, 2004; Rowan, 1999).

The need for self-actualisation and self-transcendence was reflected by P6 as well as P3. These participants desire to use the insight they gained through their disability in order to help others. In addition to developing a desire to help people, these participants expressed that their aspirations for the future, their priorities, and their outlook on life was affected, even changed significantly by their disabilities. P3 reported that the quadriplegia has "shut down" his dreams of studying (see Table 4, code 3:20[127:132]). P6 expressed that her search for cognitive abilities and education increased and assumed greater importance after the onset of her disability, thus it now has a greater impact on quality of life than it did before. The emphasis used to be working, but it changed and she is now considering studying and pursuing a career in psychology, tourism, or media (See table 4, code 6:179[890:900]).

As much as the future is influenced by the past, the participants' desires for their future are also affected by their environment and economic situation. Furthermore, the person-environment fit theory indicates that, each individual engages in a continuous cognitive comparison of his or her needs and desires against the perceived environment (Edwards, 1996). P6, who is more affluent and lives in a more comfortable, adapted environment, is able to look forward to the possibility of studying, thus fulfilling her cognitive needs. The participants from low-income backgrounds may view their environment and economic circumstances as unable to meet their needs. Thus, they (including P2, who lives in an informal settlement) long for much more basic comforts such as having cattle and a house, which reflects safety needs. P4 and P5 also reflect similar aspirations as P2. This is not surprising based on their similar backgrounds. Prior to the accident, these participants were focussed on satisfying their needs for safety and security, thus all their efforts are still focussed on this basic deficiency need and they have not been able to move towards the growth needs yet. An individual is ready to act upon the growth needs if and only if the deficiency needs are met (Huitt, 2004). Furthermore, several participants, including P1 and P4, also expressed the importance of what they have achieved in life as well as a desire to achieve certain things in the future. In this manner, P4 spoke fondly of his achievements and the pride he felt as a successful athlete in the past (see table 4, code 4:56[428:430]).

The theme of aspirations reflects the participants' desire for self actualisation. However, for a number of participants it reflects a desire to secure their safety and security as well as belongingness and love needs. It is also evident that aspirations

are influenced by the participants' positions in life prior to their accidents. It proves to be essential for the participants to be able to do something meaningful with their lives. However, the participants' accounts reveal that a shift in priorities is eminent after a major traumatic life event such as the onset of a disability.

The importance of the aspiring towards set goals and looking at future plans was a common theme for all but one participant. Aspirations deals with the individuals' outlook on life, their hope for of a better future and opportunities for improving their quality of life. Aspirations affect emotional wellbeing, which is the following theme under discussion.

6.3.1.2. Emotional wellbeing

Emotional wellbeing refers to the most common emotions that are experienced by the participants and how these emotions are related to the way they experience life. According to research, traumatic events, including the onset of disability, force people to deal with emotions such as anger, shame, fear, humiliation, and insecurity, frustration, loneliness, hopelessness, as well as loss of control (Cagnetta & Cicognani, 1999). All the participants in the present study expressed that they experience the above mentioned emotions on a frequent basis. In the midst of daily trials, tribulations and fluctuating emotions, the individuals express a need for an overall sense of being content with life, and this desire is also encompassed in the theme of emotional wellbeing. It reveals the participants search for stability and reassurance, which may reflect the search for safety and security on Maslow's

hierarchy of needs. Emotional wellbeing has an effect on an individual's sense of control and is identified as an important contributing factor to quality of life.

Once an individual becomes paraplegic or quadriplegic, they may face difficulty interacting with their environment. Day to day living is markedly different from the way it was before their disability. The individual may feel that they are not strong enough to accomplish certain tasks such as transferring themselves from the bed to the wheelchair. In addition, the environment might not be conducive to support the individual's needs. For example, the surroundings at the individual's house might not be wheelchair friendly as is the case for P4 and P5 whose homes are at the village which has a lot of sand and gravel. Consequently, they have no choice other than to live in the hospital. They express feelings of hopelessness, lack of choice, and loss of control due to their inability to live at home (See Table 5 and Table 9). Person-environment fit theorists postulate that stress increases if there is a mismatch between the environmental supplies and demands and the individual's values and abilities (Cummings & Cooper, 1979; French et al., 1982; Schuler, 1982). Thus, an individual may have a need which he is unable to fulfil because the environment is not conducive. P2 expressed that, as hard as he might try, he is unable to do things he used to be able to do (see Table 5, code 2:32[174:176]). These difficulties escalate and may translate into stress. The above mentioned circumstances often result in a feeling of loss of control, not just over the individual's body, but over their life

The majority of the participants' accounts reveal that a loss of control over their bodies is followed by a perceived loss of control over their lives. P2 clearly

expressed emotional turmoil and feelings of complete loss of control as he told of his continuous attempts to walk. In his thoughts, he is able to move his legs, but his legs never respond. In a similar manner, P6 often forgets that she is unable to walk. She frequently wakes up in the morning and attempts to climb off the bed, only to be reminded of her paralysis (see Table 11). Such experiences bring about, and reinforce feelings of depression, hopelessness, lack of control and sadness. P6 also reported being unable to accept her situation and she often resorts to questioning her ability to make peace with the circumstances she faces daily. According to P4, he has no option but to ask for help and accept help from who-ever is available, as he does not have a personal caregiver. This situation results in a feelings of loss of control, unhappiness and helplessness (see Table 5, code 4:51[385:38]). P3 also expressed a complete lack of choice and control (see Table 5, code 3:100[729:734]).

The above mentioned stress and loss of control resulting from the disability may give rise to very painful circumstances. In order to face these circumstances, each participant finds expression for their emotions in various ways. P3 expressed feelings of deep sadness as he is “always crying” (see Table 5, code 3:92[660:661]) and P6 reported that she frequently feels emotional and depressed (see Table 5, code 6:54[515:516]). Several other participants also reported that spinal cord injury increased pain and consequently increased their feelings of depression. Such feelings are expressed by P6, P3, and P7 (see Table 5 and Table 16). These reports may be linked to previous research findings by Budh and Österaker (2006). According to them, pain, depression, and anxiety are interrelated and are experienced by a distinctly higher proportion of spinal cord injured individuals compared to able-

bodied individuals of a similar background. In addition P2 reported that, emotionally, he felt much better when he was in the hospital. When he is at home, he often feels sad and depressed. Especially, because he lives far from his family, he misses them and feels isolated (see Table 5, code 2:151[955:958]). These feelings are consistent with findings by McAweeney et al. (1996). According to them, once an individual who is suffering from paraplegia or quadriplegia return home, they often experience significantly more psychological distress, including a sense of isolation, compared to their psychological wellbeing during their stay in the hospital. Consequently, they may suffer from psychological ailments such as depression.

In addition to hopelessness, helplessness, and sadness, fear is a common emotion expressed by several participants. The loss of the ability to do things for themselves as well as the lack of mobility causes a great deal of fear and anxiety for participants. P5 prefers being amongst people, instead of alone. He fears being unable to escape from dangerous situations such as an attack from criminals (see Table 5, code 5:49[433:435]). P4 recalled experiencing fear after his motor vehicle accident, and this fear impacts on his quality of life (see Table 5, code 4:125[734:738]). It is evident that he experienced symptoms that resemble PTSD as Butler et al. (1999) pointed out that survivors of motor vehicle accidents may develop significant post traumatic stress symptoms and many others may have reactions that resemble symptoms of PTSD. As indicated by Maslow (1970), these participants become preoccupied with ensuring their safety and security, which they perceive as being threatened. In this manner, P4 refrains from being alone and P3 avoided travelling in motor vehicles, unless it was really necessary.

Collectively, the participants expressed disappointment, helplessness, anger, fear, desperation, hopelessness, shame and embarrassment. These feelings reported by the participants correspond with research findings by researchers such as Cagnetta and Cicognani (1999), Butler et al. (1999) as well as the National Center for PTSD (2007). Cagnetta and Cicognani (1999) discovered that anxiety, anguish and depression ingrain themselves into the depths of the people who survive traumatic events. As P6 said, she just longs to be herself, to feel like herself, not the changed person that she has become. This account of her desire is an expression of how she feels that she has changed, not just physically, but emotionally as well.

Participants desire to be happy, satisfied and content with life, even in the midst of difficulty. This theme was present in all the participants' accounts and is one of the themes that came across as being one of the main components of quality of life. Therefore, emotional wellbeing is an essential theme which contributes to quality of life.

The following theme of identity is closely linked to emotional wellbeing, because an individual's state of mind and emotions determines how they view themselves.

6.3.1.3. Identity

As mentioned earlier, the WHO regards an individuals' perception of their position in life as an important factor, which contributes to quality of life (refer to section 6.2). Their perception of themselves is also essential in determining their position in

life. Related to the above mentioned, the theme of identity refers to this perception, including how the individuals feels about and views themselves. Erickson (1968) referred to identity as an overall sense of wellbeing, as well as feeling at home in your own body, and he also placed importance on receiving recognition from others (as cited in Triseliotis & Hill, 1990). Thus, an individual's sense of identity may change over the course of time and it may be influenced by several factors such as being handicapped. Paraplegia and quadriplegia are types of handicap, thus both affect an individual's identity. Particularly sudden onset paraplegia or quadriplegia may have a severely negative impact on an individual's identity as the individual's body image may change instantaneously. P1 expressed particular concern regarding the negative changes in her body, which were brought on by her quadriplegia (see Table 6, code 1:64[399:400]). Apart from apparent changes to her body, P1 complained about "walking like an old lady" and that "everything has changed". These expressions are indicative of her concern for her image and appearance which refers to her identity.

The theme of identity also encompasses the participants' self-perception prior to their disabling injuries and how this view has been challenged and changed. "I am no longer a mother" (see Table 6, code 1:36[258:258]). This statement reveals that before the onset of her disability, P1's identity was linked to being a mother. Due to the disability, her identity was challenged and consequently she doubts herself and her motherhood. Similarly, P7's identity as a mother is challenged as she is unable to take care of parenting tasks, which she was able to attend to before the onset of her disability. According to P7, she is also no longer able to fulfil her duties as a

grandmother and a wife. In addition, she is unable to take care of her house the way she used to. Caring for her family and her house formed a large part of P7's self-perception. Thus, as a result of her disability, she has partially lost her sense of identity.

Furthermore, identity includes self-esteem and self-confidence. Many of the participants specifically, spoke of feelings of insecurity, inadequacy, low self-confidence and low self-esteem. Table 6 reveals how participants see themselves after the onset of paraplegia or quadriplegia. P2 compares himself to a "parasite" and he believes that his self-worth has decreased, P3 mentioned that he lost his dignity, while P5 who has lived in the hospital for eight years, feels as if he is "just a patient". P6 explained that her self-image, self-confidence, and self esteem has changed (see Table 6, code 6:35[390:391]). It is evident that each of these individuals experienced a change of perception. Consequently, their sense of identity changed after the onset of their disabilities.

As mentioned previously, identity refers to an individual's self-perception, which may be affected by an individual's self-esteem and self-confidence. Many of the participants specifically, spoke of feelings of insecurity, inadequacy, low self-confidence and low self-esteem. Table 6 reveals how participants see themselves after the onset of paraplegia or quadriplegia. It is evident that the majority of the participants in this study experienced a change of perception regarding themselves. Consequently, their sense of identity changed after the onset of their disabilities. It is evident that the individuals such as P3 and P6 are incessantly fighting a daily battle,

with themselves and the outside world, to hold on to their own sense of identity. P6 expresses this desire through her desire to be seen as herself and not the girl in a wheelchair. In essence, they long for validation from themselves and others, which will help them, gain back their self-confidence and self-esteem.

According to Cagnetta and Cicognani (1999), individuals in wheelchairs often define their physical appearance based on their wheelchair. Similarly, this research study found that participants struggle to separate their identity from their wheelchair. Most participants hold strong perceptions of their identity as it was before the onset of the disability. This old identity is often perceived as markedly different from their new identity as an individual with a disability, and they often find themselves comparing these two identities. Although many participants struggle to reconcile these two identities, their new identity as a person in a wheelchair is often most prominent.

The participants expressed concern related to the way able-bodied people perceive them. P3 revealed with sadness that, as a result of his disability and wheelchair, people look down on him and think he might be unintelligent (see Table 10).

According to him, people are unable to separate his identity from his disability and wheelchair. P6 also indicated the desire for her identity to be divorced from her disability and wheelchair. She prefers to be seen “like a passport photo”, as she was before the disability (see Table 6, code 6:113[1235:1246]). This also ties in with Erickson’s (as cited in Triseliotis & Hill, 1990) conceptualisation of identity as a sense of wellbeing, feeling good in one’s body as well as recognition or affirmation

from others. If the participants do not feel good and receive recognition, their identity is affected.

In-depth data analysis revealed that the female participants, particularly, P1 and P6 placed more emphasis on aspects related to identity and appearance than the male participants. This finding could be attributed to societal expectations and behaviour. As the gentler sex, over the years, women have been the ones who are more concerned about their appearance, who spend more money on cosmetic products and clothing (Schiffman & Kanuk, 1997).

This desire for a sense of identity may be a reflection of a need for esteem. Esteem needs refer to status, reputation and responsibility according to the Maslow's theory of human motivation (1970). In addition to self-esteem, esteem needs include the regard an individual derives from others (Simons et al., 1987). Simons et al., further add that most working people are able to meet their esteem needs through relationships and work. Similarly, in the past, these participants' esteem needs may have been partially fulfilled through the recognition they received as working adults. This may be assumed as the semi-structured interviews revealed that most participants' self-perception, self-confidence, and self-esteem are linked to the work they did prior to becoming disabled. For example, P6 expressed her perception that people are recognised for the quality of the work they do (see Table 17). All the participants are currently unemployed. In addition to low self-esteem, unemployment results in a lack of financial resources and unmet financial needs may in turn influence many other areas of the individuals' lives. Lack of resources translates into

needs not being met and this has had a negative impact on the participants' identity, resulting in lowered confidence, esteem, and consequently lowering their quality of life.

Based on the perceptions expressed by the participants, it is evident that having a sense of identity is an important contributing factor to quality of life. It also became apparent that the female participants emphasised aspects related to identity more than the male participants. All the participants desire to be perceived positively, preferably in the manner that they saw themselves before the onset of their disabilities. They want to be seen for who they are, not as the individual in a wheelchair. In addition to the physical handicap, a changed bodily image, being in a wheelchair, and not having financial independence lowers the participants' self esteem and negatively impacts on their identity as well as their quality of life.

6.3.2. Summary of intrinsic factors

The participants referred to intrapersonal aspects such as their hopes and dreams for the future, their emotions, as well as their self-confidence and self-esteem. These aspects were grouped together as they are all associated with the psychological state of the participants. The themes which were derived from the above mentioned are referred to as intrinsic themes. They include aspirations, emotional wellbeing and identity. These intrinsic themes may be influenced by external factors such as the environment, but are not determined by external factors. Not all seven participants

emphasised the different themes to the same extent, however these three intrinsic themes affect all the participants.

The disability impacts on the participants' aspirations, because it has an impact on the plans each individual has had for their life and their future. They are either unable to achieve their goals, or it might take them longer to achieve them, or their priorities have changed and their future plans also changed accordingly. In addition, the onset of disability brought on an influx of emotions for the individuals to deal with. P1, P2, P3 and P6 each expressed that the position they are in due to the spinal cord injury makes them feel like a baby (see Table 5). Feeling like a baby, in addition to feelings of lowered self-control, self-confidence, and changed body image is representative of feelings of helplessness and lack of control over the participants' lives. It also signifies the negative effect the disability has had on the participants' identities. All three intrinsic themes are very important, however emotional wellbeing found to be the most emphasised theme amongst the three, while identity affects the female participants more than the males.

