

**The psycho-social experiences of significant others of post-acute
tetraplegia in-patients after rehabilitation**

by

IlanieKriel

(12018318)

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Supervisor: Dr. C.L. Carbonatto

Co-supervisor: Dr. M. Coetzee Spies

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DECLARATION OF ORIGINALITY

Name of the student: Ilanie Kriel

Student number: 12018318

Degree: MSW (Healthcare)

Topic: The psycho-social experiences of significant others of post-acute tetraplegia in-patients after rehabilitation

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I give all the glory and honour to my Heavenly Father for completion of this degree. I am blessed and humbled beyond measure.

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Dedicated to Daniel Lombard – “The only way to move past trauma is to accept change”

ABSTRACT

Title: The psycho-social experiences of significant others of post-acute tetraplegia in-patients after rehabilitation

Candidate: Ilanie Kriel

Department: Social Work and Criminology

Degree: MSW (Healthcare)

Supervisor: Dr. C.L. Carbonatto

Co-supervisor: Dr. M. Coetzee-Spies

Tetraplegia is the result of sustaining a spinal cord injury, and refers to the impairment or loss of motor and/or sensory function, including function in the arms, legs, trunk and pelvic organs. Every aspect of a person's life can be affected and the perceived losses and long-term implications result in significant psycho-social implications for the affected person and significant other. Implications may include loss of independence and mobility; pain and spasticity; loss of control of the bowel and bladder function; altered self-perception; sexual dysfunction and subsequent relational difficulties. Tetraplegia can also result in possible secondary complications including pressure ulcers and urinary tract infections. A life-long process of readjustment to the profound changes brought on by tetraplegia is to be anticipated (ASCoN, 2015:5; Singh, Tetreault, Kalsey-Ryan, Nouri & Fehlings: 2014:310; Fehlings, Vacarro, Boakye, Rossignol, Ditunno Jnr & Burns. 2013:56; Marino, Barros, Biering-Sorensen, Burns, Donovan, Graves, Haak, Hudson & Priebe: 2003:50; Medical Dictionary, 2017; Sisto, Druin & Sliwinski, 2010:114; Somers, 2010:52).

In many cases, the psycho-social implications of tetraplegia can be as devastating as the physical changes themselves (ASCoN, 2015:5). An estimated 20-30% of people with a spinal cord injury show clinically significant signs of depression (Orenczuk, Slivinski, Metha, & Teasel, 2009:1; WHO, 2017). Experiencing losses and grieving these losses are an integral part of the emotional and psychological reactions after sustaining tetraplegia. Adaptation is often a life-long process after sustaining tetraplegia and personal characteristics play an important role to the often life-long

process, including coping mechanisms; personality traits; cognitive styles; attitudes; values; and psychological health, coupled with the social support provided by loved ones, health care professionals and peer supporters significantly influence adaptation and participation after sustaining the injury (Fehlings et al., 2013:207; Orenczuk et al., 2009:1; Somers, 2010:54). Persons and significant other are faced with the challenge of redefining roles and responsibilities in the household. This often causes a significant amount of emotional distress (Sisto et al., 2010:114; Somers, 2010:51).

The impact of tetraplegia and the long lasting effects are not only limited to the person, but extend to the significant other, who also go through stages of readjustment. In some cases pre-morbid family functioning is exacerbated by the diagnosis of tetraplegia. Significant other have comparable stress to that of the person as changes associated with the loss of mobility and sensation may often result in difficulty mobilising independently in a variety of social settings. Persons often find themselves paralysed, incontinent, immobile, dependent and isolated. They are also faced with social and physical difficulties when engaging in social activities, therefore not only themselves but also their significant other are susceptible to hostility and isolation which has psycho-social consequences for all systems involved (Fehlings et al., 2013:208; Sisto et al., 2010:115; Somers, 2010:52).

This study utilised a qualitative research approach, which was appropriate as the researcher aimed to answer questions about the complex nature of tetraplegia with the purpose of understanding and describing the phenomena from the significant other's point of view (Fouché & Delpont, 2011:64). The type of research appropriate for this study was applied research as this study aimed to address the psycho-social experiences of significant other and the service delivery to significant other by the multidisciplinary team, which will in turn improve the quality of life of the person and significant other (Leedy & Ormrod, 2014:27; De Vos & Strydom, 2011:42). A collective case study design was utilised as the purpose of this study was to gain collective information from different sources to ultimately gain an understanding of the psycho-social experiences of significant other after a spinal cord injury resulting in tetraplegia. The study population was significant other who support a tetraplegic person in the Gauteng province. The significant other were not necessarily responsible for the

physical care of the person, but rather fulfilled the role of the emotional and social companion of the person.

In this study the sample was chosen by means of non-probability, purposive sampling, and the sample included significant other of persons who sustained tetraplegia, and completed the in-patient rehabilitation phase of recovery for at least 6 months onwards.

For this study the sampling criteria was as follows:

- Significant other which included spouses, partners, parents or siblings of all ages of tetraplegia persons
- The person who sustained the spinal cord injury (SCI) must have completed the initial post-acute in-patient rehabilitation process and have been discharged from a rehabilitation centre for 6 months onwards
- Significant other and person with SCI had to live in Gauteng province
- Both male or female participants
- The person with SCI had to be in age group ranging from 18-50 years
- From any cultural or religious affiliation
- Fluent in English or Afrikaans

The researcher identified possible participants by approaching The Quadpara Association of South Africa (QASA) and provided them with an information letter regarding the study, to recruit possible participants. Those who showed interest then gave their contact details to QASA for the researcher to contact them.

Ten participants were selected after contacting the potential participants recruited by QASA. The letter of informed consent was read with them and discussed and if it was agreed on voluntarily to participate, it was signed and the interview commenced thereafter. The duration of the interviews was approximately 45 minutes and voice recorded for transcribing purposes with the permission of the participants.

Individual one-on-one interviews were conducted and voice recorded with the permission of ten significant other participants, representing ten different persons who sustained tetraplegia. Each participant shared their own psycho-social experiences regarding the post-acute tetraplegia in-patient after rehabilitation with the researcher,

in order to compare findings. The researcher transcribed the digitally recorded interviews and then analysed the content, generating themes and sub-themes from the data.

The themes included the following:

- Theme one: Understanding of spinal cord injury
- Theme two: Significant other' experience of rehabilitation
- Theme three: The emotional impact of tetraplegia on significant other
- Theme four: Social changes associated with tetraplegia
- Theme five: Changes in relationship dynamics after tetraplegia
- Theme six: Needs of significant other

The data revealed the participants' psycho-social experiences and the researcher used their verbatim responses to support the themes generated and substantiated it further with literature. The conclusions of the study are that tetraplegia is a life changing event, resulting in major psycho-social changes for the person who sustained tetraplegia as well as their significant other. Grieving losses; role changes within the household; social isolation; employment challenges and relational difficulties are often part of the long-lasting effects of tetraplegia.

Recommendations in this study can be used by the multidisciplinary team, and social workers to better understand the psycho-social experiences of significant other of persons who sustained tetraplegia, to improve the psycho-social intervention and support of significant other.

LIST OF KEY TERMS

Experiences

In-patient

Psycho-social

Post-acute

Rehabilitation

Significant others

Social work

Tetraplegia

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LIST OF ACRONYMS

ASIA	American Spinal Injury Association
IASP	International Association for the Study of Pain
ICU	Intensive Care Unit
NSCICS	National Spinal Cord Injury Statistical Centre
SACSSP	South African Council for Social Service Profession
SCI	Spinal Cord Injury
WHO	World Health Organization

CHAPTER 1: GENERAL INTRODUCTION

1.1 Introduction and contextualisation

Tetraplegia results from a person sustaining a spinal cord injury and refers to the impairment or loss of motor and/or sensory function, including function of the arms, legs, trunk and pelvic organs. Every aspect of a person's life can often be affected, and the perceived losses and long-term implications result in significant psycho-social implications for the affected person and significant other. Implications may include loss of independence and mobility; pain and spasticity; loss of control of the bowel and bladder function; altered self-perception; sexual dysfunction and subsequent relational difficulties are prevalent. Tetraplegia can also result in possible secondary complications including pressure ulcers and urinary tract infections.

A life-long process of readjustment to the profound changes brought on by tetraplegia is to be anticipated (ASCoN, 2015:5; Singh et al., 2014:310; Fehlings et al., 2013:56; Marino et al., 2003:50; Medical Dictionary, 2017; Sisto et al., 2010:114; Somers, 2010:52). In support of their findings this research study emphasises the far reaching consequences for the person physically when diagnosed with tetraplegia.

The impairments evident after sustaining tetraplegia are often addressed through the process of physical rehabilitation. The World Health Organisation (WHO) defines rehabilitation of people with disabilities as a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels (WHO, 2017). Rehabilitation provides people with disabilities the tools necessary to attain independence and self-determination (WHO, 2017). The goal of the rehabilitation process is to empower persons to ultimately return home and be reintegrated into the community as independent and healthy as possible, striving for the best quality of life. A significant amount of emphasis is placed on discharge planning and post-discharge quality of life while the person is receiving rehabilitative services (Medicare, 2013:215; Somers, 2010:2; WHO, 2017). This research study proposes that a person and their subsequent significant other are in need of holistic intervention strategies (including physical, psychological/emotional, social and economic support) to empower the person to reintegrate successfully back into their home and community environment.

Asian Spinal Cord Network (ASCoN, 2015:5) stated that the psycho-social needs of the person and significant other can be so overwhelming that in many cases rehabilitation cannot proceed. Yet, in many countries, psycho-social issues tend to be overlooked and neglected both during rehabilitation and after discharge. The review of literature found little research on intervention strategies to guide social work aimed at empowering and supporting the significant other of specifically tetraplegic persons during the in-patient rehabilitation phase. The life changing consequences of tetraplegia for persons and significant other are acknowledged by ASCoN (2015:5) which states that tetraplegia results in disruptions in physical, psychological and social, vocational and behavioural domains of the person and significant other. This study is striving therefore to fill the gap and contribute to the existing body of knowledge focussed on addressing the psycho-social experiences of significant others of post-acute tetraplegia in-patients after rehabilitation.

There is no reliable estimate of global prevalence of spinal cord injury, but (WHO, 2017) estimated the annual global incidence to be 40 to 80 cases per million. Up to 90% of these cases are due to traumatic causes, though the proportion of non-traumatic spinal cord injury appears to be growing (WHO, 2017). Males are most at risk in young adulthood (20-29 years) and older age (70+). Females are most at risk in adolescence (15-19 years) and older age (60+). Studies done by the WHO (2017) reported male-to-female ratios of at least 2:1 among adults, sometimes much higher.

Although few epidemiological data are available on spinal cord injuries in South Africa, the worldwide reviews often include South African data. A study done at the Groote Schuur Hospital during 2013 reported that the total number of persons admitted to the Acute Spinal Cord Injury Unit was 2 042, with an average of 185 admissions per year. The male/female ratio was 5.25:1. The age category from 21 - 30-years was the largest, comprising 33.5% of the cases. The most prevalent cause of injury was motor vehicle accidents (44.6%), followed by violence-related injuries (27.2%) (Sothmann, Stander, Kruger & Dunn, 2015:836).

For the purpose of this study, the focus is on the psycho-social experiences of significant others of the post-acute tetraplegia in-patient after rehabilitation. To gain a better understanding of tetraplegia, the relevant aspects of a spinal cord injury focussing on tetraplegia will be discussed in the literature review in Chapter 2.

1.2 Key concepts

Key concepts for the purpose of this study are defined as follows:

- **Experiences:** A direct observation of/or participation in events as a basis of knowledge (Meriam Webster Dictionary, 2019). For the purpose of this study, experiences can be defined as the knowledge participants required through taking on the role of significant other of a person who sustained tetraplegia
- **In-patient:** Refers to persons who are receiving care and treatment from health care professionals within an institution (Barker, 2014:313). For the purpose of this study, in-patient refers to the in-patient rehabilitation phase of persons who sustained tetraplegia.
- **Psycho-social:** Summary of information about the history, cultural, environment in which a person lives, information on the resources that might be available (Barker, 2014:348). For the purpose of this study, psycho-social refers to the psychological and social information made available by the participants in order to gain an understanding of their experiences.
- **Post-acute:** For the purpose of this study, post-acute is referred to as the period after being discharged from the in-patient rehabilitation unit.
- **Rehabilitation:** Refers to goal directed services aimed at optimizing function returning to health after sustaining a spinal cord injury. These services include enabling a person to fulfil an independent lifestyle as far as possible; facilitating the process to return to participation in accustomed tasks and roles in their family and society; psychological, sexual, vocational and a-vocational adjustment; the acquisition of functional skills; appropriate equipment (like a wheelchair) and the knowledge and behaviours required for health maintenance (Somers, 2010:2). For the purpose of this study rehabilitation refers to services rendered to tetraplegic persons through a multidisciplinary team consisting of medical practitioners and specialist neurologist and orthopaedic surgeons, nurses, occupational therapists, physiotherapists, social workers and psychologists aimed at readjustment and successful discharge after sustaining tetraplegia.

- **Significant other:** Can be described as a person who is considered by an individual as being special and as having an effect on that individual (Mosby's Dictionary of Medicine, Nursing & Health Professions. 2013:1759). Significant other can also be explained as one who because of affection, closeness, family relationship or co-dependency need is considered more important than others (Barker, 2014:392). For the purpose of this study significant other refers to an individual who does not necessarily engage in the physical care of the person but renders emotional and social support to the person and is in close relationship to the person. These relations may include mother; father; siblings; grandparents; extended family members; friends; romantic partners and/or spouses.
- **Social work:** The applied science of helping people achieve an effective level of psycho-social functioning and effecting societal change to enhance the wellbeing of all people (Barker, 2014:408).
- **Tetraplegia:** Paralysis of the arms, legs, and trunk of the body below the level of the associated injury to the spinal cord (Mosby's Dictionary of Medicine, Nursing & Health Professions. 2013:1759). Tetraplegia for the purpose of this study refers to the condition characterized by loss of sensation and movement in all four limbs, trunk control and loss of bowel and bladder control.

1.3 Theoretical framework: Ecological systems theory

This study will be underpinned by the Ecological systems theory, as this theory retains the notion of environmental wholeness which includes the recognition that the parts of the system can never be entirely separated from each other. Thus the researcher is inclined to explore the experiences of significant other in conjunction with the changes in interaction within their environment brought on by the momentous changes associated with tetraplegia.

The merging of Ecological and Systems theory emerged in 1970's in response to criticisms of the Systems theory and in the pursuit of unifying conceptual framework for practice (Nash, Munford & O'Donogue, 2005:36; Healy, 2005). Ecological systems theory is of the belief that there is an interaction and reciprocal transaction between a person and their environment. These interactions and transactions are complex and

non-linear (Healy, 2005:136; Nash et al., 2005:36). The Ecological systems theory retains the General Systems Theory's notion of environmental wholeness which includes the recognition that the parts of the system can never be entirely separated from each other (Mattaini and Meyer, 2002:6) as seen in (Healy, 2005:136). The Ecological environment is conceived as an arrangement of concentric structures, each contained within the next (Bronfenbrenner, 1979:22; Bronfenbrenner, 2005:101). These structures are referred to as the micro-, meso-, exo-, macro- and chrono systems, defined as follows:

A *micro system* can be defined as a pattern of activities, roles and interpersonal relations experienced by the person in a given setting with particular physical and material characteristics. A micro system is the environment closest to the person, and in which most interaction will take place on a face-to-face basis namely home environment, family and community (Bronfenbrenner, 1979:22; Bronfenbrenner, 2005:101).

In this study the micro system includes the significant other and their primary link which is the person who sustained tetraplegia. The researcher aims to explore the effect of tetraplegia on the primary system, involving the significant other, and the effect tetraplegia has on the interaction between the significant other and person who sustained tetraplegia. Aspects like quality of relationship after the injury; role changes; impact on privacy; dependence on significant other and the emotional impact of tetraplegia on the person as well as significant other will be explored.

A *meso system* comprises the interrelations among two or more settings in which a person actively participates such as family, work and social life (Bronfenbrenner, 1979:25; Bronfenbrenner, 2005:101). A meso system is thus a system of micro systems and is formed or extended when a person moves into a new setting. Besides the primary link, interconnections may take a number of additional forms: other persons who participate actively in both settings; intermediate links in a social network; formal and informal communications among settings (Bronfenbrenner, 1979:25; Bronfenbrenner, 2005:101). In this study the meso system includes the family, significant other, colleagues, work and social life of the person with tetraplegia. The researcher aims to explore the effect of tetraplegia on significant other in terms of social interaction and participation with family, friends and the community.

An *exo system* refers to one or more settings that do not involve the person as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing the person (Bronfenbrenner, 1979:25; Bronfenbrenner, 2005:101). In this study the *exo system* will depict the effect of the evident life changes associated with tetraplegia, focussing on lack of employment and the financial implication on the household if a person with tetraplegia is no longer able to generate an income; the interaction between significant other and the identified caregiver; the financial implication of identifying a caregiver; evident role changes in the household; the financial implication of accessible transport to mobilise in their community.

A *macro system* refers to the consistencies, in the form and content of the lower-order systems (micro-, meso- and *exo-* systems) that exist or could exist, at the level of the subculture or the culture as a whole, along with any belief systems or ideology underlying such consistencies (Bronfenbrenner, 1979:26; Bronfenbrenner, 2005:101). In this study, the *macro system* can include the micro-, meso-, and *exo* systems of significant other. The researcher aims to explore the experiences of significant other focussing on the changes in beliefs; ideologies; perceptions after their loved one sustained tetraplegia.