6.3.3. Extrinsic themes

People interact with their environment on a continuous basis. This interaction is discussed extensively by the person-environment fit theorists (refer to chapter three). The person-environment fit theory stipulates that human behaviour as well as attitude is a result of the interaction between the individual and their environment. A match or mismatch between the environment and the individual may influence the

success or failure in the individuals' efforts (Lewin, 1951; Murray, 1938; Orford, 1992; Pervin, 1989). Efforts may include the individual's attempts to adapt to a life with a disability.

When attempting to adapt to a life with a disability, the individual with paraplegia or quadriplegia may realise that they no longer fit comfortably into the environment they lived in prior to their disability. In order for adaptation to be successful a variety of effective coping methods are required and this may include making adjustments to their environment (Degraff & Schaffer, 2008). Adjustments must be made to the individual's physical environment (for example, they may need to build a ramp to replace stairs). The individual must also modify their behaviours as well as their attitude towards their environment. In addition, since interaction does not only occur between the person and their physical environment, the environment also includes people. Therefore, the effect other people's reactions and attitudes have towards people with disabilities impacts on the participants perceptions as well as their quality of life.

The following section focuses on a discussion of the themes extrinsic themes. They were grouped together, based on what the participants identified as important aspects of their environment, which influences them and consequently affects their quality of life. These themes include recreation, spontaneity, effort and comfort, stigma and discrimination as well as mobility and accessibility.

6.3.3.1. Recreation

Several participants highlighted the importance of being able to do activities which they love and take pleasure in. Engaging in recreational activities such as sports, listening to music as well as taking time for relaxation is recognised as essential factors that add to individuals' quality of life. Enjoying the above mentioned recreational activities may act as a means for the participants to satisfy their aesthetic needs. Aesthetic needs are referred to as the search for beauty, balance, and order, the desire to appreciate life, based on Maslow's hierarchy of needs (Huitt, 2004).

Activities such as sports may contribute to quality of life because social interaction provides opportunities for self-definition (Youngkhill & McCormick, 2006). It also provides an opportunity for individuals to relate to others and build relationships. Thus, it may also fulfil the need for belongingness and love as identified by Maslow (1970). Sport such as soccer, basketball and athletics are particularly meaningful to P2, P3, P4 and P5. Although, these participants share a love for sport, P5 is the only individual who is still able to actively take part in sport, following the onset of disability. He plays wheelchair basketball and not only does it provide him a platform to socialise with his friends, but it is also beneficial to his health. P5 used to take part in different sport prior to the disability; however basketball is the only sport he still participates in. Thus, basketball provides him with some form of familiarity as well as a sense of identity (see Table 7, code 5:3[42:47]).

In addition to the above mentioned sport; reading, window shopping, as well as spending time chatting to friends and family are relaxing activities which participants use as a means of recreation. P1 and P7 provide good examples of such recreational activities which are important to the participants. P7, who is quadriplegic, is unable to push her own wheelchair. Thus, she appreciates being able to go outdoors with family, relaxing and enjoying some fresh air (see Table 7). According to P1, going to church, relaxing, and chatting to friends gives meaning to her life (See Table 7, code 1:11[72:75]).

The theme of recreation is vital, as it enables individuals to enjoy their lives. This theme is essential in contributing to the quality of life of all the participants. However, each participant puts different emphasis on the type of recreational activity which is important to them. The participants' ability to engage in their favourite recreation may be hampered by their disability. For example, P4 and P7, who have to count on others to push their wheelchairs, are not able to do any activity at will. P1 is also not able to go to church regularly and take long walks in town like she used to. Consequently, this limits their degree of spontaneity. Thus, spontaneity is also identified as a theme that contributes to the participants' quality of life and spontaneity is the theme which will be discussed next.

6.3.3.2. Spontaneity

As mentioned earlier, disability affects multiple areas of individuals' lives. In section 6.3.3.1, it became apparent how engaging in recreational activities may be hampered

by the limitations of disability. Participants' expressed their desire for the ability to make impulsive decisions as well as do things and go places at the spur of the moment. This desire may be translated into the need for spontaneity. Furthermore, they expressed how their ability to be spontaneous is impeded by their disability. The ability to be spontaneous may enable the individual to satisfy their need for esteem needs, derived from the individual's achievements. Esteem needs may include a sense of efficiency, capability and confidence (Maslow, 1943, 1970). Thus, being limited in their ability to exercise spontaneity may result in lowered self-esteem. This lack of spontaneity affects all the participants, as indicated in the following section.

According to several participants, their lives, even day to day activities require much more planning than before the onset of their disabilities. As a consequence, they also expressed sadness. P6 complained that, following the onset of her disability, activities require much more planning. She must consider her self-catheterising schedule, her medication as well as defecation- routine before she is able to consider going anywhere, especially travelling. She also expressed that, it is not possible for her to do things, such as catching a taxi or going to town, at the spur of the moment. This is not only expressed by P6, it is also important for many of the other participants as the majority of them travel most frequently by taxi. Two of the participant own motor vehicles, however the motor vehicles are not adapted for people with disability, thus they still rely mostly on taxis. As mentioned earlier, the participants' physical limitations require adaptations to their environment, such as modifications to their motor vehicles (Degraff & Schaffer, 2008). According to the

person-environment fit theory, for a paraplegic or quadriplegic individual, owning a motor vehicle which is not adapted may result in stress for the individuals. This is due to a mismatch or a discrepancy between personal characteristics (disability) and environmental supplies (motor vehicle which is not adapted) (Kahana et al., 2003).

In addition to affecting the individuals' ability to travel, lack of spontaneity has an impact on the participants work as well as living arrangements. It limits the possibility of finding employment for P2, who worked as a handyman, prior to becoming disabled (see Table 8, code 2:27[169:169]). It has a similar effect on P6, although her work as a supervisor involved less physical activity than P2, lack of spontaneity also impacts on her ability to return to work. This lack of spontaneity also has an impact on P6's decisions of where to live (see Table 8, code 6:97[1113:1118]).

In addition to the above mentioned, the participants' accounts, clearly illustrate that a lack of spontaneity affects P4, who has a higher level, quadriplegic injury, to a greater degree than it does the paraplegic participants. This finding may be linked to reports by Trieschmann (1980), who states that a higher level injury is associated with more complex and stressful issues, such as more health complications and it requires more daily assistance. In this way, P4 is unable to move around by himself. He is unable to do basic activities such as going to the bathroom or visiting a friend (see Table 8, code 4:73[580:588]). Furthermore, P4 has no control over brushing teeth, feeding himself drinking, as well as moving from one room to another.

Spontaneity (or lack of spontaneity) in daily activities was frequently reported as an aspect that affects the quality of life of the participants. It affects their personal life, including their ability to travel, as well as where they chose to live and their work. Furthermore, the lack of spontaneity affects the participants with quadriplegia more than it affects the participants with paraplegia. In addition to needing to plan their life more extensively following the disability, participants also report that activities require more energy, time and effort. They also report that they do not experience the same comfort levels as able-bodied individuals. Therefore, effort and comfort is discussed in the next session as an important theme of quality of life.

6.3.3.3. Effort and comfort

All of the participants in this study expressed that, following the onset of paraplegia or quadriplegia, they have had to adapt to new and more challenging ways of taking care of themselves as well as daily activities and tasks. Furthermore, they expressed a desire to take care of everyday tasks with ease and the need to be comfortable. As a result of the common nature of this desire amongst the participants, the desire for ease and comfort was identified as an important contributing factor to quality of life for these participants.

This theme refers to the way participants' experience daily life and the effort required for doing basic activities such as cooking, bathing as well as other household chores. For example, P2 lives in an informal settlement where basic living necessities are not easily available and sanitation facilities are non-existent. Tasks

such as fetching water for drinking or bathing are made significantly difficult by his disability. He stated that the lack of comfort causes a lot of sadness and pain. P2 also referred to experiencing problems with disposing of his diapers, as there is no municipal garbage disposal facility at the informal settlement (see Table 9, code 2:193[863:865]). These uncomfortable living conditions lower his quality of life (see Table 9, code 2:133[832:835]). Similar to the experiences of P2, P4 and P5 also report that living at their homes in the village has become very difficult and uncomfortable. These difficulties are caused by the lack of electricity (see Table 9, code 4:23[192:193]), safety, comfortable cooking facilities other than on the fire, lack of water, and too much sand, which makes it difficult to move around in their wheelchairs (see Table 9, code 5:28[248:252]).

The above mentioned difficulties experienced by the individuals may be as a result of what is referred to as, low compatibility or mismatch between individual characteristics (ability to carry a bucket of water or cook by the fire) and situational characteristics (the lack of running water or electricity) by the person-environment fit theory (Livingstone et al., 1997). Due to their disabilities, the participants may lack certain physical abilities such as lifting heavy things (e.g. bucket of bath water). In addition, if their environment (e.g. informal settlement) requires such activities on a daily basis, there is a mismatch. Lack of person-environment fit may cause chronic stress which, in turn, may result in poor health, low life satisfaction and consequently lead to poor quality of life (Kahana et al., 2003). Based on the researchers' knowledge, even though many other African countries such as South Africa have similar poverty stricken informal settlements, the above mentioned

circumstances are unique to the Namibian population and it differs from living circumstances for the participants of research studies that were reviewed in the literature. The researcher did not come across studies on the quality of life of paraplegics and quadriplegics in neighbouring African countries. This may be a contributing factor as to why this theme was uniquely identified, and stressed by these individuals.

In addition to the problems related to fetching water, bathing and lack of sanitation facilities, cooking is identified as particularly difficult by P2, P4 and P5, who are accustomed to cooking on the fire. However, P1, P6 and P7, who have the facilities to cook on a stove, also complain of more effort that is required during cooking. P7 is unable to cook or do any of her household chores, which she regularly took care of prior to her disability. P6 conveys that activities which able-bodied people do with ease are experienced as complicated and difficult (see Table 9, code 6:92[1074:1075]). Seeing that this theme refers to performing basic daily activities such as cooking and bathing, the theme of effort and comfort may be related to the basic physiological and biological needs on Maslow's hierarchy of needs.

All the participants conveyed that they have had to adapt and acquire extra patience to deal with more daily activities which are very challenging and time-consuming. The participants also expressed a reluctance to go places because they are not able to sit for long periods of time. They are also unable to travel comfortably. Whenever they travel, they must keep schedule of medication, self-catheterising routines, and using suppositories to aid in excretion, amongst other matters. In addition, these

individuals often need help with activities such as washing clothes and cooking which they were able to do comfortably prior to the accident.

Overall, participants' quality of life is affected by their living environment and level of comfort. However they are also affected by the opinions of people in their environment. These opinions tend to translate into actual and perceived stigma and discrimination. The following section is devoted to a discussion of how the opinions of people in the participants' lives affect their quality of life.

6.3.3.4. Stigma and Discrimination

According to the person-environment fit theory, the characteristics of the individual, the environment, as well as the manner in which the individual and the environment interact determine the individual's feelings and behaviours. Therefore, the individual's perceptions of themselves and their environment are essential contributing factors to satisfaction in life and happiness (see chapter three), and ultimately, it affects quality of life (Orford, 1992). In addition to physical features, the environment includes other people, consequently other people's perceptions regarding the individual, influences the individual.

Based on these participants' accounts (see Table 10), they are of the opinion that stigmatisation and discrimination are present in most of their lives. Stigma refers to the perception, beliefs, preconceived ideas and prejudices that the external world holds regarding disability. Stigma may be expressed in the form of comments made

or assumptions and myths. For example, P3, a quadriplegic, accounts that he has experienced such stigmatisation, first hand. He reports that people look down at him and think he is stupid or dull because he is in a wheelchair (see Table 10, code 3:57[364:370]). Stigma also represents the perceptions individuals with spinal cord injuries have of other's perceptions and attitudes toward them as people with disabilities. P3's account indicates that his perception of how others view him influences his experience of stigmatisation. In the same manner, P6 thinks she is viewed as "a pretty girl in a wheelchair". The above mentioned supports research findings by Manns and Chad (2001), which states that able-bodied people frequently perceive spinal cord injured individuals as being physically deformed, unattractive, and mentally challenged.

Possibly as a result of false assumptions and myths, many able-bodied individuals may express curiosity regarding disability. According to P6, able-bodied people are often curious about the way people with disabilities look and they have preconceived notions regarding disability. To satisfy their curiosity, able-bodied individuals often stare when they encounter somebody in a wheelchair or with any form of disability. For that matter, she experiences immense discomfort when people stare at her in this manner (see Table 10, code 6:109[1207:1222]). The feelings reported by P6 are shared by P1 who expresses that, when she goes to the shops, people stare, point at her, and talk about her (see Table 10, code 1:67[426:429]).

In addition to the above mentioned stigmatisation, discrimination may be experienced by the participants. From the participants accounts, it may be deduced

that discrimination could refer to individuals' experiences of being disadvantaged based on their disability. Discrimination may be reflected in different forms. For example, a parking area at a mall might not make provisional parking for people with disabilities or a government policy might neglect to inclusively cater for individuals with disability. Such discrimination is expressed by P1. She conveys that her family members are also very prejudice and treat her differently due to her disability. They also do not give her a chance to really attempt to go places and do certain activities (see Table 10, code 1:70[436:437]).

As can be seen by the above mentioned responses, when participants perceive that stigma and discrimination are present in their lives, it has a negative effect on their perceived quality of life. The presence of stigmatisation and discrimination is distressing and may negatively impact on the participants' need for self-esteem as is reflected by P3's account. He mentioned that in the presence of discrimination, an individual is unable to do anything because "discrimination is totally the knife or sharp thing that cuts down a person" (see Table 10, code 3:38[246:250]). Based on these feelings, it may be deduced that stigmatisation negatively impacts on the need for self esteem, according to Maslow's theory of human motivation.

Based on the participants' perceptions, it is evident that the presence of perceived stigmatisation and discrimination adversely impacts on quality of life. The participants convey that the lack of stigmatisation and discrimination is experienced as an ideal and positive situation. Thus, people's perceptions are part of the environmental features that impact on the individual's emotions and behaviours. In

the same manner, other environmental features may create obstacles, which may cause additional difficulties for the individual. These difficulties may include difficulties with mobility and accessibility. These will be discussed in the following section.

6.3.3.5. Mobility and accessibility

From the participants' accounts, it was apparent that paraplegia and quadriplegia result in major difficulties, as previous researchers have indicated. Individuals with paraplegia or quadriplegia experience significantly higher levels of stress compared to able-bodied individuals. Primarily, the stress is caused by barriers such as their natural environment, transportation, help at home, health care, and government policies related to disability (Whiteneck et al., 2004). For this reason, the theme of mobility and accessibility for these participants, refers to their need to move around without restrictions, as well as the physical accessibility or inaccessibility of their environment (i.e., at home, work, or recreational facilities). Concerns regarding mobility and accessibility frequently surfaced during the interviews, and this theme was evidently essential for every one of the participants.

Each participant revealed some aspect of mobility and accessibility that has an effect on their quality of life. However, inaccessibility of certain places and buildings was a common concern shared by all the participants. P5 conveyed feeling constricted and limited due to his inability to move around (see Table 11). For both P4 and P5, the theme of mobility and accessibility mainly entails concerns such as being able to

move around comfortably. They are unable to live in their respective villages due to the sandy environment which makes impassable for wheelchairs (see Table 11, code 4:22[183:191]). P2, who lives in an informal settlement, also expressed concern regarding being mobility. He finds it very stressful and challenging to ride his wheelchair around his neighbourhood, especially after there have been road works and there are loose stones in the gravel roads. This stress, which these participants experience, may be unique to the Namibian context. As mentioned earlier, most of the existing research, regarding the quality of life of individuals with spinal cord injury, was conducted in developed countries, as opposed to developing countries, such as Namibia. Thus, none of the participants in such studies, for example, the study by Manns and Chad (2001), lived in such rural areas as P4 and P5, or an informal settlement, as P2 does.