A *chrono system* refers to a scale for ordering individuals in terms of how long they have lived, reflecting developmental changes within the individual and thus not directly related to external conditions or events, but rather speaks to a purely personalogical construct. It further refers not only to age but ordering events in their historical sequence and context. (Bronfenbrenner, 2005:82). Thus the *chrono system* aims at permitting one to identify the impact of prior life events and experiences of an individual impacting their functioning (Bronfenbrenner, 2005:82). In this study, the *chrono system* will be explored as tetraplegia not only affects the external systems of significant other, but also has an impact on personal characteristics of significant other. The effect of tetraplegia on life phases, past events and how that impacts their current and future functioning will be explored.

The Ecological systems theory is further of the notion that problems of difficulty arise due to a poor fit between the person's environment and their needs, capacities, rights

and aspirations. This lack of fit can occur for different reasons including life transitions, and chronic environmental stressors (Healy, 2005:136; Nash et al., 2005:36).

It is important for the researcher to acknowledge that a family system is more than a collection of individuals, but instead a whole larger than the sum of its parts. Individual experience specifically that of the significant other must be understood within the context of the whole. The researcher is of the understanding that the Ecological systems theory is applicable for this study, as the purpose of this study is to understand and respond to persons in their environment as is confirmed by Barker (2014:135), stating that Ecological systems theory attempts to depict phenomena in their connectedness and complexity. This study aims to explore psycho-social experiences of significant others of post-acute tetraplegia in-patients after rehabilitation, thus encompassing the interaction between the person who sustained tetraplegia and the significant other surrounding the tetraplegic person on the micro-, meso-, exo-, macro and chrono level of functioning. Every aspect and all systems connected to the significant other is seemingly affected by the psycho-social effects of tetraplegia.

1.4 Rationale and problem statement

Every level of functioning of a person's life is affected when sustaining a life changing event like tetraplegia. Various losses occur in the physical, emotional and social domains and long-term implications result in psycho-social implications for the affected person and significant other. Readjustment to the profound changes brought on by tetraplegia is to be anticipated throughout the life of the person and significant other (ASCoN, 2015:5; Singh et al., 2014:310; Fehlings et al., 2013:56; Marino, Marino et al., 2003:50; Medical Dictionary, 2017; Sisto et al., 2010:114; Somers, 2010:52).

The researcher has come to the understanding that tetraplegia has detrimental effects and life changing consequences for not only the person but also the significant other. The researcher has been employed in psycho-social service delivery at an in-patient physical rehabilitation centre since 2015. The researcher identified a lack of formal support services rendered to the significant other of persons who sustained tetraplegia receiving intensive post-acute in-patient rehabilitation services. The researcher further identified most support services from all disciplines in the multidisciplinary team were focussed on supporting the persons with tetraplegia, without inclusion of significant

other. Often the focus of service delivery lack consideration of the importance of significant other and the importance of ensuring adequate psycho-social and supportive service delivery to significant other, as confirmed by (Sisto et al., 2010:115) who state that researchers argue that social and family support is the most significant predictor of positive readjustment after spinal cord injury.

The researcher believes that in as much as the person who sustained the injury resulting in tetraplegia is in need of support and education in the rehabilitation process, the significant other are also desperately in need of empowerment and support services such as acquiring information, education on tetraplegia, addressing the losses experienced and facilitating the readjustment process of the significant other in the rehabilitation process and after discharge. The need for holistic service delivery rendered to both the person and significant other is confirmed by (Marino et al., 2003:50) stating that psychological interventions following tetraplegia typically consist of individual and family therapy in consultation with the rehabilitation team.

The researcher identified through the literature study and practical experience that there is a need to explore psycho-social and supportive services rendered to significant other of persons who sustained tetraplegia, receiving post-acute in-patient therapy at a rehabilitation centre. The purpose of this research study is consequently to identify and explore the psycho-social experiences of significant other of persons who sustained tetraplegia, after completing the acute in-patient rehabilitation phase. The researcher is aspiring to identify the psycho-social experiences of significant other to ultimately be able to contribute to rendering the necessary psycho-social and support services to significant other during and post-acute rehabilitation.

To conclude the problem statement and rationale of this study, the researcher stresses the importance of considering tetraplegia from a holistic perspective. It became clear to the researcher through the literature review that significant other play a substantial role in the readjustment and quality of life after sustaining tetraplegia. Psycho-social experiences of significant other play a vital role in the readjustment of the person and thus the researcher stresses the importance of formulating and rendering effective psycho-social services to significant other during and post-acute rehabilitation in order to empower them to effectively support the person who sustained tetraplegia. The researcher is of the notion that the outcome of this study can contribute to the body of

knowledge and service delivery rendered to significant other of persons who sustained tetraplegia.

The research question of this study was:

What are the psycho-social experiences of significant others of post-acute tetraplegia in-patients after rehabilitation?

1.5 Goal and objectives

The goal of this study was to explore and describe the psycho-social experiences of significant others post-acute tetraplegia in-patients after rehabilitation.

The objectives of the study were:

- To conceptualise and contextualise the nature, treatment and rehabilitation of tetraplegia
- To explore the psycho-social experiences and needs of significant other in the care and support of the post-acute tetraplegic patient after rehabilitation
- To explore and describe the psycho-social challenges of significant other in the care and support of the post-acute tetraplegic patient post-discharge
- To make recommendations to the multidisciplinary team for improvement of post-discharge support services to significant other of tetraplegic patients.

1.6 Overview of research methodology

This study utilised a qualitative research approach, which was appropriate for this study as the researcher aimed to answer questions about the complex nature of tetraplegia with the purpose of describing and understanding the phenomena from the significant other's point of view (Fouché & Delpont, 2011:64). The type of research appropriate for this study was applied research, as this study aimed to explore the current psycho-social experiences of significant other of post-acute tetraplegic in-patients after rehabilitation, and contribute to improving the services rendered by the multidisciplinary team, which will in turn improve the quality of life of the person with tetraplegia and significant other (Leedy & Ormrod, 2014:27; De Vos & Strydom, 2011:42). A collective case study design was utilised to gain collective information

from different sources to ultimately improve understanding of the psycho-social experiences of significant other after a spinal cord injury resulting in tetraplegia (Mark, 1996) as seen in (Fouché & Schurink, 2011:322).

The study population was significant other who support a tetraplegic person in the Gauteng province. The significant other was not necessarily responsible for the physical care of the person, but rather fulfilled the role of the emotional and social companion of the person. In this study the sample was chosen by means of non-probability, purposive sampling, and the sample included significant other of persons who sustained tetraplegia, and completed the in-patient rehabilitation phase of recovery for at least 6 months onwards.

For this study the sampling criteria was as follows:

- Significant other which included spouses, partners, parents or siblings of all ages of tetraplegia persons
- The person who sustained the spinal cord injury (SCI) must have completed the initial post-acute in-patient rehabilitation process and have been discharged from a rehabilitation centre for 6 months onwards
- Significant other and person with SCI had to live in Gauteng province
- Both male or female participants
- The person with SCI had to be in age group ranging from 18-50 years
- From any cultural or religious affiliation
- Fluent in English or Afrikaans

The researcher identified possible participants by approaching QuadPara Association of South Africa (QASA) and provided them with an information letter regarding the study, to recruit possible participants. Those who showed interest then gave their contact details to QASA for the researcher to contact them. Ten participants were selected after contacting the potential participants recruited by QASA. Individual one-on-one interviews were conducted and voice recorded with the permission of significant other participants, representing ten different persons who sustained tetraplegia. Each participant shared their own psycho-social experiences regarding the post-acute tetraplegia in-patient after rehabilitation with the researcher in order to compare findings.

A pilot study was conducted with two participants. These two participants met the same sampling criteria as the participants of the main study. After the pilot study the researcher made minor adjustments to the interview schedule in order to refine the interview schedule.

Data was collected utilising semi-structured face-to-face interviews, an interview schedule and a voice recorder to collect data from the participants. The letter of informed consent was read and discussed and if it was agreed on voluntarily, it was signed, and the interview commenced thereafter. The duration of the interviews was approximately 45 minutes and was voice recorded for transcribing purposes with the permission of the participants.

The researcher transcribed the digitally recorded interviews and then analysed the contents according to the qualitative data analysis steps, generating themes and sub-themes from the data. The researcher used their verbatim responses in chapter 3 to support the themes and sub-themes and also substantiated these findings with relevant literature.

A detailed description of the research methodology used in this study, including the research methods in sampling, data collection, analysis and quality of data will be provided in chapter 3.