The above mentioned difficulties may be as a result of stress due to a mismatch between the individuals and their respective environments, as indicated by the person-environment fit theory. Accordingly, strain increases when supplies, such as P4's lack of an electric wheelchair, fall short of values, which are his need to move around freely, without the help of others (Cummings & Cooper, 1979; French et al., 1982; Schuler, 1982). Such a mismatch between the environment and P4's needs, results in feelings of extreme restriction, and enjoying a good quality of life is hampered by such feelings of restriction.

In addition to feeling restricted, several participants feel threatened due to their lack of mobility, as they fear not being able to escape from dangerous situations. This

may reflect their need for basic safety and security, which Maslow's theory of human motivation identified as the need for protection from elements, security, order, law, limits, stability, and being free from fear and deprivation (Reisinger, 2009). A prime example of fear based on an individual's inability to walk is given by P5. He expressed his fear of being home alone for the reason that if he is in danger, he might not be able to escape fast enough. He prefers being amongst a crowd as well as to live with people. Several other participants also voiced their fear of not being able to help themselves out of dangerous situations. P2 expressed his fear of burning while sitting by the fire (see Table 11, code 2:194[378:380s]).

Besides threatening the participants' safety and security, the theme of mobility and accessibility may also represent a need for esteem as identified on Maslow's hierarchy of needs. The lack of accessibility threatens their esteem needs due to feelings of restriction to their freedom, choice and confidence. Being able to access places regardless of the disability gives the quadriplegic or paraplegic individual a sense of freedom, confidence, and self-esteem. This is illustrated by P6, who stated that being able to go to town, find parking easily, go to shopping malls, and go inside shops and other buildings without struggling or needing assistance is very important. In addition, she expressed a desire to be able to use facilities such as public rest rooms in the same manner as able-bodied individuals. Having access to the same facilities and being given the same opportunities as able-bodied individuals is important for increased self-esteem. Thus, it is an important contributing factor to how individuals with disability perceive their quality of life (see Table 11, code 6:123[1367:1373]).

As Whiteneck et al. (2004) stated environmental barriers cause a significant amount of stress for individuals with disabilities. Participants in this study also recognised the significance of environmental barriers. Participants' such as P6 also refer to barriers, including pavements and stairways at malls without any ramps or other modifications for people in wheelchairs (see Table 11). P6 also believes that it is the responsibility of authorities and the community at large to make provision for people with disabilities by adjusting the environment to suit the people with disabilities. The required adjustments include public restrooms and other facilities which are equipped for people with disabilities, interlocks on pavements, and ramps in front of buildings. These adjustments will allow the people with disability to feel less restricted and more independent.

As the above mentioned highlights, the theme of mobility and accessibility was identified as a theme which has a significant impact on the participants' quality of life. Mobility affects participants in their homes as well as in public places. On the other hand, accessibility mainly refers to the accessibility of public places such as shops, public restrooms, and buildings.

6.3.4. Summary of extrinsic themes

After the onset of disability, individuals experience immense challenges and stress in their daily activities and interactions with others. In order for them to adapt successfully, adjustments must be made. Adjustments involve changes to the environment, attitudes and behaviour. All the participants' emphasised the

importance of this process of adaptation and interaction with the environment. Based on this, these aspects which they emphasised were grouped together as extrinsic themes. They are determined by the individuals' interaction with others as well as their outside environment during the process of adaptation. Therefore the effect other people's reactions and attitudes have towards people with disability impacts on the participants perceptions and their quality of life. Effort and comfort is a theme that was identified as unique to this specific sample. Recreation, spontaneity, effort and comfort, stigma and discrimination as well as mobility and accessibility are external themes of quality of life.

The following section continues to focus around the individual in relationship with their environment. It refers to their relationships with close family and friends, as well as the resources which they need.

6.3.5. Support themes

Support refers to the assistance individuals with disabilities require in order to adapt successfully. It is represented in the form of relationships and resources.

Relationships refer to relationships which the individual engages in with family, friends and other loved ones. Resources refer to essential facilities and equipment such as a catheter and a colostomy. Resources also include all the equipment which is meant to make coping easier such as an electric wheelchair and caretakers.

6.3.5.1. Relationships

The theme of relationships refers to the significance of personal relationships and the value found in such relationships. Personal relationships with family, friends and significant others such as spouses provide valuable support during the process of adaptation to the disabilities. The significance of supportive relationships in enhancing quality of life became clearly visible throughout the interviews and data analysis.

From their accounts, it is evident that most of the participants have been relying on family members as their primary caregivers and main source of support. Only P4 and P5 permanently live in the hospital, thus their main caregivers are the hospital staff. However, these two participants also often need help from family members and friends. The theme of relationships refers to the need for belongingness and love according to Maslow's (1943) hierarchy of needs. Belongingness and love needs may manifest as the desire to be part of a work group, the desire to have a family, affection and relationships (Reisinger, 2009). As indicated above, the participants in this study mainly satisfy their belongingness and love needs through family.

According to Manns and Chad (2001), participants in their study reported that forming new friendships and relationships with potential partners was more difficult following a disabling spinal cord injury. They also found that these relationship difficulties negatively affected their quality of life. Romantic relationships are part of the major areas that were identified, by the participants of this study, as having been

impacted by their disabilities. Although all the participants' relationships were affected, each subjective experience was different. P5 lost a vital relationship when his girlfriend decided not to continue their relationships after he became disabled (see Table 12, code 5:70[618:620]).

On the other hand, P2 expressed that his disability impacts on the possibility for him to have a girlfriend. This saddens him because he believes that a girlfriend would have supported him immensely (see Table 12). P3 and P6 described that their relationships were affected through the sense that they have changed emotionally and this has had an impact on and changed their relationships. While P6 ended her romantic relationship in order to concentrate on her rehabilitation, P3 has lost confidence and distances himself from the opposite sex. On the other hand, P7 regards her relationship with her husband as stronger, following the onset of her disability. However, emotionally she feels low and unhappy as she is not able to accompany him to events (see Table 12, code 10:78[1194:1210]).

In addition to romantic relationships, several participants referred to friendships that have been negatively affected or lost and the pain it has caused them. P3 feels abandoned, disappointed and betrayed as he revealed the hurt caused by friendships lost (see Table 12, code 3:125[97:103]). Similar sentiments were also shared by other individuals such as P6. In particular, P6's account regarding lost friendships ties in with literature, which states the likelihood that, even when an environment is fully adapted, a certain degree of discrepancy may exist between psychological needs and environmental demands (Okubo et al., 2007). This is based on her report

that, prior to the onset of her disability, friendship was the most important aspect in her life. A year after becoming disabled, she has the equipment needed to improve her functionality, her medical bills are taken care of by the MVA Fund, she lives with her mother who helps her with her daily activities and tasks, she is also very positive as well as proud of having learned how to care for herself. However, even though she has all the above mentioned resources, she is still very hurt and reports being depressed regularly, because of friendships that were lost (see Table 12). Thus P6's perception of herself and others may influence her emotions to the extent that she feels depressed and fails to adapt positively in a fully adapted, conducive environment. Thus, it is clear that a lack of relational support has a negative impact on the participants, regardless of the availability of resources and medical expertise.

P6 also reports changed relationships similar to the research finding of Manns and Chad (2001). They established that some people experience improved relationships with their families following the spinal cord injury as they no longer take their family for granted. P6 came to the realisation that although she has always valued relationships, she now recognises the importance of family relationships and the need to cultivate these relationships more than friendships. Many other participants, even those who are not married, also expressed a desire to have a family in the future. P1, who is widowed, mentioned that the spinal cord injury has affected her plans of travelling to see her children and this affects her negatively. P7 also feels that becoming paraplegic negatively affected her relationship with her husband, children and friends (see Table 12, code 10:51[784:794]). It is especially difficult for her to see the impact that her disability has on her family because her family is her

major source of support. As mothers, P7 and P1 fulfilled the caretaker role; therefore it is especially difficult for them to see their families struggling.

Apart from searching for affection from family and friends, participants such as P5, may search for such acceptance and belonging from engaging in recreational activities such as basketball (see section 6.3.3.1). This need for belongingness and love may only be satisfied if there is a match between the individual and the people providing the support. Thus, following the onset of their disability, the individual, as well as family and friends, might need to make adjustments to their attitude in order to best interact. As mentioned earlier, even though he lives in hospital, P4 often also relies on family and friends for support. Yet, his account is a prime example of a possible mismatch between his needs and the attitude of the people from whom he needs help. He is of the opinion that family members and acquaintances, sometimes do not want to help, or are happy when he is suffering (see Table 12, code 4:177[944:949]).

A notable factor regarding the relationships of the participants in this study is that only P6 refers to peer-pressure as part of relational concerns that affect an individual's quality of life. She mentioned that peer pressure is partly to blame for the situation she is in (see Table 12, code 6:75(786:786)). Furthermore, findings indicate that spinal cord injury has affected the way the individuals interact with people. While P2 still loves spending time with people and seeks their approval, P1, P3, P7 as well as P6 report becoming more withdrawn. P6 mentioned that she used

to love people very much and found it easy to interact. However, she has now become “the shy girl who would rather sit in the corner and cry”.

For these participants, it is evident that relationships are identified as significant in contributing to quality of life. The theme of relationships includes romantic relationships, family as well as friendships. After a spinal cord injury, many people rely on family as the main source of emotional support and rely on the value and significance of these relations to cope and adapt to their disabilities. In addition to relationships, resources are a source of support for individuals as they adapt and learn to cope with their disability. Resources are discussed in the following section.

6.3.5.2. Resources

Resources refer to the equipment, medication and additional material needed to enhance the individuals’ health or the lack of which may negatively affect their health. In essence, the theme of resources refers to three levels of resources. Firstly, basic resources that are essential for survival; secondly resources which are used to make daily activities easier for the individuals, and finally human resources which are essential for assisting the individuals.

Basic resources include elements such as food, housing and water. These resources may be used to satisfy what Maslow (1943) identified as basic physiological and biological needs as well as the need for safety and security. Sudden-onset paraplegia and quadriplegia threaten the individuals’ sense of safety and security by robbing

them of control. Devins and Shnek (2001) report that disability with a sudden onset lower the individuals' feelings of personal control, by limiting the ability to obtain positive outcomes or avoid negative ones through one's own actions. Often, quadriplegic individuals and some paraplegic individuals are unable to work and earn money, thus they experience many challenges. They may be unable to buy their own food, pay rent, or take care of household tasks such as cooking, cleaning and laundry. Some quadriplegic individuals are even unable to feed themselves. All these challenges result in a sense of lost control and create concerns related to daily sustenance, safety, and survival.

During the interviews, some of the participants revealed their concern for basic needs such as food, shelter and water. This may be in response to a perceived threat to their safety and security needs as well as biological and physiological needs. This perceived threat may be as a result of emotional difficulties and a lack of control as discussed in section 6.3.1. 2. One of the participants who gave a prime example of such basic needs is P4. He stated that the most important things in people's lives are basic needs such as water and shelter (see Table 13, code 4:176[57:60]). In addition, basic resources include chronic medication, wheelchairs, and supplies such as hydrations pack, colostomies, and catheters, each with their additional parts. P4, who does not have sufficient functionality in all four limbs, views the need for an electronic wheelchair as a vital resource. He repeatedly emphasised this need throughout the interview (see Table 13, code 4:126[136:136]).

As mentioned earlier, resources also include equipment, which make day to day activities easier and thus promote further enhancement of the individuals' quality of life. Such equipment may include a commode, which is a chamber-pot in a chair that may also be used for showering. It may also include an electronic wheelchair as opposed to a manual wheelchair for a paraplegic individual such as P7, who often suffers from fatigue and finds it difficult to operate a manual wheelchair, even though her arms are functional. Ramps, pavements with interlocks and improved public facilities such as wheelchair friendly bathrooms and parking areas are also identified as important resources. P6 exclaims in frustration: "Put a ramp, then nobody has to help me" (see Table 13, code 6:133[1478:1478]). Additionally, P1, who is quadriplegic, but has little functionality in her hands, has difficulty dressing herself. Thus, for her, resources also include "special dresses" (see Table 13, code 1:88[556:557]) and money in order to buy these dresses. P4, who is quadriplegic, has a greater need for basic resources such as an adapted toothbrush, cup or water bottle, as well as an electric wheelchair, to mention a few.

Furthermore, P2, P3, P4 and P5 referred to the importance of electricity and running water as essential resources. All the participants referred to the importance of cooking facilities. Although, only P2, P3, P4 and P5, compared cooking on the fire to cooking on a stove and they verbalised the importance of having a stove as an actual resource. The difference in emphasis on the cooking facilities may be ascribed to the participants' different living environments, economic circumstances, and level of needs prior to the onset of disability. As Maslow's theory of human motivation proclaims, individuals who are driven by a deficiency need, for instance basic

resources such as cooking facilities, are preoccupied with that need (Maslow, 1970). Thus, it is important to note that, in this study, only the participants who have a shortage of certain resources emphasised the importance of such resources. For instance, the participants who lived in the villages and the ones living in informal settlements as well as poorer neighbourhoods refer to the importance of cooking on a stove as well as having running water and electricity. They may also be the participants who experience most stress due the discrepancy or lack of fit (see chapter three) that exists between their physical abilities and the challenges posed by their life-circumstances (see section), which constitutes their environment. Their life-circumstances (see section 6.1) may include lack of water, electricity, transport as well as tarred roads. These environmental aspects were also identified by Whiteneck et al. (2004), as the most common barriers that are experienced by individuals with spinal cord injury during the process of adaptation.

In addition to physical resources, human resources are essential for adaptation. These resources refer to the assistance needed from medical staff, physiotherapists and caregivers. P4 is a severely impaired quadriplegic and P7 is paraplegic, but complains of fatigue and severe headaches. Most of the participants, particularly P4 and P7, need care on a continual basis. These findings are congruent with research findings by Trieschmann (1980), who concluded that many people with quadriplegia require more daily assistance due to greater health complications than those with paraplegia. However, individuals who have regained some functionality also need help. In the same manner, participants in this study believe that, even though they can manage to do many things by themselves, they are still in need of daily

assistance for basic activities such as cooking, washing clothes and bathing (see Table 13, code 5:77[388:389]).

In addition, P4 expressed the need for the counselling. He recognised counselling as an essential resource for the improvement of an individual's quality of life. He also refers to the need for better care from nurses and caregivers as he is often faced with the problem that nurses and caregivers do not respond quickly enough to his requests for assistance. Thus, the need for quick response and quality care from caregivers is recognised as an essential aspect of human resources. This need for better care was also identified in a previous study of life satisfaction amongst spinal cord injured individuals. Satisfaction with assistance from caregivers was ranked the highest priority by disabled individuals. Having personal assistance serves to maintain the well-being, personal appearance, comfort, and safety of the individual (Chase et al., 2000). Individuals thus grow emotionally and gain strength as well as confidence from effective and prompt assistance.

According to P6, the help she received and the knowledge she gained from the human resources as well as the equipment she had access to at the rehabilitation centre is invaluable. She is able to take this knowledge with her and apply it daily to improve the quality of her life. Another participant who views the care at the hospital as a critical resource, without which he would not be able to function successfully, is P2. He reported that the care he received in the hospital was far better than the care he receives at home. This view corresponds with previous research findings by Manns and Chad (2001). They concluded that many participants believe they receive

better care in the hospital than they do when at home. In addition, P4 is of the opinion that people, who do not know him, such as nurses in the hospital, treat him better than people who know him, for instance some of his friends and acquaintances in the community.