1.7 Contents of research report

Table 1.1: Contents of the research report

Chapter 1	General Introduction and research methodology
Chapter 2	Literature study of tetraplegia. Specific areas of focus include: Definition of medical concepts; prevalence of spinal cord injuries; causes of spinal cord injuries; pathophysiology; composition of the spine; biological implication of spinal cord injuries; physiological overview; classification and symptoms of spinal cord injury; complete versus incomplete lesion; levels of spinal cord injuries; medical and surgical management; neurological assessment and classification; complications of tetraplegia; bowel management; urological management; Integumentary complications- pressure ulcers; pain management; psycho-social aspects related to tetraplegia; psychological adjustment for the person with tetraplegia; losses;

	emotional reactions of significant other; social factors of tetraplegia; relationships and intimacy; support systems; socio-economic status; rehabilitation and tetraplegia; role of the social worker.
Chapter 3	Research methodology including: the research approach; type of research; research design; research methods; study population and sampling; method of data collection; pilot study; methods of analysis; data quality; ethical considerations and research findings.
Chapter 4	Summary, conclusions and recommendations including: The goal and objectives of the study; achievement of objectives; limitations of the study; key findings conclusions and recommendations of the literature study; key findings conclusions and recommendations of Theme one: Understanding of spinal cord injury; Theme two: Significant other's experience of rehabilitation; Theme three: Emotional impact of tetraplegia on significant other; Theme four: Social changes associated with tetraplegia; Theme five: Changes in relationship dynamics after tetraplegia; Theme six: Needs of significant other. Lastly, recommendations for future research, practice and policy is also discussed.

The following chapter focuses on the literature study.

CHAPTER 2: LITERATURE STUDY

2.1 Introduction

A spinal cord injury can typically be defined as an acute and traumatic lesion of the spinal cord. Tetraplegia results in disruptions in physical, psychological and social domains of a patient (ASCoN, 2015:5; Singh et al., 2014:310). The physical loss of functioning may be temporary or permanent in nature, including loss of various degrees of motor (movement) and sensory (feeling) ability, as well as bladder and bowel dysfunction. Tetraplegia usually results in very distinctive physical changes, including the loss of movement and sensation in all four limbs (to varying degrees), trunk control and the pelvic muscles are also affected. Bladder and bowel control are affected and the person who sustained tetraplegia is often completely dependent on others to assist in managing the physical changes associated with tetraplegia (Fehlings et al., 2013:56; Marino et al., 2003:50; Medical Dictionary, 2017; Sisto et al., 2010:114; Somers,2010:52). These losses can often understandably pose significant psycho-social and socio-economic consequences for persons with tetraplegia and significant other (Somers, 2010:52). In many cases, the psycho-social experiences, needs and challenges of the person with tetraplegia and significant other can be equally distressing (ASCoN, 2015:5; Fehlings et al., 2013:56).

2.2 Definition of medical concepts

The medical terms used in this chapter will subsequently be defined:

Autonomic nervous system: Part of the nervous systems that regulates involuntary body functions, including the activity of the cardiac muscle, smooth muscles, and glands. It has two divisions: the sympathetic nervous system; accelerates heart rate, constricts blood vessels, and raises blood pressure; the parasympathetic nervous system; slows heart rate, increases intestinal peristalsis and gland activity (Mosby's Dictionary of Medicine, Nursing & Health Profssions, 2013:165).

Axons: *An extension, usually long and slender of a neuron capable of conducting action potentials or self-propagating nervous impulses (Mosby's Dictionary of Medicine, Nursing & Health Professions, 2013:170).*

Autonomic dysreflexia: *Uninhibited reflex of the autonomic nervous system, symptoms include severe headache; seating; flushing; changes in heart rate and can cause hemorrhagic retinal damage or stroke syndrome (Miller-keane, 2003:180; Mosby's Dictionary of Medicine, Nursing & Health Professions, 2013:165).*

Aspiration: *Inhalation of foreign material usually food or particles of vomit into the bronchi in the lungs (Stedman's Medical Dictionary, 2012:150).*

Atelectasis: *Reduction or absence of air in part of or all of a lung, with resulting loss of lung volume (Stedman's Medical Dictionary, 2012:155).*

Cardiac arrhythmia: *Cardiac dysrhythmia- any abnormality in the rate, regularity or sequence of cardiac activation (Stedman's Medical Dictionary, 2012:277).*

Cardiovascular system: *The heart and blood vessels considered as one entity (Stedman's Medical Dictionary, 2012:281).*

Catheter: *A tube designed to be passed through the urethra into the bladder to drain it of urine, usually composed of latex, silicone or soft plastic (Stedman's Medical Dictionary, 2012:290).*

Deep venous thrombosis: *Formation of one or more thrombi in the deep veins, usually of the lower extremity or in the pelvis; carries a high risk of pulmonary embolism (Stedman's Medical Dictionary, 2012:448).*

Gray matter: *Those regions of the brain and spinal cord that are made up primarily of the cell bodies and dendrites of nerve cells (Stedman's Medical Dictionary, 2012:722).*

Haemorrhage: *A loss of a large amount of blood in a short period, either externally or internally (Mosby's Dictionary of Medicine, Nursing & Health Professions, 2013:827).*

Ischemia: *A decreased supply of oxygenated blood to a body part (Mosby's Dictionary of Medicine, Nursing & Health Professions, 2013:965).*

Interneurons: *Combinations or groups of neurons between sensory and motor neurons that govern coordinated activity (Stedman's Medical Dictionary, 2012:882).*

Involuntary regulation: *Regulation of the body independent of the will (Stedman's Medical Dictionary, 2012:895).*

Medulla oblongata: *The most caudal subdivision of the brainstem, continuous with the spinal cord, extending from the lower border of the decussation of the pyramid to the pons (Stedman's Medical Dictionary, 2012:1034).*

Motor functioning: *Denoting those neural structures that, by the impulses generated and transmitted by them cause muscle fibres or pigments cells to contract, or glands to secrete (Stedman's Medical Dictionary, 2012:1090).*

Neuropathic pain: *Neuropathic pain can often develop acutely or after one year post-injury and often presents at or below the level of the injury (Hadjipavlou et al., 2016:264; Sisto et al., 2010:33).*

Nociceptive pain: *Capable of appreciation or transmission of pain (Stedman's Medical Dictionary, 2012: 1162).*

Oedema: *An accumulation of an excessive amount of watery fluid in cells, tissues or serious cavities (Stedman's Medical Dictionary, 2012:527).*

Orthostatic hypotension: *A form of low blood pressure that occurs in a standing patient (Stedman's Medical Dictionary, 2012:211).*

Parasympathetic nervous system: *Slows heart rate, increases intestinal peristalsis and gland activity (Mosby's Dictionary of Medicine, Nursing & Health Professions, 2013:165).*

Paraplegia: *Paraplegia refers to impairment or loss of motor and or sensory function in the trunk, lower extremities (limbs) and pelvic organs, but motor and sensory function is normal in the upper extremities (limbs), bladder and bowel control is often affected (Mosby's Dictionary of Medicine, Nursing & Health Professions. 2013:1759; somers, 2010:21).*

Pressure ulcer: *An inflammation, sore or ulcer in the skin over a bony prominence, most frequently the sacrum, elbows, heels, outer ankles, inner knees, shoulders (Mosby's Dictionary of Medicine, Nursing & Health Professions.2013:1450).*

Pneumonia: *Inflammation of the lungs (Mosby's Dictionary of Medicine, Nursing & Health Professions, 2013:1411).*

Pulmonary embolism: *A blockage of a pulmonary artery by fat, air, tissue or a thrombus that usually arises from a peripheral vein (Mosby's Dictionary of Medicine, Nursing & Health Professions.2013:1491).*

Sensation: *A feeling, impression, or awareness of a body state or condition that results from the stimulation of a sensory receptor site and transmission of the nerve impulses along an afferent fiber to the brain (Mosby's Dictionary of Medicine, Nursing & Health Professions, 2013:1622).*

Spinal cord: *The major column of nerve tissue that is connected to the brain and lies within the vertebral canal and from which the spinal nerves emerge. thirty-one pairs of spinal nerves originate in the spinal cord: 8 cervical; 12 thoracic; 5 lumbar; 5 sacral; and 1 coccygeal. the spinal cord and the brain constitute the central nervous system (Medicinenet, 2018).*

Sympathetic nervous system: *Accelerates heart rate, constricts blood vessels, and raises blood pressure (Mosby's Dictionary of Medicine, Nursing & Health Professions, 2013:165).*

Suprapubic catheter: *A suprapubic catheter is a type of urinary catheter. It empties the bladder through an incision in the belly instead of a tube in the urethra (Berry, 2017).*

Tetraplegia: *Tetraplegia refers to the impairment or loss of motor/ and or sensory function in the upper and lower extremities (limbs), trunk and pelvic organs. Bladder and bowel control is affected and patients are left dependent on others for most of their needs (Mosby's Dictionary of Medicine, Nursing & Health Professions, 2013:1759; Somers, 2010:21).*

Thermoregulatory disorders: Disorder of thermoregulation which is the control of heat production and heat loss, specifically the maintenance of body temperature through physiological mechanisms activated by the hypothalamus (Mosby's Dictionary of Medicine, Nursing & Health Professions, 2013:1764).

Urinary tract infection: Infection of one or more structures in the urinary system, and is caused by gram-negative bacteria. May be asymptomatic but symptoms may include blood and pus in the urine, vomiting and burning sensation (Mosby's Dictionary of Medicine, Nursing & Health Professions, 2013:1846).