In their study of quality of life Manns and Chad (2001) found that participants addressed resources as a foundation for quality of life and emphasised that level of resources corresponded with a degree of ability to direct energy into other areas such as work. Similarly, P1 mentioned that when people give her ideas, it is not very helpful as long as she does not have the resources such as the capital to invest in the ideas (see Table 14). Thus, even if you have the desire and ability to do something, it can not be done without the appropriate resources and help.

It is difficult to have a good quality of life if your basic needs are not met. As you obtain housing, clothing, family needs taken care of, you are able to have an improved quality of life. Manns and Chad (2001), found that although the ability to create and contribute were significant factors influencing individuals quality of life, the opportunities to achieve in these areas was strongly influenced by the availability and level of resources. In the same way it was found that the participants in this study also require a certain level of resources to improve their quality of life. As is evident, resources cover a wide range of products, medication and human resources. The required resources vary from individual to individual and even when the exact same resources are in demand, the degree of importance of each resource also varies.

6.3.6. Summary of support themes

The participants in this research study identified support an essential part of daily life. Support may be obtained through relationships with friends, family and romantic relationships. It may also be obtained through resources such as equipment, medication, caretakers and medical staff. Receiving sufficient support is essential in order for individuals with paraplegia or quadriplegia to adapt successfully to the changes brought on by their disabilities. As is evident, support may be obtained through various means and the required support is unique to each person. The participants distinctly refer to the support they require in terms of resources are just as essential as relationships.

Collectively, the themes which were discussed thus far were grouped under intrinsic, extrinsic and support themes. The following four themes which will be discussed are the ones which did not fit into any of the three above mentioned categories. In addition, based on the emphasis that participants placed on these themes, they were found to be the most relevant themes which determine the quality of life of the participants in this study.

These themes will be discussed in the following order; coping, independence, physical wellbeing, and work and money.

6.3.7. Coping

Paraplegia and quadriplegia are extremely challenging conditions that affect multiple areas of a person's life. According to Bishop (2005) significant physical, psychological, social, and environmental changes are inevitable following a spinal cord injury. These changes are extremely challenging, demanding, as well as physically and emotionally draining. Employing effective coping mechanisms to deal with these challenges is an important factor that contributes to quality of life after a spinal cord injury.

Coping mechanisms are efforts employed to help an individual manage external or internal demanding situations (Lazarus & Folkman, 1984). They may be seen as serving a similar function as defence mechanisms, which reduce anxiety due to external as well as internal forces, or reinforce pleasurable emotions (Carlson, 1990; Meyer et al., 2003). According to the DSM IV (APA, 2005) defence mechanisms and coping strategies are defined as similar. Coping strategies may be subdivided into problem-focussed (actively dealing with the problem) and emotion-focussed (lessening emotional distress) coping mechanisms (Pienaar & Rothmann, 2003). Problem-focussed coping thus includes the defence mechanism of acting out and emotion focused coping includes denial, which refers to refusing to acknowledge some painful aspect of reality (APA, 2005).

Denial is one of the most commonly used types of defence mechanisms (APA, 2005). The participants in this study also exhibited various forms of coping

mechanisms. For example, being quadriplegic renders P4 bedridden, often for most of the day. Thus, he listens to the radio and watches television, as a means to keep in touch with the external world (see Table 14, code 4:6[59:60]). In a similar manner P5 as well as P7 who are both paraplegic are also often bedridden. P5, due to bedsores that have been troubling him for six years and P7, due to constant feelings of fatigue, headaches, and dizziness. These two participants also use television, radio and reading as a means of coping. As long as it is used within healthy limits to prevent feelings of isolation, not as a means of escape and denial, the above mentioned methods of coping may be referred to as acting out. According to P2, the best methods of dealing with challenges include following instructions of doctors and other experts, as well as exercising, which makes him feel better. Such effective coping mechanisms may contribute to an enhanced quality of life. Problem-focussed coping is also represented by P5 who is acting out by playing basketball and going out with friends (see Table 14, code 5:85[288:289]). Often, the participants feel overwhelmed by their condition and their circumstances as P1 indicates: “Yes, my whole image was affected, and there’s nothing I can do even if I say I don’t like it. Nothing I can do to change it” (see Table 14, code 1:66[413:413]). While attempting to accept her condition, P1 experiences feelings of helplessness. Thus, she adopts an attitude of passive acceptance in order to accept the situation she is unable to change.

As the above mentioned reveals, each one of the participants employs a variety of coping mechanisms to deal with the challenges they are facing. Thus, coping was identified as one of the most prominent themes. This is not surprising; in light of literature confirming that daily life for an individual with a disability presents

numerous stressful situations which require a variety of coping methods (Degraff & Schaffer, 2008). They also stress that, individuals employ varieties of coping methods and sometimes more than one method is employed simultaneously.

Through-out data-analysis, it became evident that many of the participants mainly employ emotion-focussed coping mechanisms. According to Lazarus and Folkman (1984), it is assumed that, because emotion-focused coping does not actively address a given problem, it may not be an effective means of addressing problems. However, Lazarus and Folkman are of the opinion that, at times, it may be a very productive and realistic address to stressors. Such times refer to when the source of stress can neither be reduced nor resolved as is often the case with paraplegia and quadriplegia. As mentioned earlier, defence mechanisms may be activated once conscious attempts at coping are unsuccessful (see chapter three). Defence mechanisms mainly operate unconsciously and individuals basically have a largely distorted and unreal image of themselves and their environment, thus overuse of defence mechanisms such as denial may be damaging to the individual (Meyer et al., 2003). However, some degree of defensive distortion, such as the tendency for people to see themselves more positively than is warranted by reality, may be useful (Westen, 1999). An example of such a coping mechanism is employed by P2 who praises himself for being very helpful and believes that people need him just as much as they did before he became disabled (see Table 14, code 2:145[916:920]).

According to Cagnetta & Cicognani (1999) attitudes that influence coping as well as the coping mechanisms employed may be linked to an individual's level of

functioning prior to the disabling motor vehicle accident. People often try to face the new situation by adopting coping strategies that proved to be successful in the past because they adapt familiar defence mechanisms, as Meyer et al. (2003) indicate. For instance, some participants resort to asking others for help, while certain participants actively attempt to generate income for themselves. The participants who feel most helpless are the ones who, prior to the disability, coped by depending on others in difficult situations. Participants such as P2 and P3 who could only count on themselves prior to their disabilities attempt to cope by solving their problems following the disability without help.

Depending on their level of functioning on Maslow's hierarchy of needs, participants employ specific coping mechanisms that correspond with their level of functioning and their attempt to satisfy their needs (Norwood, as cited in Huitt, 2004).

Furthermore, Norwood suggests that an individual's level of functioning on Maslow's hierarchy may be an indication of the kinds of information the individual seeks. Thus, their coping mechanisms may also be influenced by the type of information the individuals search for. For example prior to the accident P5 was focussed on finding a job and attempting to satisfy his needs for safety and security as well as belongingness and love. Currently, he feels hopeless and helpless about living at the hospital as well as the bedsores he suffers from. At this level, Norwood indicates that individuals search for helping information, seeking help and ways to be safe and secure. In order to cope with the current situation, he mostly uses denial and passive acceptance as a coping mechanism. He uses this form of coping mechanism possibly as a means of creating safety and security for himself.

Subconsciously, he perhaps assumes that he will feel safer if he does not have to face the problem and deal with it actively.

Furthermore, P5's aspirations for the future also reflect a need for safety and security as well as having a family to fulfil his need for love. The coping mechanisms he mostly employs also reflect his tendency to use emotion-focussed coping. This reflects a need to satisfy the emotional needs and indicates a sense of powerlessness (see Table 14, code5:14[104:106]). Similarly, P2 also uses emotion-focussed coping. He often tells himself that he is capable of doing many things, sometimes he goes as far as saying he is capable of doing everything he was able to do before the onset of his disability (see Table 14, code 2:20[132:132]). Even though he may be employing denial which is mainly recognised as a negative defence mechanism (Vaillant et al., 1986), it may serve a positive function as it helps him believe in himself and cope better. Thus, the emotion focussed coping employed by P2 and P5 may serve the purpose of helping them deal with situations that they are unable to change.

Similar to P5, prior to the accident P1 was focussed on satisfying her need for safety and security. She was focussed on searching for a means to feed herself and her children. The coping mechanisms she now employs are mostly emotion focussed through help-rejecting complaining (see Table 14, code 1:106[485:488]) as well as passive acceptance (see Table 14, code 1:82[495:496]). Help-rejecting complaining involves complaining or making repetitious requests for help, however this may be a means to disguise covert feelings of hostility or reproach toward others (APA, 2005). Although some forms of emotion-focussed coping may be effective, help-rejecting

complaining may be an example of negative, ineffective attempt of coping.

However, contrary to the feelings of helplessness and hopelessness she expresses, P1 is the participant who has shown the most significant recovery of functional ability in the past year. Yet her main coping mechanism of help-rejecting complaining remains negative. P1 resorts to such coping because she perceives the problems that she has had to deal with as too difficult and overwhelming, to such an extent that she is not able to start planning for her future. This may be a reflection of the type of coping she resorted to prior to her accident. As mentioned earlier, several participants such as P1 and P5 are searching to satisfy safety and security needs.

Other individuals such as P3 and P6 resorted to withdrawing and secluding themselves in their homes and their family environments, which represent the places where they feel sheltered and free to reflect (see Table 14, 3:32[202:203]).

Furthermore, the crucial matter for some participants was finding an answer to the question: Why? Thus a search for meaning ensues following their disability. Several participants often resort to rationalisation as a means of coping and searching for cognitive understanding and meaning. This is representative of Maslow's (1970) cognitive needs and a search for meaning and knowledge. Rationalisation may also be what Norwood (as cited in Huitt, 2004) refers to as seeking edifying information, which is what is desired by people in the growth levels of cognitive, aesthetic, and self-actualization (see Table 3, code 6:159[241:246]). In this way, P7 rationalises by telling herself that she is in this situation only because she is strong enough to endure. She also turns to her faith as a means of coping, and often draws her strength

from daily prayer which allows her to gather fresh hope and enables her to continue (see Table 14, 10:24[234:235]).

Throughout the study it became evident that at some point during the process of adaptation, most of the participants attempt to cope actively by keeping themselves engaged and distracted by talking with friends and family. They search for a distraction and keep themselves occupied by watching television, listening to the radio or music, reading, as well as taking part in or watching sport. It also became evident that most of the time, the majority of the participants employ emotion-focussed coping as opposed to problem-focussed coping. Each individual employs the type of coping mechanisms that is most effective for them. Satisfaction arises when participants realise that they are able to solve difficult problems (Cagnetta & Cicognani, 1999). Thus, employing effective coping mechanisms that allow them to overcome the limitations imposed on them by the disability is seen as an essential part of a good quality of life.

6.3.8. Independence

All the participants referred to their desire to be able to live alone or with minimal help as well as to be able to manage their daily tasks by themselves. These daily tasks encompass eating, drinking, cooking, bathing, washing clothes, cleaning, and being able to turn around in bed, getting in and out of a wheelchair, being able to clean up after defecation, self catheterising, and the ability to clean their colostomies. Furthermore, being able to cook for themselves, washing clothes, bathing as well as

cleaning the house are amongst the important, basic tasks that were identified as essential contributing factors to feeling independent. The above mentioned desire translate to the need for independence, therefore, this theme was named accordingly. Thus, the theme of independence mainly refers to the need for self-sufficiency, in terms of performing day to day tasks independently.

A need for independence corresponds to the esteem needs, which Maslow (1943) refers to as the desire for responsibility, identity and reputation. Thus, the participants desire to feel accomplished, self sufficient and able. This desire is expressed by several participants. For example, P6 says: “You know, because I don’t want the most important is for me..... I don’t want to be dependent on another person, I want as much as possible to be as independent as possible” (see Table 15, code 6:70[701:703]).

Other than reporting that paraplegia and quadriplegia make it much more difficult to do things independently, participants also conveyed that, relying on other people for most of your needs robs them of their independence. P4, who is quadriplegic, expressed dismay due to his lack of ability to perform basic tasks such as eating, drinking, and pushing his wheelchair by himself. He has lost all sense of independence as he now relies on others to assist him with every detail in his life (see Table 15, code 4:8[89:91]). Furthermore, P4 is unable to continue the business he started before he became paralysed (see Table 15, code 4:90[689:691]). It is evident that P4 feels restricted in multiple areas of his life, including personal hygiene, eating, drinking, business or work and all other activities involving

movement. Bishop (2005) refers to quality of life as being determined by the individual's evaluation of satisfaction across a set of important areas in life. Thus, reduced satisfaction and happiness that P4 experiences in these areas contributes to a perceived lower quality of life.

Based on the participants' accounts (see Table 15), it may be deduced that independence has multiple dimensions including, functionality, privacy and the ability to live unaided. Currently, none of the participants are employed and are able to afford living by themselves, financially or otherwise. Even so, every one of them, excluding P7, who is married, desires to be able to live alone. However, all of them are under the impression that they might never be able to live independently. Apart from not being able to live independently, there is an apparent lack of privacy which affects all participants. P1 expressed extreme frustration and hopelessness as she referred to her lack of privacy and her constant need for assistance (see Table 15, code 1:50[328:330]).

All the participants' needs for independence reflected their desire to be able to live as autonomously as possible. However, based on the analysis it is evident that the level of independence is much less for the quadriplegic participants than it is for the paraplegic participants. This is due to the loss of motor or sensory function in all four limbs as opposed to paraplegia, which results in the loss of function only in the lower limbs (Elliott & Rivera, 2002). Most paraplegic individuals are thus able to perform tasks involving the upper body and arms, which grants them a higher degree of functionality and subsequently, more independence, compared to the quadriplegic

individuals. Thus, physical functionality involving the upper body is more important for the quadriplegic participants than it is for the paraplegic participants.

Quadriplegic participants, P1, P3 and P4 as well as P7, even though she is paraplegic, all have more difficulties with independence than do the rest of the participants.

Evidently, in this study, P4 who has the least functionality repeatedly expressed his lack of independence, and he puts greatest emphasis on his need for an electronic wheelchair to improve his independence (see Table 13). This is in support of previously stated research by Trieschmann (1980), which implies that quadriplegia results in more limitations and added stress, compared to paraplegia. Furthermore, the aspects that are more important to P1, P3 and P4, who are quadriplegic involve aspects such as the ability to transfer to and from the wheelchair by themselves, being able to grasp a cup in the hand, brush their own teeth, dress themselves, as well as the ability to control their own bladder and defecation. P4 also states that being able to have a tool such as a colostomy will improve his independence (see Table 15, code 4:36[250:251]). P1 who has regained the ability to walk and has regained limited functionality in her hands, expressed relief at the level of independence she has achieved since regaining some functionality in her body (see Table 15, code 1:17[125:127]). These participants expressed that it is very important to their quality of life to physically be as independent as possible within their limitations.

Manns and Chad (2001) found that individuals who are paraplegic or quadriplegic strongly suggest that an important aspect of physical function and independence is energy expenditure for everyday activities. According to several participants, it takes them much more energy to accomplish tasks than it does able-bodied individuals. P2 referred to such energy expenditure as something that affects his quality of life. However, he as well as other participants, clearly attempt to discover alternative ways to do things by themselves (see Table 15, code 2:38[183:185]).

Participants often compare their independence, abilities and quality of life to the way it was before the onset of their disabilities (see Table 15, code 5:20[162:163]). P7 refers to her ability to take care of her children and husband before her disability and how she is unable to do so lately (see Table 15, code 10:20[182:190]). Independence is influenced by the level of functionality and quadriplegic individuals experience more problems related to a lack of independence than paraplegic individuals. All of the participants agree that having a sense of independence is essential to enhance the way they perceive their quality of life. A lack of independence has a negative effect on the way individuals experience their quality of life. Other than not being able to walk paraplegia or quadriplegia has far reaching implications for the individual's physical health. Therefore, the following essential theme is physical wellbeing.