Ventilator: Several devices used in respiratory therapy to provide assisted respiration and intensive positive-pressure breathing (Mosby's Dictionary of Medicine, Nursing & Health Professions, 2013:1867).

Vertebral column: 33 vertebrae that fit together to form a flexible, yet extraordinarily tough, column that serves to support the back through a full range of motion. The vertebral column also protects the spinal cord, which runs from the brain through the hollow space in the middle of the vertebral column. There are 7 cervical (C1-C7), 12 thoracic (T1-T12), 5 lumbar (L1-L5), 5 sacral (S1-S5), and 3 to 5 Coccygeal vertebrae (Medicinenet, 2018).

Visceral pain: Visceral pain is most likely to originate from the abdomen, and could mainly be attributed to constipation (Hadjipavlou et al., 2016:264).

2.3 Prevalence of spinal cord injury and tetraplegia

There is no reliable estimate of global prevalence of spinal cord injury, but estimated annual global incidence according to the WHO is 40 to 80 cases per million population. Up to 90% of these cases are due to traumatic causes, though the proportion of non-traumatic spinal cord injury appears to be growing (WHO, 2017). Males are most at risk in young adulthood (20-29 years) and older age (70+). Females are most at risk in adolescence (15-19 years) and older age (60+). Studies done by the WHO report male-to-female ratios of at least 2:1 among adults, sometimes much higher (WHO, 2017).

Few epidemiological data are available on spinal cord injuries in South Africa. Worldwide reviews often include South African data, a study done at the Groote Schuur Hospital during 2013 concluded the following findings; the total number of patients admitted to the Acute Spinal Cord Injury Unit was 2 042, with an average of 185 admissions per year. The male/female ratio was 5.25:1. The 21 - 30-year-old age category was the largest, comprising 33.5% of the patients. The most prevalent cause of injury was motor vehicle accidents (44.6%), followed by violence-related injuries (27.2%) (Sothmann et al., 2013:836).

2.4 Causes of spinal cord injury

Spinal cord injuries are regarded as '*traumatic*' or '*non-traumatic*.' Traumatic injuries are caused by an abrupt traumatic hit to the spine which results in damage to one or more of the vertebrae, or a severing of the spinal cord. *Non-traumatic injuries* are the result of slow internal damage to the spinal cord region (International perspectives on spinal cord injury, 2013; ISCoS, 2012; Mayo Clinic, 2017).

A *traumatic* spinal cord injury may stem from a sudden, traumatic blow to the spine that fractures, dislocates, crushes, or compresses one or more of the vertebrae. The most prevalent causes of traumatic spinal cord injuries result from motor vehicle accidents, falling from heights, occupational as well as sports injuries, and violence. *Non-traumatic* spinal cord injury, on the other hand, usually involves an underlying pathology including infectious diseases, tumours, musculoskeletal disease such as osteoarthritis, Tuberculosis of the spine (International perspectives on spinal cord injury, 2013; ISCoS, 2012; Mayo Clinic, 2017).

2.5 Pathophysiology

A spinal cord injury can either be classified as a primary injury or secondary injury.

2.5.1 Primary injury

Initial damage results from direct cord compression, haemorrhage, and traction forces. The commonest mechanism in trauma is subluxation of the vertebral elements causing a pincer like direct damage to the cord. This can cause complete cord transection in extreme cases (Bonner & Smith, 2013:226; Rouanet, Reges, Rocha, Gagliardi & Silva, 2017: 387).

2.5.2 Secondary injury

Within minutes after injury, secondary damage begins. Haemorrhage in the central grey matter occurs and axons and neuronal cell membranes become damaged. These events lead to spinal cord oedema and subsequent spinal cord ischemia. Loss of auto regulation with high thoracic lesions contributes to neurogenic shock (Bonner & Smith, 2013:226; Rouanet et al., 2017: 387).

2.6 Composition of the spine

The composition of this spine including the structure of the spinal cord, the components and the functioning of the spinal cord will be discussed.

Figure 2.1 shows the structure and functions of the spinal cord:

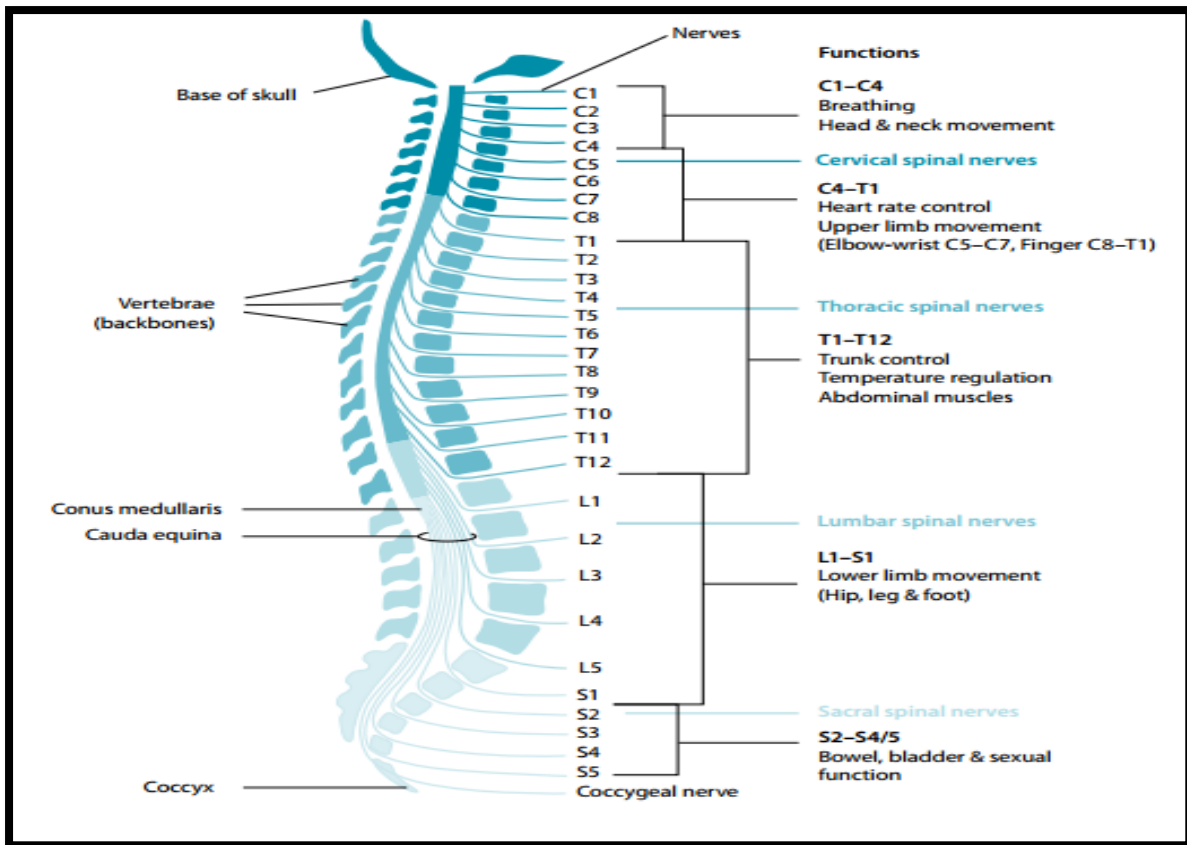
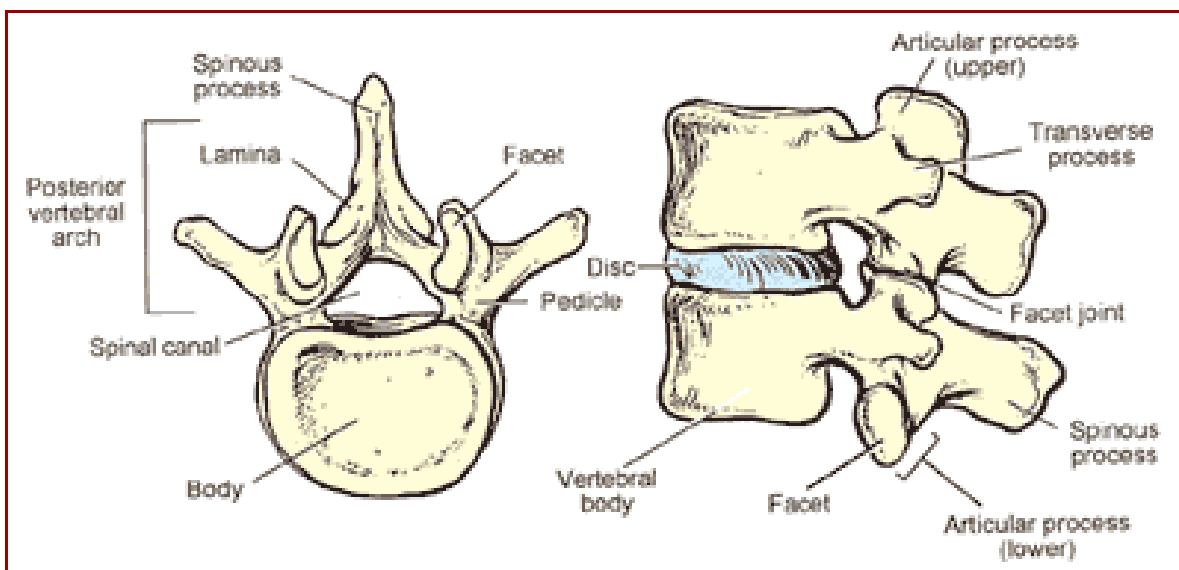


Figure 2.1: The structure and functions of the spinal cord (World Health Organisation, 2017; ISCoS, 2012; Walker, 2009:48).