6.3.9. Physical wellbeing

As mentioned earlier (see chapter two) spinal cord injury has a variety of related health complications. These include problems with arm and hand strength, dexterity,

bowel and bladder control, sexual function, infections, spasticity, pressure sores, and pain (Crewe & Krause, 2002). Experiencing poor health on a regular basis, wears an individual down and according to their reports, such poor health is experienced by the majority of the participants. Therefore, this theme under discussion was named physical wellbeing. It refers to the physical health and illnesses which paraplegic and quadriplegic individual's experience. Researchers also believe that costly, multiple medical problems and poor self care due to spinal cord injury has an adverse impact on the way the individual experiences and enjoys life, thus it may lead to decreased quality of life (Bishop, 2005; Crewe & Krause, 2002; Whiteneck, 1994).

Examples of physical health problems that affect the participants' physical wellbeing regularly include urinary tract infections, dizziness, chronic pain, pressure sores, and frequent muscle spasms. Many participants suffer from physical ailments as a consequence of their disability. P6 suffers from low blood pressure and dizziness and P7 started experiencing epileptic seizures as well as high blood pressure soon after becoming paraplegic. This finding is consistent with the view of Dijkers (1996) who suggested that, at their healthiest people with disability are still more prone to sickness than able-bodied people. Paraplegic individuals and quadriplegic individuals frequently struggle with various acute illnesses as well as activity restrictions. These factors combined, have a compounding effect that causes major stress and lower perceived quality of life.

Pain is a major complaint of individuals with spinal cord injury, it affects occupational status, leisure, recreational activities, quality of sleep, as well as

sexuality, and it plays an important role in long-term satisfaction with life (Budh & Österaker, 2006). Pain is also expressed as a problem for all the participants in this study. Some of the major sources of complaints regarding pain by these participants include headaches, backache, and pain caused by urinary tract infections. For several individuals, pain, especially when they need to defecate or urinate, is a major problem that continuously threatens their wellbeing and negatively affects their comfort levels. Such pain is particularly emphasised by P3 and P4 (see Table 16, code 3:59[393:399]). As mentioned earlier pain is also related to anxiety and depression, which is experienced by several of the individuals in this study (see section 6.3.1.2). Such spinal cord injury-related pain may be assumed to have a negative impact on perceived quality of life (Budh & Österaker, 2006).

These participants' affirmation of the importance of physical wellbeing confirms that health and wellbeing are vital components in the determination of quality of life. The need for physical wellbeing and the attempt to remain healthy is similar to the physiological and biological needs. These needs are the most basic needs for air, food, drink, shelter, warmth, sex and sleep that people express based on the hierarchy of Maslow's human motivation theory. Compromised physical health impedes on the individual's ability to enjoy basic things such as food and sleep. For instance, P7 reported loss of appetite and the majority of the participants refer to difficulty sleeping, especially due to sweating and stomach pain (see Table 16, code 3:59[393:399]). Often, the stomach pain is mainly due to urinary tract infections (see Table 16, code 10:38[423:431]), and the need to go to the toilet or muscle spasms.

Many of the participants, such as P4 and P7 are unable to turn themselves every two hours as required, and that also adds to the discomfort and inability to sleep.

The measures the participants engage in to promote and ensure their own health, as well as things that might hamper or negatively affect their health and wellbeing, are also included under physical wellbeing. According to P2, such measures include preventative behaviour such as regular exercise, drinking lots of water and keeping his feet warm to prevent urinary tract infections. He realises that, for optimum health, it is essential to prevent becoming ill as much as possible (see Table 16, code 2:90 [480:482]). Each individual attempts to maintain their health and enhance it in their own unique way. P5 believes that his main physical ailment is caused by his pressure sores (see Table 16, code 5:16[118:118]). He believes that pressure sores are caused by his hip bones during exercise. Thus, he decided to avoid exercise as a preventative measure against the sores.

Spinal cord injury often causes physical health complications and individuals with paraplegia or quadriplegia are more prone to becoming ill than able-bodied individuals (Crewe & Krause, 2002). Hence, disabled people need to be extra careful what they expose themselves to. For example, P4 fears inhaling too much smoke from the home-cooking fires as he fears suffering from breathing difficulties, which occur often (see Table 16, code 6:8[155:157]). Several other participants, including P1, P3, P6 and P7 also reported breathing difficulties as well as feeling tired and being out of breath. Often, it is a prerequisite to take medication to keep ailments under control. Such medication is prescribed for P6 who drinks Akrinor daily for

dizziness. She frequently experiences dizziness as well as shortness of breath (see Table 16, code 6:8[155:157]). On the other hand, P7 suffers from high blood pressure and she is also on medication for epilepsy that she started suffering from soon after becoming paraplegic. All the participants also refer to medication to control muscle spasms. Muscle spasms have been found to be one of the physical health problems related to paralysis which is perpetual or chronic. Over the course of years, individuals simply learn to manage this problem (DeSanto-Madeya, 2006).

Participants refer to various physical ailments such as bladder infections and chronic pain, which may be extremely stress provoking, causing emotional problems such as anxiety and depression. As a result it may affect their psychological wellbeing, and consequently negatively affect their quality of life. Paraplegia and quadriplegia are often associated with lowered physical wellbeing, coupled with physical health complications. These medical conditions affect an individuals' ability to live a productive life adversely, lowering their perceived quality of life.

6.3.10. Work and money

Throughout the research process, it became apparent that the participants of this study attach great value to work. The MVA Fund reported that economically active young people (21 years to mid thirties, followed by 31 to 40 years) are at greatest risk of injury or death in a motor vehicle accident. It is also evident that young males are at higher risk for road traffic fatalities as well as injuries (Accident & Injury Prevention Sub Unit, 2009). In line with this report, all of the participants were

economically active young people; five out of the seven were 30 years or younger and four are male. The participants' economic situation also gives insight into their perception of work. They view work as an essential as a source of income, a determinant of confidence and identity, and as an important contributing factor to creating meaning to life. All of the research participants have been unemployed since the onset of their disabilities, they have lost any means of income and their sense of identity has also been affected. P6 expressed her strong belief that a individual is respected and identified by the quality of the work they do, thus losing her job was a very difficult experience for her (see Table 17, code 6:12[264:267]).

In a previous study, Manns and Chad (2001) reported that people desire to work mainly because working has a "positive effect on self-worth and self-esteem". However, in this study, the researcher established that for most of the participants, work mainly fulfils a need to ensure survival. Losing the ability to work and earn money thus, has a major impact on the participants' quality of life. Many participants identify the need for money to ensure basic survival as the most important factor that is needed for quality of life. This need for work and money in order to support themselves and the families refers to the basic physiological and biological needs such as food and shelter on Maslow's hierarchy of needs. However, when work is the source of meaning and purpose, it may satisfy the need for personal growth and fulfilment, thus it may fulfil a self-actualisation need, which Maslow stated as being, the individual's desire to do that which they believe they were born to do (Meyer et al., 2003).

Thus, the need to work and earn money may be motivated by physiological and biological needs as well as self-actualisation needs. This is in line with Maslow's (1943) theoretical viewpoint that, every act has more than one motivation and is able to satisfy more than one need. By rationalising work and all its connotations, the participants are attempting to fulfil more than one need at the same time as Rowan (1999) points out that satisfaction of needs is not always a linear process. Individuals such as P3 may attempt to satisfy safety and security needs, which are being threatened by their disability while simultaneously attempting to become self-actualised. P3 infers that work is a source of self-actualisation and it adds to an individuals' self worth (see Table 15, code 3:5[44:44]). P2 also derives great meaning and satisfaction out of the ability to do meaningful work with his life as well as the ability to help people (see Table 17, code 2:5[44:47]).

The participants also link the loss of their jobs to a loss of their financial independence. In addition to not being able to buy things for themselves, the loss of income has a major impact on the participants' ability to contribute financially to their daily lives. This may include paying for the daily expenses and some financial obligations in helping out family members.

The lack of money, which is needed for sustenance, is a major contributing factor to a perceived lower quality of life. P1 clearly stated how important money is in an individual's life (see Table 17, code 1:109[37:46]). P7 expressed being overwhelmed by her daily expenses, as she is no longer able to make a financial contribution to the household expenses (see Table 17, code 10:80[1231:1235]). P3 also regards the

ability to work and earn money as an essential factor. In the past, working enabled him, as the son in the house, to provide for himself and support his family. However, the disability hampers him from working and fulfilling his duty (see Table 17, code 3:111[176:186]). The rest of the participants also strongly expressed a sense of duty towards supporting their families and that, to a certain extent, this duty has been negatively influenced by losing the ability to work.

Analysis indicates that, only P6, who is from a more affluent family, desires to work for the purpose of loving her job. She refers to wanting to work with people and do counselling because she understands people in wheelchairs better than non-disabled people. She also links working in order to be independent with living alone and affording her own household property (see Table 17, code 6:182[984:993]). She does not refer to any financial obligation towards family members.

Moreover, none of the participants have tertiary education. Several of them are from rural areas and may have left school without completing grade 12. They do not have the required qualifications to apply to mainstream tertiary education facilities. It is possible that, for cultural or financial reasons, people in rural areas place less emphasis on education and often leave school before completing. Thus, these particular participants have no qualifications and only possess manual labour skills they have learned in their respective jobs, prior to becoming disabled. Almost all of them were involved in manual work, such as bricklaying, painting, and sowing that require physical abilities and strength. P6 is the only individual who did supervisory work. However, her job also required her to be mobile, and even though returning to

work may be more comfortable for than for the others, it may still require major adjustments to work while she is in a wheelchair.

Due to the above mentioned and because most participants are from low-income backgrounds, who, according to LARRI (2008), earn a monthly salary of N\$ 1676 and less, the loss of employment and income has devastating effects on these particular participants. Only P6 is currently exploring the option of a tertiary education. She is also the only participant who has sufficient qualifications to be accepted into a tertiary institution and has the financial capability to do so.

The theme work and money encompasses the need for paid employment, which allows one to provide for oneself as well as others. It gives one a sense of meaning and purpose in life. Although work and money is a very important theme, it is critical to point out that all of the participants have not been employed since they have been involved in their motor vehicle accidents. All of the participants are of the opinion that they are unable to work because of their disability and for them, being unemployed translates into a lowered quality of life. Apart from providing financially, work encompasses the ability to feel needed, useful, and fulfilled. Thus, for this sample of participants, the need for work and money is consistent with the basic physiological and biological needs such needs as needing food, water and shelter. It also encompasses the need for safety and security. However, working also has secondary benefits of feeling meaningful, which adds to self-worth, thus it also refers to the need for self-actualisation.

Based on the above mentioned, it is apparent that theme of work and money was identified by every one of the participants, thus it is one of the most essential themes which influences quality of life.

6.4. Conclusion

Findings indicate that, of the 14 themes of quality of life, many of the themes under intrinsic themes (such as emotional wellbeing), extrinsic themes (such as mobility and accessibility as well as stigma and discrimination), and relationships, independence and physical wellbeing correspondent with themes that have been previously identified by researchers such as Boswell et al. (1998), Manns and Chad (2001), as well as Youngkhill and McCormick (2006). This similarity might be ascribed to the notion that many of the human needs are similar, globally. For instance, the need for acceptance, relating to others, and the desire to receive love as well as support was identified by Maslow (1943) as a need for belongingness and love. This is a universal need that all humans strive to fulfil.

However, aspirations as well as effort and comfort are themes, which have not been highlighted in previous research and literature that was reviewed for the present study. The theme, effort and comfort is unique to this sample and might be ascribed to the socio-economic situation of the participants as well as their living environment. Several participants come from low-income backgrounds, for instance P4 and P5 live in hospitals and their homes are huts in the village, while P3 lives in an informal settlement, in a house built out of corrugated iron sheets. Such living

circumstances are generally difficult and these difficulties are compounded by the sudden onset of disability.

Furthermore, the theme work and money, although similar themes have been identified in previous literature, is also unique to this sample. The motivation behind work for the participants in this study is different from the motivation that participants in other studies provided. The majority of these participants are motivated to work mainly for sustenance and survival compared to participants in developed countries whose main motivation to work may include deriving a sense of meaning from work. In addition, all of the participants are currently without formal employment. For these participants, money and employment is difficult to come by. The background of poverty and unemployment largely influences the manner in which the participants' view employment and finances as well as their aspirations.

6.5. Chapter summary

In chapter six, the definition of the concept, quality of life was discussed. This definition was followed by a discussion of the themes of quality of life, as they were identified by the participants. The 14 themes of quality of life were discussed according to the order in which they were grouped. Out of the 14 themes, ten were grouped into, three intrinsic themes, four extrinsic themes, and three support themes. Grouped under intrinsic themes are aspirations, emotional wellbeing, and identity. Themes grouped under extrinsic themes include recreation, spontaneity, effort and comfort, stigma and discrimination as well as mobility and accessibility. Lastly,

under support we have the following themes, relationships and resources. The remaining four ungrouped themes include coping, independence, physical health, and work and money. These themes were emphasise to a great extend by each of the participants. Therefore these are identified as the most prominent themes that influence quality of life for the individuals. Thus, they are possibly, the most prominent themes for these individuals. These four themes were discussed individually. In addition to these four themes, the theme of emotional wellbeing was also prominent among the participants.

In the following chapter, the findings will be summarised and recommendations will be made based on these findings.

CHAPTER SEVEN

SUMMARY OF FINDINGS, RECOMMENDATIONS AND CRITICAL REVIEW

The main findings of the present study are summarised in this chapter, followed by the shortcomings, limitations, and recommendations for future studies and rehabilitation professionals. Critical review, challenges and benefits of the study are also provided.

7.1. Main findings

Semi-structured interviews were conducted with seven participants. The interviews were transcribed and analysed for emerging themes with the aid of ATLAS.ti (Muhr & Friese, 2004). The main findings are presented firstly, by defining the concept quality of life. Secondly, the 14 themes representing quality of life for the participants are summarised. Lastly, the main findings are discussed with regards to the Namibian context.

7.1.1. Findings with regard to the definition of quality of life

The definition of quality of life is presented in this study, as it was defined by the participants. Thus, direct input from the paraplegic and quadriplegic individuals was used to determine the definition. The findings regarding the definition and

determination of quality of life from this study reinforce the findings from numerous other researchers. It indicates that quality of life is a subjective construct that should be represented by subjective measures or by a combination of subjective and objective measures (Boswell et al., 1998; Budh & Österaker, 2006; Gill & Feinstein, 1994; Hammell, 2004; Lanig et al., 1996; Manns & Chad, 2001; Raeburn & Rootman, 1996; Renwick & Friefeld, 1996; Youngkhill & McCormick, 2006). The participants of the present study summarised quality of life as a developmental, subjective evaluation of an individual's life, which is determined by an individual's health, psychological wellbeing, living environment, relationships, as well as their future outlook.

7.1.2. Findings with regard to the quality of life themes

The process of interpretive data analysis yielded 14 themes of quality of life. Names for several themes were inherited from previous research findings, while others were named according to unique aspects identified in this present study. These unique themes include aspirations, recreation, effort and comfort, and coping. The themes are grouped as, intrinsic themes (aspirations, emotional wellbeing, and identity), extrinsic themes (recreation, spontaneity, effort and comfort, stigma and discrimination, as well as mobility and accessibility), support themes (relationships and resources), coping, independence, physical wellbeing, and work and money. The latter were discussed as individual themes.

Several themes were emphasised by some participants more than others, and not all

14 themes were present in every one of the participants' accounts. The following themes were present in all the participants' accounts; coping, independence, physical wellbeing, and work and money. As a result, it is possible that they might be the most important themes affecting quality of life for these participants. The theme of emotional wellbeing was also identified as being very important and affecting every one of the participants. This may be linked to research findings by Cagnetta and Cicognani (1999). They reported that spinal cord injury results in an uproar of emotions, which the individual is forced to deal with. In this manner, the participants in the present study were faced with a surge of emotions, which were voiced in the semi-structured interviews. Emotional wellbeing particularly, includes a perceived lack of control following a spinal cord injury. Although the above mentioned themes might be the most prominent, none of the themes may be seen in complete isolation. There is significant evidence of interrelatedness between all the themes. For example, the intrinsic themes such as emotional wellbeing may be affected by the support themes. The theme of independence may be affected by resources, and independence, in turn may affect emotional wellbeing.

An aspect, which was unique to this sample, is that, the theme of identity was most prominently present in the transcripts of the female participants compared to the male participants. This could be ascribed to the importance women place on appearance, compared to men (Schiffman & Kanuk, 1997). Although the theme of work and money has been identified in previous research, this theme is very unique to the Namibian population. Participants in the present study view work as essential for the purposes of sustenance, supporting family members and providing for basic

needs such as food and housing. Contrary to, wanting to do volunteer work, needing work for personal fulfilment, and using work as something to look forward to, as was suggested in a previous study by Manns and Chad (2001).

All the participants identified the need for resources; however they placed more emphasis on basic resources such as cooking facilities, food, water as well as electricity, as opposed to medication and other medical supplies. The above mentioned may be as a result of the MVA Fund providing for all their medical supplies. One of the most significant resources that were mentioned as essential is the need for caregivers to assist the individuals. Caregivers are required by most of the participants, even though the assistance they require differs. With regards to relationships and sexual function, all of the male participants believe that their disability has reduced their chances of marriage and having a family. Overall, the themes of physical wellbeing as well as mobility and accessibility are mentioned by and affect the participants with quadriplegia to a greater extent than the paraplegic participants.

7.1.3. Findings with regard to the Namibian context

In the Namibian context, there are a number of variables to consider which makes research such as this, unique.

The participants of the present study mainly consist of individuals from low-income groups, which may constitute people earning a minimum wage of N\$ 1676 and

below (LARRI, 2008), who do not have access to medical aid and cannot afford private health care. They make use of the public health facilities. Namibia has a free healthcare system; however, when compared to the healthcare systems in developed countries, it is not as advanced. The World Health Organisation (WHO) rated the world's health systems in 2000, and Namibia was ranked far below developed countries such as Canada and America (WHO, 2000). Due to the difficulties related to public healthcare, generally individuals from low-income groups, may exhibit a preconditioned negative mindset towards health and illness. As a result, any form of illness may be perceived as crippling and lowers quality of life, more extensively than individuals who have access to better health care. These concerns are compounded by severe illnesses and disabilities. The above mentioned background of these participants influences their perception of quality of life and makes it unique to this sample.

The availability and quality of health care, rehabilitation facilities, and resources in the rehabilitation facilities available in Namibia, affect the degree of improvement, adjustment, as well as the quality of life of the participants. One participant in this study spent a few months in a better equipped rehabilitation facility in South Africa. Following a comparison of her experiences in the two facilities, she concluded that, her experience in South Africa was valuable and positively changed her perception. Hence, people's subjective experiences and the treatment that Namibian paraplegic and quadriplegic population receives may be unique to the Namibian context. Therefore, it may have a unique impact on the quality of life of these participants.

As mentioned earlier, the majority of the participants are from low-income backgrounds, already ridden by financial burdens and focussed on basic sustenance. Spinal cord injury increases the concerns related to day to day survival. Even though the quality of life themes of these participants may be similar to the themes which determine quality of life of participants from developed countries, the emphasis participants put on the themes varies. The participants of this study put main emphasis on basic needs for sustenance and safety, even their outlook in life is influenced by their basic needs. Whereas participants in developed countries whose basic needs are satisfied on a regular basis put less emphasis on basic needs.

7.2. Shortcomings, limitations and recommendations for research

Several shortcomings and limitation of the present study should be acknowledged. Recommendations are made based on these shortcomings and limitations, as well as in more general terms.

This study's main limitations revolve around the researcher's bias, a lack of reproducibility, and a lack of generalisability. According to the researcher's knowledge, no study of this nature has previously been conducted in Namibia, and this particular study, is being carried out with a limited number of research participants. Therefore, other researchers are cautioned not to merely extrapolate findings to other populations suffering from motor vehicle accident injuries. An attempt to extrapolate findings may not be valid as it is not open for cross controlling.

Only people who were involved in motor vehicle accidents participated in the study, thus the findings may not be generalised to individuals who were injured in another way or who have other disabilities. In addition, only seven participants were used out of a possible 30 candidates who were on the MVA fund database, thus the sample may not be representative of the entire Namibian population. Namibia is a country with a diverse population. It has a minimum of nine ethnic groups and at least 13 language groups, as identified by The World Factbook (CIA, 2009). Due to such diversity, this small study was unable to be representative of all ethnic and language groups. The lack of representation can also be due to the cultures and backgrounds, which are specific to those in the sample, and whether their stated opinions were truly representative of their perceptions. It should be kept in mind though, that the process of building rapport with the participants prior to the interviews ensured trust. Thus, it validates the findings, making them a truthful representation of the participants' perceptions and feelings.

It was not the purpose of this study to provide reproducibility, or generalisability, or for other researchers to extrapolate the findings. Nor was it to prove or disprove assumptions, solve a practical problem or to explain a specific phenomenon. The purpose was merely to explore the participants' subjective views related to their quality of life. This proved to be an important study, as paraplegic and quadriplegic individuals belong to a disadvantaged, minority group that is often overlooked and discriminated against (Dijkers, 1996). The proposed study may help raise awareness of this group and their needs and experiences among the Namibian society.

The subjective nature and biasness of the research may be linked to the fact that only semi-structured interviews were used to collect data. On the other hand, it is essential to note that this type of data collection is recommended for in-depth qualitative studies. Therefore, it should be kept in mind that this study was conducted to obtain the participants subjective views and research indicates that subjective views are essential in the assessment of quality of life. Guidelines by several researchers were followed in order to ensure that the research findings are valid (see chapter 4, section 4.1.2). In addition, the researcher was aware of the social context of the participants and the research findings are presented in a congruent and comprehensiveness manner.

Although this study is not representative of the entire Namibian population, the study, however points to important issues that need to be addressed in future research. It is envisioned that follow-up studies will be needed to expand the body of research findings.

It is recommended that future research consider using a mixed method of both subjective and objective measurements to assess quality of life as to improve generalisability, reproducibility as well as to avoid the researcher's bias. Research with a larger number of candidates is also advocated for, and future studies may use the results from this study as a baseline to establish quality of life themes for research.

An additional limitation was the researcher's language. The researcher is fluent in English, Afrikaans and Damara-Nama. Therefore the research was limited to candidates who speak either one of these three languages. The two candidates who were interviewed in English may have been disadvantaged as they may not have been able to express themselves as honestly and earnestly as they would have been able to in their home language, which is Oshiwambo. Future studies may benefit from several researchers who are able to interview the individuals, each in their preferred language.

7.3. Recommendations to medical and rehabilitation professionals

To be more effective, treatment and rehabilitation programs for paraplegic and quadriplegic individuals should focus on enhancing specific areas of quality of life, which the individuals themselves identify, in addition to focusing on physical health and functionality. Programs which utilise a combination of subjective as well as objective assessments of quality of life may have a clearer understanding of individuals' quality of lives and may thus improve their quality of lives successfully (Gill & Feinstein, 1994; Hall et al., 1997). Thus, it may lead to reduced costs and length of stay in hospitals or rehabilitation facilities, it may also lead to less frequent rehospitalisation (Chase et al., 2000).

Rehabilitation programs should focus on empowering individuals with paraplegia and quadriplegia by allowing them to exercise greater choice in self directing their rehabilitation, and care giving at the hospital as well as at home. As far as possible,

rehabilitation should attempt to remove barriers or give the individuals tools to deal and cope with barriers such as stigma. Stigma which is limiting may even exist from friends and family as is the case with some of the participants in the present study. Such barriers obstruct the individuals' opportunities to participate in the community. The individual may benefit from services such as psychological therapy as part of rehabilitation program. Empowerment may include, not only encouraging and helping the client adapt, but also raising awareness and teaching family and friends. It may involve teaching people the basic facts related to spinal cord injury, as well as how to show support and be more sensitive to the needs of people with disabilities.

The need to feel in control, accompanied by feelings of a lack of control are major components of the theme of emotional wellbeing, which contributes to quality of life for the participants in this study. Given these findings; policy makers and health care providers may need to rethink their philosophy on service delivery. They may need to allow the paraplegic or quadriplegic individuals to assume more control over their rehabilitation programs and process of adaptation. This recommendation is in line with what was recommended by English (as cited in Chase et al., 2000), more than a decade ago. According to them, the health care system requires a transformation, away from the traditional health care system, which regards the expert's opinion above that of the patient. Changes have since been taking place, however, the assessment of quality of life (see chapter two) is still not routinely incorporated in the evaluation of a patient's progress or overall health.

Furthermore, the theme of mobility and accessibility stressed the participants' need to be able to utilise public facilities such as restrooms and parking areas, as well as to have better access to public buildings. For that reason, policy makers may reconsider policies related to enforcing regulations for making public places more accessible and friendly to wheelchair users as well as other disabled people. Additional aspects, which government legislatures should be encouraged to pay attention to are, enforcing stricter penalties for disobeying signs related to parking for people with disabilities and building ramps for easier access to pavements.

7.4. Critical review of the study

The research was guided by the following objectives:

- Determining the definition of quality of life from the perspective of paraplegic and quadriplegic individuals.
- Identifying the self-perceived themes that determine quality of life.
- Examining the level of satisfaction or lack of satisfaction with the identified themes.
- To use the results from the study to make recommendations for improving the rehabilitation program provided to the MVA Fund clients.

7.5. Challenging aspects of the study

The researcher has an awareness of the participants' current ailments and complications associated with spinal cord injuries, therefore, appointments were scheduled, taking this into consideration. For instance one participant was unable to sit for long periods; consequently, researcher rescheduled the appointment and conducted the interview over two consecutive days.

The researcher also found it challenging to investigate this particular topic, as the participants had very little knowledge about the concept of quality of life. In addition to spending time building rapport with the participants, the researcher needed to use analogies and examples to ensure that the participants have a clear idea of the type of investigation, before proceeding with the interviews. This resulted in several interviews lasting longer than expected, particularly the interviews with the participants who were interviewed in English.

7.6. Benefits

One of the major benefits of this study is that it provided an opportunity for individuals with spinal cord injuries to participate in the process of establishing a database of information pertaining to their quality of life. The findings from this study clarify issues related to individuals with spinal cord injuries. These findings may be helpful to families of such individuals as well as health care professionals, rehabilitation professionals, law makers, researchers and educators.

Understanding the themes, which are essential in determining and contributing to quality of life, is the first step in making a change to improve the quality of life of people with paraplegia and quadriplegia. The information entails the essential components to be incorporated in their rehabilitation process. This experience may make the individuals feel empowered and may assist in the appropriate selection of a quality of life measurement tool and help establish the validity of that chosen measure.

Through increasing our understanding of the important themes of the quality of life of an individual with paraplegia or quadriplegia, the results of this investigation may provide a basis for the development and implementation of rehabilitation programs that are aimed at enhancing quality of life.

Researchers emphasise the need to use subjective means to measure quality of life (Boswell et al., 1998; Manns & Chad, 2001). The present study obtained subjective views of the quality of life of Namibians, including people with foreign nationality, but who live in Namibia. It provides a wealth of information about people with paraplegia and quadriplegia in the Namibian context.

This study may be used as a baseline for future studies into quality of life in clinical settings in Namibia, without needing to resort to applying foreign research findings to the Namibian context.

These findings may be useful for supplementing in the adaptation of rehabilitation programs in Namibia to improve people's quality of life.

One of the greatest strengths of this study is that, as Smith and Osborn (2006) point out regarding such exploratory studies, it is a rich and detailed exploration of how individuals make sense of their personal and social world. As mentioned in Chapter two and four, to the researcher's knowledge, no previous research assessing quality of life of individuals with paraplegia or quadriplegia has been conducted in the Namibian context. Consequently, the findings of this study may shed more light on the tremendous impact a traumatic experience, such as a motor vehicle accident and subsequent spinal cord injury, may have on individuals' quality of life.

In conclusion, the WHO best described the essential contributing factors to quality of life as an individual's physical health, psychological state, personal beliefs, social relationships and their relationship to significant features of their environment (Barbotte et al., 2001). Furthermore, quality of life is related to an individual's assessment of their satisfaction with their life in different domains, and quality of life should be viewed from the subjective perspective of the individuals being assessed (Bishop, 2005; Hampton, 2004; Manns & Chad, 2001). In line with the above, the present study attempted to obtain subjective perceptions of paraplegic and quadriplegic individuals, to determine themes which they perceive as essential in contributing to and ultimately determining their quality of life.

According to the National Planning Commission Secretariat (NPC), in June, 2004, Namibia launched Vision 2030. This was after long, careful deliberation and consideration since the former president, Dr. Sam Nujoma, had called on the Namibian cabinet, in January 1998. He had asked them to deliberate on what he saw as a vision for Namibia. Vision 2030 is expected to transform Namibia into a healthy nation, where people enjoy high standards of living, have access to quality education, health facilities, and other vital services, and enjoy a good quality of life. The researcher is under the impression that, by studying the quality of life of our Namibian people, studies such as the present one, which are deliberately geared at improving the future quality of life of the Namibian paraplegic and quadriplegic community, may help Namibia achieve vision 2030. Thus, this study is in line with what Dr. Nujoma saw as, “. . . a vision that will guide us to make deliberate efforts to improve the quality of life of our people to the level of their counterparts in the developed world, by the year 2030” (NPC, 2008).

Furthermore, the researcher believes that, to begin at the end is normally the popular, common way of doing things, but to start from the beginning is a proven formula for success, especially with this particular study. It begins with the participants, who, having gone through a traumatic accident, have come out on the other side seeking answers to rebuild their lives. Starting with them, understanding their perspectives on the issue of quality of life is the key to finding solutions, answers that work for them, and help them rebuild or redefine their lives.

In this light, an individual may not impose their understanding on others, or attempt to understand others, based on their own perception. It begins with the others view and it must end with it. Once we can do that successfully, we may begin to help others improve their quality of life. On that note, let us not forget, “. . . most important, we have to shift our understanding of ourselves as separate individuals, each seeking our own welfare, to an understanding of how we fit into social, biological, and physical environments” (Ornstein, as cited in Khalid, 2010).

References

- Accident & Injury Prevention Sub Unit. (2009). *Motor Vehicle Accident Fund (MVA Fund) road traffic collisions statistical report: Mid-year analysis: Draft report* (No.1). Windhoek: MVA Fund. Retrieved October 11, 2009, from <http://www.mvafund.com.na>.
- Albrecht, G. L., & Devlieger, P. J. (1999). The disability paradox: High quality of life against all odds. *Social Science & Medicine*, *48*(8), 977-988.
doi:10.1016/S0277-9536s(98)00411-0.
- Allison, P. J., Locker, D., & Feine, J. S. (1997). Quality of life: A dynamic construct. *Social Science & Medicine*, *45*, 221–230. doi: 10.1016/S0277-9536(96)00339-5.
- American Psychological Association (APA). (2002). *Ethical principles of psychologists and code of conduct*. Washington, DC: Author.
- American Psychiatric Association (APA). (2005). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.
- Amiot, C. E., Vallerand, R. J., & Blanchard, C. M. (2006). Passion and psychological adjustment: A test of the person-environment fit hypothesis. *Personality and Social Psychology Bulletin*, *32*, 220-229. doi: 10.1177/0146167205280250.
- Bach, C. A., & McDaniel, R. W., (1993). Quality of life in quadriplegic adults: A focus group study. *Rehabilitation Nursing*, *18*, 364-367.