2.6.1 The structure of the spinal cord

The vertebral column is divided into cervical, thorax, lumbar, sacral and coccygeal regions. The spine is made up of seven cervical vertebrae (C1-C7); 12 thorax (T1-T12); five lumbar (L1-L5) vertebrae, five fused sacral vertebrae (S1-S4) and four fused



coccygeal vertebrae as is illustrated in Figure 2.1 above. The vertebral bodies are separated by intervertebral discs and the sacral and coccygeal vertebrae are fused (Bonner & Smith, 2013:2224; Somers, 2010:8).

Figure 2.2 illustrates the components of the vertebrae:

Figure 2.2: Components of the Vertebrae (Walker, 2009:48)

The vertebrae are stacked on top of each other like building blocks with a cartilage cushion, the intervertebral disks between each vertebra. Each of these vertebrae has a large oval bony portion called the vertebral body. The vertebrae also have a large hole in the back part of the bone, behind the vertebral body called the spinal canal. The spinal cord and nerves travel within the spinal canal extending from the brain down to the tailbone. These nerves carry the signals from the brain to the muscles and the rest of the body (Somers, 2010:8; Walker, 2009:48).

2.6.2 The functioning of the spinal cord

The function of the spinal cord is to allow both sensory and motor information to pass between the body and the brain (Bonner & Smith, 2013:225; Walker, 2009:48)

The spinal cord extends from the medulla oblongata just above the foramen magnum to the level of the L1 or L2 vertebrae. The spinal cord contains long axons of upper motor neurons descending from the brain, lower motor neurons (somatic motor neurons) with axons that travel to the periphery to innervate skeletal muscles, sympathetic and parasympathetic visceral motor neurons, long axons of sensory neurons ascending to the brain and interneurons (segmental and intersegmental) that interconnect neurons with the cord itself (Somers, 2010:9; Walker, 2009:48).

Normal voluntary and reflexive motor function, sensory function and autonomic control involve complex interactions between supraspinal systems, lower motor neurons, visceral motor neurons, peripheral afferents and networks of interneurons (Somers, 2010:9; Walker, 2009:48).

The spinal cord also contains glial cells, nonneuronal cells that are essential to the neurons' functioning and survival. The spinal cord has an H-shaped area of gray matter centrally, see image below. This gray matter is composed of the cell bodies of

neurons, their dendrites and the initial segments of their axons; the terminals of axons that synapse on these neurons and glial cells. The ventral (anterior) horn contains the bodies of lower motor neurons innervating skeletal muscles. The gray matter of the spinal cord is surrounded by white matter, consisting of ascending and descending fibers- the axons of sensory and motor neurons (Somers, 2010:9; Walker, 2009:48).

2.7 Biological implication: spinal cord injuries

The biological implication of spinal cord injuries will be discussed, including the physiological overview; classification and symptoms of spinal cord injury; complete versus incomplete lesion; levels of spinal cord injuries and medical and surgical management.

2.7.1 Physiological overview

Spinal cord injuries are regarded as '*traumatic*' or '*non-traumatic*.'

Traumatic spinal cord injuries may stem from a sudden, traumatic blow to the spine that fractures, dislocates, crushes, or compresses one or more of the vertebrae. The most prevalent causes of traumatic spinal cord injuries include gunshot wounds; motor vehicle accidents; falling from heights; acts of violence; sports injuries (WHO, 2017; ISCoS, 2012; Mayo Clinic, 2017; Sothman et al., 2015:836; Walker, 2009:49).

Non-traumatic spinal cord injuries can be caused by disease such as cancer/tumours, Guillian-Barre Syndrome and Multiple sclerosis (Fehlings et al., 2013 :56; ISCoS, 2012; Mayo Clinic, 2017; Sothman et al., 2015:836; WHO, 2017; Walker, 2009:49).

2.7.2 Classification and symptoms of spinal cord injury

Sustaining a spinal cord injury can either be classified as tetraplegia or paraplegia;

- *Tetraplegia* refers to the impairment or loss of motor/ and or sensory function in the upper and lower extremities (limbs), trunk and pelvic organs. Bladder and bowel control are affected and persons with tetraplegia are left dependent on others for most of their needs. This is indicated from injury level C1-C7 (Mosby's Dictionary of Medicine, Nursing & Health Profssions. 2013:1759; Somers, 2010:21).

- *Paraplegia* refers to impairment or loss of motor and or sensory function in the trunk, lower extremities (limbs) and pelvic organs, but motor and sensory function is normal in the upper extremities (limbs), bladder and bowel control is often affected (Mosby's Dictionary of Medicine, Nursing & Health Professions. 2013:1759; Somers, 2010:21).

2.7.3 Complete versus an incomplete lesion

The extent of the spinal cord injury is either considered as a complete or incomplete injury. The levels of injury are an indication of the extent of the loss of sensory or motor control of the lower limbs, trunk and upper limbs, as well as loss of autonomic (involuntary) regulation of the body (Figure 2.1). This autonomic regulation can affect the breathing, heart rate, blood pressure, temperature control, bowel and bladder control, and sexual function (ISCoS, 2012; WHO, 2017). A person has sustained an incomplete spinal cord injury if some sensory and/or motor function is preserved below the level of the lesion. A person with a complete injury has no sensation or movement below the level of their injury (ISCoS, 2012; Mayo Clinic, 2017; Somers, 2010:24).

2.7.4 Levels of spinal cord injuries

Most spinal cord injuries occur as a result of trauma to the vertebral column. This trauma is usually indirect, involving forces that create violent motions of the head or trunk. These forces cause flexion, extension, axial loading, distraction or shearing. Injury often occurs as a result of a combination of forces that occur simultaneously or in rapid succession (Somers, 2010:10). Spinal cord injury occurs when vertebral injury leads to compression, traction, or transection of the cord, or disrupts its vascular supply. Spinal nerve damage also frequently occurs (ISCoS, 2012; Mayo Clinic, 2017; Somers, 2010:24).

When the injury is caused by vertebral injury, the cord typically sustains damage due to impingement by bony or soft tissue structures, this occurs when vertebrae dislocates or a vertebral body bursts. The spinal cord can also be damaged by traction, or by direct insult from a foreign body such as a bullet or knife. Concussive shock waves caused by a bullet can also cause damage without even penetrating the spinal cord. In both penetrating and non-penetrating injuries, more severe disruption of the

spinal canal leads to more severe neurological damage. The spinal cord does not have to be severed for irreversible damage to occur (Somers, 2010:13)

According to Somers (2010:8) the spine consists of vertebral bodies separated by intervertebral discs. A flexible column is situated in the middle line and forms part of the posterior trunk. The vertebral column is divided into cervical, thorax, lumber sacral and coccygeal regions. The spine is made up of seven cervical vertebrae (C1-C7); thorax (T1-T12); five lumber (L1-L5) vertebrae, five fuse sacral (S1-S4) and four fused coccygeal vertebrae as is illustrated in Figure 2.2 earlier. The current research study will only focus on tetraplegia and discuss the different classifications of tetraplegia according to (International perspectives on spinal cord injury, 2013; Invivo Therapeutics, 2017).