- Barbotte, E., Guillemin, F., Chau, N., & Lorhandicap Group. (2001). Prevalence of impairments, disabilities, handicaps and quality of life in the general population: A review of recent literature [Electronic version]. *Bulletin of the World Health Organization*, 79(11), 1047–1055.
- Bauman, W. A., & Spungen, A. (1994). Disorders of carbohydrate and lipid metabolism in veterans with paraplegia or quadriplegia: A model of premature aging [Electronic version]. *Metabolism*, 43, 749-756.
- Bishop, M. (2005). Quality of life and psychosocial adaptation to chronic illness and disability: Preliminary analysis of a conceptual and theoretical synthesis [Electronic version]. *Rehabilitation Counselling Bulletin*, 48(4), 219-231. doi: 10.1177/00343552050480040301.
- Blanchard, E. B., & Hickling, E. J. (Eds). (1997). *After the crash: Assessment and treatment of motor vehicle accident survivors*. Washington, D.C.: American Psychological Association.
- Boswell, B. B., Dawson, M., & Heininger, E. (1998). Quality of life as defined by adults with spinal cord injuries [Electronic version]. *Journal of Rehabilitation*, 46, 27-32. Retrieved October 20, 2008, from <http://hpq.sagepub.com>.
- Brown, J., Bowling, A., & Flynn, T. (2004). *Models of quality of life: A taxonomy, overview and systematic review of the literature*. London: European Forum on Population Ageing Research.
- Budh, C. N., & Österaker, A. (2006). Life satisfaction in individuals with a spinal cord injury and pain [Electronic version]. *Rehabilitation Counseling Bulletin*, 21(1), 89-96. doi: 0.1177/10269215506070313.

- Buss, A. (1986). *Humanistic Psychology as Liberal Ideology: The Socio-Historical Roots of Maslow's Theory of Self-Actualization*. Dallas: Saybrook. (Original work published 1979).
- Butler, D. J., Moffic, H. S., & Turkal, N. W. (1999). Post-traumatic stress reactions following motor vehicle accidents. *American Academy of Family Physicians*. Retrieved November 8, 2009, from <http://www.aafp.org/afp/990800ap/-contents.html>.
- Cagnetta, E., & Cicognani, E. (1999). Surviving a serious traffic accident: Adaptation processes and quality of life. *Journal of Health Psychology, 4*(4), 551-564. Retrieved October 20, 2008, from <http://hpq.sagepub.com>.
- Calhoun, L., & Tedeschi, R. (2001). Posttraumatic growth: The positive lessons of loss. In R. Neimeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 157–172). Washington, DC: American Psychological Association.
- Carlson, N.R. (1990). *Psychology, the science of behaviour*. (3rd ed.). Needham Heights: Simon & Schuster.
- Central Intelligence Agency (CIA). (2009). *The world factbook*. Washington, D.C.: Author.
- Chase, B. W., Cornille, T. A., & English, R. W. (2000). Life satisfaction among persons with spinal cord injuries. *The Journal of Rehabilitation, 66*(3), 14-26. Retrieved October 20, 2008, from <http://www.questia.com>.
- Colman, A. M. (2006). *Oxford: Dictionary of psychology*. New York: Oxford University Press.
- Crewe, N., & Krause, J. (2002). Spinal cord injuries. In M. Brodwin, F. Tellez & S. Brodwin (Eds.), *Medical, psychosocial and vocational aspects of disability*

- (pp. 279–291). Athens, GA: Elliot & Fitzpatrick.
- Cummings, T. G., & Cooper, C. L. (1979). Cybernetic theory of organizational stress. In C. L. Cooper (Ed.), *Theories of organizational stress* (pp.102-122). Oxford: Oxford University Press.
- Davis, C. (2001). The tormented and the transformed: Understanding response to loss and trauma. In R. Neimeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 137–155). Washington, DC: American Psychological Association.
- Day, H., & Jankey, S. (1996). Lessons from the literature: Toward a holistic model of quality of life. In R. Renwick, I. Brown & M. Nagler (Eds.), *Quality of life in health promotion and rehabilitation* (pp. 39-50). Thousand Oaks, CA: Sage Publications.
- Degraff, A. H., & Schaffer, J. (2008). Emotion-focused coping: A primary defense against Sstress for people living with spinal cord injury [Electronic version]. *The Journal of Rehabilitation*, 74(1), 19.
- Delahanty, D. L., Herberman, H. B., Craig, K. J., Hayward, M. C., Fullerton, C. S., Ursano, R. J., et al. (1997). Acute and chronic distress and post-traumatic stress disorder as a function of responsibility for serious motor vehicle accidents [Electronic version]. *Journal of Consulting and Clinical Psychology*, 65, 560–567.
- de L. Horne, D. J. (1996). Traumatic stress reactions to motor vehicle accidents. In J. P. Wilson & B. Raphael (Eds.), *International handbook of traumatic stress syndromes* (pp. 499–506). New York: Plenum Press.
- DeSanto-Madeya, S. A. (2006). A secondary analysis of the meaning of living with

- spinal cord injury using Roy's adaptation model. *Nursing Science Quarterly*, 19(3), 240-246. doi: 10.1177/0894318406289493.
- Devins, G. M. (1994). Illness intrusiveness and the psychosocial impact of lifestyle disruptions in chronic life-threatening disease. *Advances in Renal Replacement Therapy* 1(3), 251–263.
- Devins, G. M., & Shnek, Z. M. (2001). Multiple sclerosis. In R. G. Frank & T. R. Elliott (Eds.), *Handbook of Rehabilitation Psychology* (pp. 163-184). Washington D.C.: American Psychological Association.
- Di Gallo, A., & Parry-Jones, W. L. (1996). Psychological sequelae of road traffic accidents: An inadequately addressed problem [Electronic version]. *British Journal of Psychiatry*, 169, 405-7.
- Dijkers, M. (1996). Quality of life after spinal cord injury – includes related information – spinal cord injury: part 1 of 3. *American Rehabilitation*, Retrieved February 15, 2009, from http://findarticles.com/p/articles/mi_m0842/is_n3_v22/ai_19568976.
- Duggan, C. H., & Dijkers, M. (2001). Quality of life after spinal cord injury: A squalitative study. *Rehabilitation Psychology*, 46, 3-27.
- Edwards, J. R. (1996). An examination of competing versions of the person-environment fit approach to stress. *Academy of Management Journal*, 39(2), 292-339.
- Edwards, J. R., & Cooper, C. L. (1990). The person-environment fit approach to stress: Recurring problems and some suggested solutions. *Journal of Organizational Behaviour*, 11(4), 293-307.
- Elliott, T.R. (1994). A place for theory in the study of psychological adjustment

- among persons with neuromuscular disorders: A reply to Livneh and Antonak. *Journal of Social Behavior and Personality*, 9, 231-236.
- Elliott, T. R., & Rivera, P. (2002). Spinal Cord Injury. In A. M. Nezu, C. M. Nezu, P. A. Geller & I. B. Weiner (Eds.), *Handbook of psychology: Vol. 9. Health psychology* (pp. 415-434). Philadelphia: John Wiley & Sons Inc.
- Fabian, E. S. (1990). Quality of life: A review of theory and practice implications for individuals with long-term mental illness. *Rehabilitation Psychology*, 35, 161-169.
- Fabian, E. S. (1991). Using quality of life indicators in rehabilitation program evaluation. *Rehabilitation Counseling Bulletin*, 34, 344-356.
- Feinstein, A. (1996). A prospective study of victims of physical trauma. In J. P. Wilson & B. Raphael (Eds.), *International handbook of traumatic stress syndromes* (pp. 157-164). New York: Plenum Press.
- French, J.R.P., Caplan, R.D., & Harrison, R.V. (1982). *The mechanisms of job stress and strain*. New York: John Wiley & Sons.
- French, J. R. P., Rodgers, W., & Cobb, S. (1974). Adjustment as person-environment fit. In G. V. Coelho, D. A. Hamburg & J. E. Adams (Eds.), *Coping and Adaptation* (pp.316-333). New York: Basic Books.
- Freud, Anna. (1937). *The ego and the mechanisms of defence* (C. Baines, Trans.). London: Hogarth. (Original work published 1936).
- Gaglio, B., Nelson, C., & King, D. (2006). The role of rapport: Lessons learned from conducting research in primary care settings. *Qualitative Health Research*, 16(5), 723-734. doi: 10.1177/1049732306286695.
- Gill, T. M., & Feinstein, A. R. (1994). A critical appraisal of the quality of quality of

- life measurements [Electronic version]. *Journal of the American Medical Association*, 272, 619-625.
- Gillett, E. (1994). The secret of successful defence. *Journal of the American Psychoanalytic Association*, 42, 103-141. doi: 10.1177/000306519404200107.
- Glasser, W. (1985). *Control theory: A new explanation of how we control our lives*. New York: Harper & Row.
- Gluhoski, V. L., & Wortman, C. B. (1996). The impact of trauma on world views. *Journal of Social and Clinical Psychology*, 15, 417-429.
- Hall, K. M., Harper, B., & Whiteneck, G. G. (1997). Follow-up study of individuals with high tetraplegia (C1–C4) 10 to 21 years post-injury. *Top Spinal Cord Injury Rehabilitation*, 2, 107–117.
- Hammell, K. W. (2004). Exploring quality of life following high spinal cord injury: A review and critique. *International Spinal Cord Society*, 42(1), 491-502. doi:10.1038/sj.sc.3101636.
- Hampton, N. Z. (2004). Subjective well-being among people with spinal cord injuries: The Role of self-efficacy, perceived social support, and perceived health. *Rehabilitation Counselling Bulletin*, 48(1), 31-37. doi: 10.1177/00343552040480010401.
- Harrison, M. A. (1978). *Introduction to formal language theory*. Massachusetts: Addison-Wesley, Reading.
- Hartmann, H., Kris, E., & Loewenstein, R. M. (1964). *Papers on psychoanalytic psychology*. New York: International Universities Press.
- Haybron, D. (2005). Life satisfaction, ethical reflection, and the science of happiness. *Journal of Happiness Studies*, 8(1), 99-138. doi:

10.1007/s10902006-9006-5.

Howard, G. S., Ralph, K. M., Gulanick, N. A., Maxwell, S. E., Nance, S. W., & Gerber, S. K. (1979). Internal invalidity in pretest-posttest, self-report evaluations and a reevaluation of retrospective pretests. *Applied Psychological Measurement, 3*, 1-23.

Hörnquist, J. O. (1982). The concept of quality of life [Electronic version]. *Scandinavian Journal of Social Medicine, 10*, 57-61.

Huitt, W. (2004). Maslow's hierarchy of needs. *Educational Psychology Interactive*. Valdosta, GA: Valdosta State University. Retrieved July 15, 2009 from, <http://chiron.valdosta.edu/whuitt/col/regsys/maslow.html>.

Janoff-Bulman, R. (1989). Assumptive world and the stress of traumatic events: Application of the schema construct. *Social Cognition, 7*(2), 113–136.

Janssen, T. W. J., Van Oers, A. J. M., Van Der Woude, L. H. V., & Hollander, A. P. (1994). Physical strain in daily life of wheelchair users with spinal cord injuries. *Medicine and Science in Sports and Exercise, 26*, 661-670.

Kahana, E., Lovegreen, L., Kahana, B., & Kahana, M. (2003). Person, environment, and person-environment fit as influences on residential satisfaction of elders. *Environment and Behaviour, 35*, 434-453. doi: 10.1177/0013916503035003007.

Karuombe, B. (2001). *PSI Pay Equity Project: The case of Namibia*. Windhoek: Labour Resource and Research Institute (LARRI).

Khalid, H. R. (2010). *Book of famous quotes*. Retrieved January 15, 2010, from <http://www.famous.quotes.com/author.php?aid=5479>.

Koltko-Rivera, M. E. (2006). Rediscovering the later version of Maslow's hierarchy

- of needs: Self-transcendence and opportunities for theory, research, and unification. *Review of General Psychology*, *10*(4), 302–317. doi: 10.1037/1089-2680.10.4.302.
- Krause, N. M., & Jay, G. M. (1994). What do global self-rated health items measure? [Electronic version]. *Medical Care*, *32*, 930–942.
- Kulka, R.A., Klingel, D. M., & Mann, D. W. (1980). School crime and disruption as a function of student-school fit: An empirical assessment. *Journal of Youth and Adolescence*, *9*, 353-370.
- Kurosawa, K. (1995). Process interactionism, process analysis, and self process: An extension of Kurt Lewin's approach to personality psychology [Electronic version]. *Japanese Journal of Personality*, *3*, 66-93.
- Labour Resource and Research Institute (LARRI). (2008). *The Namibian wage bargaining report 2007*. Windhoek: Author.
- Lanig, I. S., Chase, T. M., Butt, L. M., Hulse, K. L., & Johnson, K. M. M. (1996). *A practical guide to health promotion after spinal cord injury*. Gaithersburg, MD: Aspen.
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Lerner, R. M. (1983). *Concepts and theories of human development*. New Jersey: Lawrence Erlbaum Associates, Inc.
- Lewin, K. (1951). *Field theory in social science: Selected theoretical papers*. New York: Harper & Row.
- Livingstone, L. P., Nelson, D. L., & Barr, S. H. (1997). Person-environment fit and creativity: An examination of supply-value and demand-ability versions of fit.

Journal of Management. Retrieved February 15, 2009, from http://findarticles.-com/p/articles/mi_m4256/is_n2_v23/ai_19498951.

Livneh, H. (2001). Psychosocial adaptation to chronic illness and disability: A conceptual framework [Electronic version]. *Rehabilitation Counseling Bulletin*, 44(3), 151–160.

Livneh, H., & Antonak, R. (1997). *Psychosocial adaptation to chronic illness and disability*. Gaithersburg, MD: Aspen.

Livneh, H., & Sherwood, A. (1991). Application of personality theories and counseling strategies to clients with physical disabilities. *Journal of Counseling and Development*, 69, 525-538.

Lustig, D. C. (2005). The adjustment process for individuals with spinal cord injury: The effect of perceived premorbid sense of coherence. *Rehabilitation Counseling Bulletin*, 48(3), 146–156. doi: 10.1177/00343552050480030301.

Manns, J. P., & Chad, K. E. (2001). Components of quality of life for persons with a quadriplegic and paraplegic spinal cord injury. *Qualitative Health Research*, 11(6), 795-811. doi: 10.1177/104973201129119541.

Martin, D., & Joomis, K. (2007). *Building Teachers: A Constructivist approach to introducing education*. Belmont, CA: Wadsworth.

Maslow, A. H. (1943). A theory of human motivation. *Psychological Review*, 50, 370-396.

Maslow, A.H. (1970). *Motivation and Human Personality* (Rev ed.). New York: Harper.

Mathes, E. W. (1981). Maslow's hierarchy of needs as a guide for living. *Journal of Humanistic Psychology*, 21, 69-72. doi: 10.1177/002216788102100406.

- McAweeney, M. J., Forchheimer, M., & Tate, D. G. (1996). Identifying the unmet independent living needs of persons with spinal cord injury [Electronic version]. *The Journal of Rehabilitation*, 62(3), 29-34.
- Mehnert, T., Krauss, H. H., Nadler, R., & Boyd, M. (1990). Correlates of life satisfaction in those with disabling conditions [Electronic version]. *Rehabilitation Psychology*, 35, 3-17.
- Menter, R. R. (1993). Spinal cord injury and aging: Exploring the unknown [Electronic version]. *Journal of the American Paraplegia Society*, 16(4), 179-189.
- Meyer, W., Moore, C., & Viljoen, H. (2003). *Personology: From individual to ecosystem*. Cape Town: Heinemann Publishers (Pty) Ltd.
- Miller, S. M., Chan, F., Ferrin, J. M., Lin, C., & Chan, J. Y. C. (2008). Confirmatory factor analysis of the World Health Organisation quality of life questionnaire-brief version for individuals with spinal cord injury. *Rehabilitation Counseling Bulletin*, 51(4), 221-228. doi: 10.1177/0034355208316806.
- Muhr, T., & Friese, S. (2004). *User's manual for ATLAS.ti 5.0*. Retrieved September 02, 2008, from <http://www.atlasti.com/manual.php>.
- Murray, H. A. (1938). *Explorations in personality*. New York: Oxford University Press.
- MVA Fund. (2008). *MVA Fund today*. Retrieved October 18, 2008, from <http://www.mvafund.com.na>.
- National Center for Post Traumatic Stress Disorder. (2007). *Effects of traumatic stress after mass violence, terror or disaster: Normal reactions to an abnormal situation: Fact sheet*. New York: United States Department of

Veterans Affairs. Retrieved November 6, 2009, from <http://www>.

MVA/fs_effects_disaster.html.

National Planning Commission Secretariat (NPC). (2008). *Vision 2030*. Retrieved January 15, 2010, from http://www.npc.gov.na/vision/vision_2030bgd.htm.

Noreau, L., Shephard, R. J., Simard, C., Pare, G., & Pomerleau, P. (1993).

Relationship of impairment and functional ability to habitual activity and fitness following spinal cord injury. *International Journal of Rehabilitation Research, 16*, 265-275.

O'Boyle, C. A. (1992). Assessment of quality of life in surgery. *British Journal of Surgery, 79*, 395-398.

Okubo, T., Kurosawa, K., & Kato, H. (2007). Person-environment fit, behavioural orientation, and subjective adjustment: A test of the goodness of fit hypothesis in university students. *Research and Clinical Center for Child Development: Annual Report, 29*.17-23.

Oliver, J., Huxley, P., Bridges, K., & Mohamad, H. (1996). *Quality of life and mental health services*. London: Routledge.

Orford, J. (1992). *Community psychology: Theory and practice*. New York: John Wiley & Sons.

Pervin, L. A. (1989). *Personality: Theory and research*. (5th ed.). New York: Wiley.

Pienaar, J., & Rothman, S. (2003). Coping strategies in the South African police services. *A Journal of Industrial Psychology, 29*(4), 81-90.

Plutchik, R., Kellerman, H., & Conte, H. R. (1979). A structural theory of ego defenses and emotions. In C. E. Izard (Ed.), *Emotions in personality and psychopathology*. New York: Plenum Press.

- Price, G. L., Kendall, M., Amsters, D. I., & Pershouse, K. J. (2004). Perceived causes of change in function and quality of life for people with long duration spinal cord injury. *Clinical Rehabilitation, 18*, 164-171. doi: 10.1191/0269215504cr714oa.
- Raeburn, J. M., & Rootman, I. (1996). Quality of life and health promotion. In R. Renwick, I. Brown, & M. Nagler (Eds.), *Quality of life in health promotion and rehabilitation: Conceptual approaches, issues and applications* (pp. 14-25). Thousand Oaks, CA: Sage.
- Rapkin, B. D., & Schwartz, C. E. (2004). Toward a theoretical model of quality-of-life appraisal: Implications of findings from studies of response shift. *Health and Quality of Life Outcomes, 2*, 14. doi: 10.1186/1477-7525-2-14.
- Reisinger, Y. (2009). *Cultures and behaviour*. Oxford: Butterworth-Heinemann.
- Reynolds, M., & Tarrier, N. (1996). Monitoring of intrusions in post-traumatic stress disorder: A report of single case studies [Electronic version]. *British Journal of Medical Psychology, 69*, 371-379.
- Renwick, R., & Friefeld, S. (1996). Quality of life and rehabilitation. In R. Renwick, I. Brown, & M. Nagler (Eds.), *Quality of life in health promotion and rehabilitation: Conceptual approaches, issues and applications* (pp. 26-38). Thousand Oaks, CA: Sage Publications.
- Roberts, B. W., & Robins, R. W. (2004). A longitudinal study of person-environment fit and personality development. *Journal of Personality, 72*, 89-110.
- Rowan, J. (1999). Ascent and descent in Maslow's theory. *Journal of Humanistic Psychology, 39*, 125-133. doi: 10.1177/0022167899393010.
- Santrock, J., W. (2004). *Life-span development*. (9th ed.). New York: McGraw Hill.

- Schiffman, L. G., & Kanuk, L. L. (1997). *Consumer behavior*. (6th ed.). New Jersey: Prentice Hall, Inc.
- Schuler, M. (1982). Sexual counseling for the spinal cord injured: A review of five programs. *Journal of Sex and Marital Therapy*, 8, 241-52.
- Schulz, R., & Decker, S. (1985). Long term adjustment to physical disability: The role of social support, perceived control, and self blame [Electronic version]. *Journal of Personality and Social Psychology*, 48, 1162-1172.
- Schwartz, C.E., Sprangers, M.A.G. (1999). Methodological approaches for assessing response shift in longitudinal quality of life research. *Social Science & Medicine*, 48, 1531-1548.
- SDL Trados. (2009). SDL Trados technologies. Retrieved September 9, 2009, from <http://www.sdl.com/en>.
- Sharf, R. S. (1997). *Applying career development theory to counseling*, (2nd ed.). Pacific Grove, CA: Brooks/Cole.
- Simons, J. A., Irwin, D. B., & Drinnien, B. A. (1987). *The Search for Understanding*. New York: West Publishing Company.
- Smith, J. A., & Eatough, V. (2007). Interpretative phenomenological analysis. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative data in psychology* (pp. 35-50). London: Sage Publications.
- Smith, J. A., & Osborn, M. (2006). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51-80). London: Sage Publications.
- Sprangers, M. A. G., & Schwartz, C. E. (1999). Integrating response shift into health-related quality-of-life research: A theoretical model. *Social Science and*

- Medicine*, 48, 1507–1515. doi: 10.1016/S0277-9536(99)00045-3.
- Terre Blanche, M., Durrheim, K., & Painter, D. (Eds.). (2006). *Research in practice: Applied methods for the social sciences*. Cape Town: University of Cape Town Press.
- Tomey, K. M., & Sowers, M. R. (2009). Assessment of Physical Functioning: A conceptual model encompassing environmental factors and individual compensation strategies. *Physical Therapy*, 89(7), 705-714. doi: 10.2522/ptj.20080213
- Tourangeau, R., Rips, R., & Rasinski, K. (2000). *The Psychology of Survey Response*. Cambridge: Cambridge University Press.
- Trieschmann, R. (1980). *Spinal cord injuries: Psychological, social, and vocational rehabilitation*. New York: Pergamon Press.
- Triseliotis, J., & Hill, M. (1990). Contrasting adoption, foster care, and residential rearing. In D. M. Brodzinsky & M. Schechter (Eds.), *The psychology of adoption* (pp. 944-949). Oxford: Oxford University Press.
- United Nations Development Programme. (2005). *Human development report 2005: International cooperation at a crossroads: Aid, trade and security in an unequal world*. New York: Author.
- Vaillant, G. E., Bond, M., & Vaillant, C. O. (1986). An empirically validated hierarchy of defense mechanisms. *Archives of General Psychiatry*, 73, 786-794.
- Vash, C. (1994). *Personality and adversity: Psychosocial aspects of rehabilitation*. New York: Springer.
- Westen, D. (1999). *Psychology: Mind, brain, culture*. New York: Norton.

Whiteneck, O. G. (1994). Measuring what matters: Key rehabilitation outcomes.

Archives of Physical Medicine & Rehabilitation, 75, 1073-1076.

Whiteneck, G., Mead, M., Dijkers, M., Tate, D., Bushnik, T., & Forchheimer, M.

(2004). Environmental factors and their role in participation and life satisfaction after spinal cord injury. *Archives of Physical and Medical Rehabilitation, 85*, 1793-1803.

Wood-Dauphinee, S., & Kuchler, T. (1992). Quality of life as a rehabilitation

outcome: Are we missing the boat? *Canadian Journal of Rehabilitation, 6*, 3-12.

World Health Organization. (1980). *World health organization international*

classification of impairments, disabilities, and handicaps: A manual of classification relating to the consequences of disease. Geneva, Switzerland: Author.

World Health Organization. (2000). *The world health report – health systems:*

Improving performance. Geneva, Switzerland: Author.

Youngkhill, L., & McCormick, B. P. (2006). Examining the role of self-monitoring

and social leisure in the life quality of individuals with spinal cord injury [Electronic version]. *Journal of Leisure Research, 38*(1), 1-19.

Appendix A

15 February 2009

Motor Vehicle Accident Fund of Namibia

P. O. Box 25158

Windhoek

To: Whom it may concern

RE: PERMISSION TO CONDUCT THESIS RESEARCH

I, Ute Sinkala, am a registered psychology master's student at the University of Namibia. I am planning to conduct my thesis on the following topic:

Quality of life of individuals suffering from spinal cord injury in Namibia.

Findings indicate that a significantly higher proportion of individuals with spinal cord injury are depressed and anxious in comparison with able bodied persons of a similar background (Hampton, 2004). Improved quality of life is an inherent goal for rehabilitation programs and examination of quality of life is an important attribute of patient care evaluation in medicine and related fields (Boswell, Dawson & Heininger, 1998). Improved quality of life may thus translate into improved psychological wellbeing and more effective rehabilitation.

The proposed study aims to examine the quality of life of individuals with spinal cord injury and subsequent paraplegia or quadriplegia.

The motivation of this proposed study is founded on improving the psychological intervention provided to individuals who are paraplegic and quadriplegic, by stakeholders such as the MVA Fund. This can be done through discovering the paraplegic and quadriplegic person's subjective views on important components that contribute to their quality of life.

I hereby request permission to access your client database as a source to draw the sample for the study during April 2009.

The following conditions will be met:

1. Participation in the study is voluntary.
2. Formal consent will be obtained from each participant.
3. Appointments for interviews will be made individually and interviews will be held at a location that is suitable for the client.
4. Confidentiality will be maintained at all times and participants will be encouraged to use pseudonyms.
5. A brief summary and completed thesis will be provided to MVA Fund at completion of the thesis.

Thank you for your kind consideration of my request.

Kind regards

Mrs. Ute Sinkala

Masters Student

Tel: 061 309 376

Fax: 061 309376

Dr. I. K. E. Burkhardt

Supervisor

Tel: 061 307 385

Fax: 061 307 384

References

Boswell, B. B., Dawson, M., & Heininger, E. (1998). Quality of life as defined by adults with spinal cord injuries. *Journal of Rehabilitation, 46*, 2732

Hampton, N. Z. (2004). Subjective well-being among people with spinal cord injuries: The Role of self-efficacy, perceived social support, and perceived health. *Rehabilitation Counseling Bulletin, 48*(1), 31-37. doi: 10.1177/00343552040480010401

Appendix B

Semi-Structured Interview Guide

The following questions have been adapted from the interview guide established by Manns & Chad (2001). Question 8, 10, 11, and 12 have been formulated by the researcher.

1. What are the most essential things in your life (your quality of life)?
2. How does the spinal cord injury affect these things?
3. What are the aspects of your life that are affected by the spinal cord injury?
4. How does the above mentioned impact on how good your life is?
5. Does the spinal cord injury prevent you from complete satisfaction in these areas (the areas they discussed that are important to their life)?
6. Does the spinal cord injury affect how good your life can be presently and in the future (either negatively or positively) and how (in what ways)?
7. How satisfied are you with your life?
8. Does a spinal cord injury change what is important in your life?
9. What do you think quality of life means?
10. Are you presently happy with your quality of life?
11. If yes to question 10, why?
12. If no to question 10, why and how can it be improved?

Appendix C

01 May 2009

RESEARCH PARTICIPANT: INFORMATIVE LETTER

I, Ute Sinkala, a registered psychology master student at the University of Namibia am currently conducting research on the following topic:

Quality of life of individuals suffering from spinal cord injury in Namibia.

People with disabilities have the right to participate in deciding what the essential components are in determining their quality of life and improving their rehabilitation programs. This can be done by raising awareness about their quality of life through voicing their feelings and experiences.

In the proposed study, measurement of quality of life will be done through asking questions about an individual's satisfaction with life, with regards to physical, psychological, social, and environmental aspects.

The information obtained from this study will be focused towards providing rehabilitation professionals, such as the MVA Fund with recommendations on how to improve the psychological intervention provided to their paraplegic and quadriplegic clients. This may be done through discovering what the paraplegic and

quadriplegic individuals view as important factors that contribute to their quality of life.

This letter is a friendly request to you, a valued source, to participate in the research project.

Participation is voluntary and you will be requested to sign a consent form. Confidentiality will be maintained at all times, and you are encouraged to use a pseudonym if this will put you more at ease. The results of the research may be made available to you at your request. Should you agree to participate; an appointment will be made for an interview at a time that suits you, at a venue that suits you. The interview will last approximately 45 minutes.

Your participation will be greatly appreciated.

Kind regards

Mrs. Ute Sinkala

Masters Student

Tel: 061 309 376

Fax: 061 309376

Dr. I. K. E. Burkhardt

Supervisor

Tel: 061 307 385

Fax: 061 307 384

Appendix D

01 May 2009

CONSENT FORM

I, Ute Sinkala, a clinical psychology masters student from the University of Namibia am conducting research on the following topic:

Quality of life of individuals suffering from spinal cord injury in Namibia.

I would like to find out more about paraplegic and quadriplegic individual's perceptions regarding their quality of life, in order to provide rehabilitation professionals with possible recommendations to improve their rehabilitation programs.

The results of the research will be published for a master's thesis. No personal information of participants will be released.

I am approaching all MVA fund clients who have suffered severe spinal cord injury, resulting in paraplegia or quadriplegia, within the past 10 years to participate in the study.

Please understand that you are not obliged to take part in the research. Your participation will be greatly appreciated, however you are free to choose whether to participate or not. If you chose to participate, you are free to withdraw at any stage during the interview, or even later

after the interview. Should you choose not to participate or if you withdraw, you will not be prejudiced in any way.

During the interview I will ask you questions and request that you answer the questions as honestly as possible. Some questions that I may ask might be of a personal nature. You are free to answer only questions that you are comfortable with. You may chose to not answer some questions. There are no right or wrong answers to questions. All the interviews will be recorded. The recordings will be stored in a save place and only the researcher will have access to them.

If you have any questions or complaints about this study, you may contact Professor J. Buitendach at the University of Namibia on (061) 206 3800.

Consent

I hereby agree to participate in the research regarding the perceived quality of life of paraplegic and quadriplegic individuals, conducted by Ute Sinkala. I understand that I am participating freely; I am not being forced into participating. I also understand that I can withdraw from the research at any point and if I chose to withdraw, the decision to do so will not affect me negatively.

The purpose of the study has been explained to me and I understand what is expected of me. I understand that the purpose of the study is not necessarily to benefit me personally.

I understand that this consent form will not be linked to the interview and that my information will remain confidential. I understand that if at all possible, feedback will be provided to me upon completion of the research.

Signature of participant

Signature of researcher

In addition to the above mentioned, I hereby agree to the audio recording of the interview for the purposes of data capturing. I understand that no personal identifying information on the audio recording will be released. I understand that these recordings will be kept in a secure environment by the researcher.

Signature of participant

Signature of researcher

Kind regards

Mrs. Ute Sinkala
Masters Student
Tel: 061 309 376
Fax: 061 309376

Dr. I. K. E. Burkhardt
Supervisor
Tel: 061 307 385
Fax: 061 307 384