TABLE 2.1: Levels of tetraplegia

<p>Tetraplegia (C1-C4)</p>	<p>An injury to the C1-C4 vertebrae is classified as the greatest level of paralysis. This level of injury is characterized by complete paralysis; the person has no motor function of the arms or legs. The person is able to move their head, and possibly shrug their shoulders. The use of a power wheelchair is necessary with control by using the chin or breath. An injury resulting in C1-C4 tetraplegia will require a caregiver's assistance for most of their daily needs, including bathing, grooming, dressing, eating and drinking as well as transferring from their bed to their wheelchair. Persons with tetraplegia on this level are fully reliant on a caregiver to manage their bladder and bowel activity. They are also unable to drive a motor vehicle (International perspectives on spinal cord injury, 2013; Invivo Therapeutics, 2017; Walker, 2009:52).</p>
<p>Tetraplegia (C5)</p>	<p>Persons who sustained a C5 injury are in most cases able to flex their elbows and with the help of assistive devices they can be able to hold objects. Affected by this level are also</p>

	<p>candidates to learn how to feed and groom themselves. They have more mobility than a C1-C4 level and will be able to dress their upper body and change positions in bed with some assistance. They are candidates for a power wheelchair equipped with hand controls or possibly manual wheelchairs with grip attachments for short distances on even terrain. Persons with a C5 level injury will also rely on a caregiver to transfer from bed into their wheelchair and they are dependent on a caregiver for bladder and bowel management. Bathing and dressing the lower body is also done by the caregiver (International perspectives on spinal cord injury, 2013; Invivo Therapeutics, 2017; Walker, 2009:52).</p>
<p>Tetraplegia (C6)</p>	<p>Sustaining a C6 injury allows for the use of both the elbow and wrist. With assistive support objects are often able to be grasped. Independent transfers may be possible in some cases. Some are also able to manage their bladder and bowel with assistive devices. Persons with this injury become significantly more independent as they can learn to feed, groom and bath themselves with the help of an assistive device. The dependence on a caregiver is substantially less, they are also able to operate a manual wheelchair with grip attachments (International perspectives on spinal cord injury, 2013; Invivo Therapeutics, 2017; Walker, 2009:52).</p>
<p>Tetraplegia (C7)</p>	<p>Persons who sustained this level of injury are able to extend their elbows, which allows them greater freedom of movement. Often, persons with this level of injury are able to live independently and often do not need the full time assistance of a caregiver as with the higher levels of injury. They are able to perform most activities of daily living with or without the help of assistive devices (International</p>

	perspectives on spinal cord injury, 2013; Invivo Therapeutics, 2017; Walker, 2009:52).
Tetraplegia (C8)	Persons who sustained the C8 level of injury are often able to flex their fingers, allowing them a better grip on objects. They are able to perform activities of daily living without assistance. They are able to transfer themselves and manage their bowel and bladder independently. They make use of a manual wheelchair (International perspectives on spinal cord injury, 2013; Invivo Therapeutics, 2017; Walker, 2009:52).

2.7.5 Medical and surgical management

Initial management after sustaining a spinal cord injury is crucial to long term survival and quality of life. The primary goals for management include preserving the person's life, minimising the neurological damage, stabilizing the spine and preventing secondary complications (Bonner & Smith, 2013:224; Sisto et al, 2010:18; Grundy & Swain, 2002). When the injury occurs, emergency and medical personnel initially secure spinal immobilization by placing the injured person on a spinal board with straps. Spinal traction should not be applied until the specific diagnosis is firmly established, by means of proper imaging studies of the entire spine at a hospital. If spinal stability and decompression of the nervous tissue cannot be obtained by nonsurgical means, surgery may be indicated (Sisto et al., 2010:18).

A spinal cord injury compromises the functioning of most organs in the body, therefore places the affected person at high risk for secondary medical complications, particularly during the acute phase of an injury. Proper management is therefore pivotal to promote recovery and healing (Sisto et al., 2010:18).

2.7.5.1 Neurological assessment and classification of the patient

After initial general stabilization, it is imperative to perform a thorough neurological examination in order to determine the neurological effects of the sustained injury. The American Spinal Injury Association (ASIA) standard for neurological and functional

classification is the recommended preferred tool, as shown in Figure 2.3 below. It is a significant means of standardizing the initial and follow-up examinations, and also has a role in predicting the prognosis (Roanet et al, 2017:388; Walker, 2009:51).

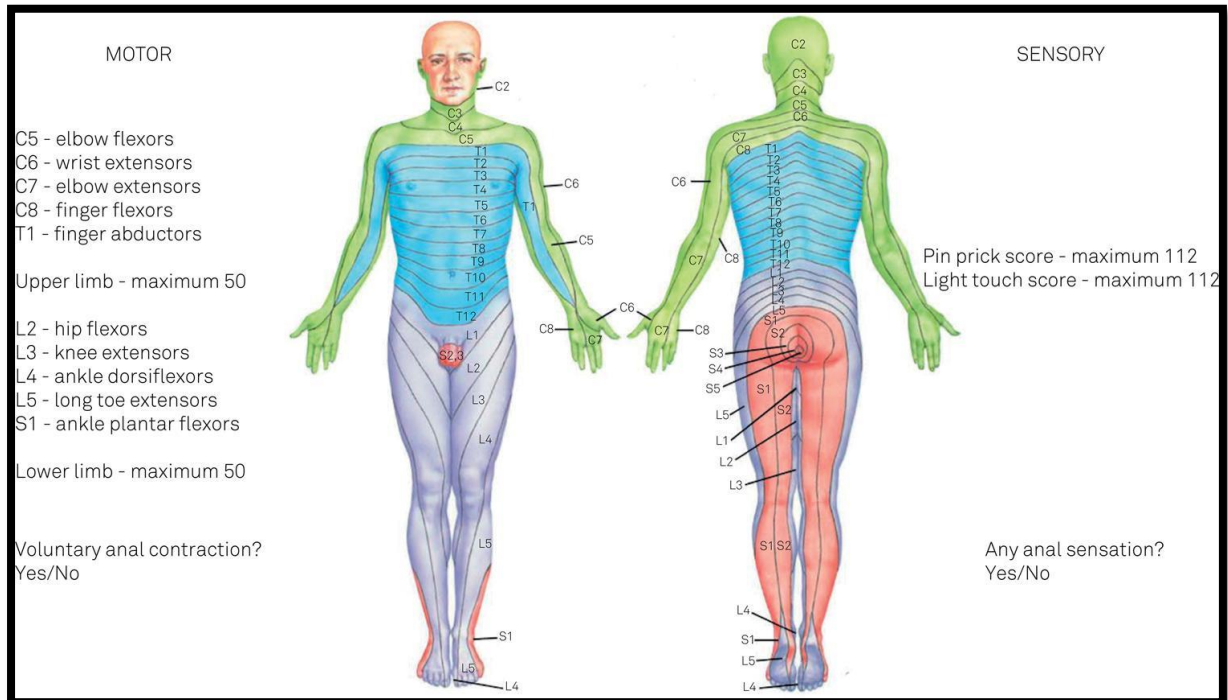


Figure 2.3: Diagrammatic representation of the ASIA Impairment scale (Roanet et al., 2017:388; Walker, 2009:51)

Figure 2.3 is a representation of the ASIA Impairment scale, the scale score has a prognostic value (Roanet et al., 2017:388; Grundy & Swain, 2002:5; Walker, 2009:51).

The tool consists of two components, the sensory and the motor. The sensory component comprises the testing of a key point in each of the 28 dermatomes (from C2 to S4-5) on the right and left sides. Light touch and pinprick sensation are also tested. Each modality is separately scored on a three-point scale, ranging from 0 (absent) to 2 (normal or intact) (Roanet et al., 2017:388; Walker, 2009:51).

The motor examination encompasses testing of key muscle functions corresponding to ten paired myotomes (C5-T1 and L2-S1). Voluntary external anal sphincter contraction should also be tested. The strength should be graded according to the Medical Research Council grading system, from 0 to 5 (Roanet et al., 2017:388; Grundy & Swain, 2002:5; Walker, 2009:51). With that, the neurological level of injury

is determined as the most caudal segment of the cord with intact sensation and antigravity muscle function strength.

The ASIA Impairment Scale can be utilized to assess the level of injury as follows:

- A = complete. No sensory or motor functions in sacral segments S4-S5.
- B = sensory incomplete. Sensory but not motor function is preserved below the neurological level of injury including S4-S5 and no motor function is preserved more than three levels below the motor level on each side of the body.
- C = motor complete. Motor function is preserved below the neurological level, and more than half the muscles below the neurological level of injury have a muscle grade less than 3.
- D = motor incomplete. Motor function is preserved below the neurological level, and at least half the muscles below the neurological level of injury have a muscle grade > 3.
- E = Normal. Sensation and motor functions are normal in all segments tested.

2.8 Complications of tetraplegia

Secondary complications are prevalent in persons with tetraplegia. The most common secondary complications are cardiovascular, respiratory as well as bowel and bladder management (Walker, 2009:49).

2.8.1 Cardiovascular complications and management

Cardiovascular complications are prevalent after sustaining tetraplegia. These complications are often due to the interruption of communication between receptor organs and brainstem centers, as well as interruption of the autonomic nervous system. These complications may include:

- Orthostatic hypotension
- Cardiac arrhythmia;
- Thermoregulatory disorders;
- Autonomic dysreflexia

- Thrombophlebitic disorders as well as
- Deep venous thrombosis (Sisto et al., 2010:21; Rouanet, 2017: 389; Walker, 2009:53).

2.8.1.1 Orthostatic Hypotension

Orthostatic hypotension can be defined as a fall in blood pressure that results from a change in body position toward the upright. Symptoms include light-headedness; dizziness; numbness around the face. Higher lesion injuries tend to experience this more than persons who sustained a lower lesion. This syndrome lessens with time as a result of the development of spinal postural reflexes that cause vasoconstriction and improved autoregulation of cerebrovascular circulation in response to low perfusion pressures (Sisto et al, 2010:22; Rouanet et al., 2017: 389). Treatment for orthostatic hypotension often involves the use of abdominal binders, compression stockings; or lower limb ace wraps while gradually bringing the person toward an upright position (Sisto et al. 2010:22; Rouanet et al, 2017: 389; Walker, 2009:53).

2.8.1.2 Cardiac arrhythmias

Cardiac arrhythmias are commonly seen in early weeks after an injury and may often occur in persons with lesions higher than T5. This might be due to inadequate supraspinal control of the sympathetic nervous system and unopposed vagal tone. This usually resolves after a few weeks as spinal shock resolves (Sisto et al., 2010:22; Rouanet et al., 2017: 389; Walker, 2009:53).

2.8.1.3 Thermoregulation

Persons who are affected especially by high lesions above T5 are unable to regulate their body temperature accurately and will often adapt to the temperature of the local environment. It is therefore important to educate persons affected as well as their significant other to protect themselves from hypo and hyperthermia (Sisto et al., 2010:22; Rouanet et al., 2017: 389).

2.8.1.4 Autonomic dysreflexia

Autonomic dysreflexia is often described as the spike of blood pressure in spinal cord injured patients. This is a medical emergency that requires quick response and at

times medical intervention. It is caused by a noxious stimulus below the level of injury that the affected person is unaware of, due to lack of sensation. These stimuli may often result from urinary bladder- indicating that the bladder is either full or the catheter is kinked or blocked; Constipation; pressure ulcers; ingrown toenails or tight clothing. Symptoms may often include headache; sweating above the level of the lesion and getting goosebumps across the surface of their skin. Often the affected person also complains of nasal congestion and severe anxiety. Potential complications of autonomic dysreflexia often include retinal haemorrhage; intracerebral haemorrhage; myocardial infarction; seizures or potential death. Treatment includes recognition of the symptoms along with prompt removal of the precipitating stimuli (Sisto et al., 2010:23).

2.8.1.5 Deep vein thrombosis

Deep vein thrombosis is the most common cardiovascular complication after an acute spinal cord injury. The risk factors associated with developing this condition is lower limb fracture; older age; obesity; history of previous thrombosis and diabetes. This condition is more common amongst persons who sustained tetraplegia especially pertaining to complete injuries (Sisto et al., 2010:23).

2.9 Respiratory complications and management

Respiratory complications are the main cause of morbidity and mortality in the acute phase of a spinal cord injury, with incidence ranging from 36%-83%. Reduced vital capacity, retention of secretions and autonomic dysfunction all play a role, including aspiration, atelectasis and pneumonia that may often require mechanical ventilation. (Rouanet et al., 2017:389). Generally the more advanced in age the person affected, the more likely this condition will develop. Pre-existing respiratory conditions such as history of cigarette smoking; chronic obstructive pulmonary disease; bronchial asthma; intrinsic lung disease and marked obesity can exasperate vulnerability for developing respiratory complications. Respiratory insufficiency during the acute stage after sustaining tetraplegia can occur for several reasons including paralysis of some or all the respiratory muscles. The injury level, and the ASIA classification are the most significant factors for the need of intubation (Rouanet et al., 2017:389). Prominently

most lesions above C5 require intubation by means of mechanical ventilation. Injuries below C3 may also require mechanical ventilation for a period of time. The persons affected may be unable to clear their secretions because of a lessened ability to cough as a result of paralysis of abdominal muscles, injuries to the chest such as rib fractures (Rouanet et al., 2017:389; Sisto et al., 2010:23; Walker, 2009:52).

Therefore, good respiratory care during acute injury is detrimental in preventing potential respiratory complications. Breathing treatments with saline solution should often be provided with a high level injury; active chest physical therapy including percussion, postdural drainage as tolerated and assistive coughing techniques are important aspects of respiratory care (Rouanet et al., 2017:389; Sisto et al., 2010:24).

2.10 Bowel management

A common complication after sustaining tetraplegia is altered bowel elimination. Common complaints or symptoms are often related to bowel elimination; haemorrhoids; abdominal distention, and autonomic dysreflexia caused by rectal impaction. Factors contributing to these symptoms may include altered colonic compliance; impaired transit time and poor dietary intake (Sisto et al., 2010:26). Prevention of these symptoms is often promoted by an effective bowel program, which allows the affected person to have control over the time and frequency of bowel elimination. The combination of oral medications (including stool softeners and oral stimulants) suppositories; and digital stimulation is usually effective for elimination of stools. The goals of an effective bowel program are to minimise or eliminate the occurrence of unplanned bowel movements, to evacuate stools at a regular and predictable time and to prevent gastrointestinal disturbances (Sisto et al., 2010:26). It is important to comply with the regime of the bowel programme for persons affected by tetraplegia, to enhance the daily living activities and enhance a feeling of being in control of functioning.

2.11 Urological management

Bladder dysfunction often remains a major care management challenge. During the immediate post-injury period, an indwelling catheter is recommended. During the period of spinal shock, urinary retention is the rule due to the bladder becoming a-reflexic, meaning messages from the spinal cord are not able to reach the bladder in order to contract the muscles to let the urine pass voluntarily. An indwelling catheter provides adequate bladder drainage. Retention of urine or the presence of foreign bodies in the bladder including the catheter may lead to frequent urinary tract infections. Intermittent catheterization is recommended as early as possible provided that the affected person is medically stable; is able to tolerate fluid restriction and is able to perform the intermittent catheterization process independently. The goals of management of the neurogenic bladder are to achieve acceptable method of bladder drainage which in turn is aimed at preventing complications such as urinary tract infections; stone formations and bladder associated autonomic dysreflexia. Bladder drainage by an indwelling or suprapubic catheter is an option for patients unable to perform self-intermittent catheterization (Sisto et al., 2010:25).

2.12 Integumentary complications- pressure ulcers

Pressure ulcers are a common secondary complication after sustaining a spinal cord injury. Pressure ulcers are caused by pressure and shear forces. Paralysis; loss of sensations; incontinence of urine and stool; infections; obesity; spasticity; joint contracture and poor nutrition are factors contributing to developing a pressure ulcer. The most common sites for developing a pressure ulcer are the sacrum followed by the heels. All bony prominences must be considered as potential places for pressure ulceration. Pressure ulcers are categorized according to the depth and extent of tissue damage (Sisto et al., 2010:32).

A pressure injury is localized damage to the skin and/or underlying soft tissue usually over a bony prominence or related to a medical or other device. The injury can present as intact skin or an open ulcer and may be painful. The injury occurs as a result of intense and/or prolonged pressure or pressure in combination with shear. The tolerance of soft tissue for pressure and shear may also be affected by microclimate,

nutrition, perfusion, co-morbidities and condition of the soft tissue (NPUAP, 2017). The stages of pressure ulcers are discussed in Table 2.2.

Table 2.2: National Pressure Ulcer Advisory Panel Stages of Pressure Ulcers (NPUAP, 2017).

STAGE	DESCRIPTION
Stage 1 Pressure Injury: Non-blanchable erythema of intact skin	Intact skin with a localized area of non-blanchable erythema, which may appear differently in darkly pigmented skin. Presence of blanchable erythema or changes in sensation, temperature, or firmness may precede visual changes. Color changes do not include purple or maroon discoloration; these may indicate deep tissue pressure injury.
Stage 2 Pressure Injury: Partial-thickness skin loss with exposed dermis	Partial-thickness loss of skin with exposed dermis. The wound bed is viable, pink or red, moist, and may also present as an intact or ruptured serum-filled blister. Adipose (fat) is not visible and deeper tissues are not visible. Granulation tissue, slough and eschar are not present. These injuries commonly result from adverse microclimate and shear in the skin over the pelvis and shear in the heel. This stage should not be used to describe moisture associated skin damage (MASD) including incontinence associated dermatitis (IAD), intertriginous dermatitis (ITD), medical adhesive related skin injury (MARS), or traumatic wounds (skin tears, burns, abrasions).
Stage 3 Pressure Injury: Full-thickness skin loss	Full-thickness loss of skin, in which adipose (fat) is visible in the ulcer and granulation tissue and epibole (rolled wound edges) are often present. Slough and/or eschar may be visible. The depth of tissue damage varies by anatomical location; areas of significant adiposity can develop deep wounds. Undermining and tunneling may occur. Fascia, muscle, tendon, ligament, cartilage and/or bone are not

	exposed. If slough or eschar obscures the extent of tissue loss this is an Unstageable Pressure Injury.
Stage 4 Pressure Injury: Full-thickness skin and tissue loss	Full-thickness skin and tissue loss with exposed or directly palpable fascia, muscle, tendon, ligament, cartilage or bone in the ulcer. Slough and/or eschar may be visible. Epibole (rolled edges), undermining and/or tunneling often occur. Depth varies by anatomical location. If slough or eschar obscures the extent of tissue loss this is an Unstageable Pressure Injury.
Unstageable Pressure Injury: Obscured full-thickness skin and tissue loss	Full-thickness skin and tissue loss in which the extent of tissue damage within the ulcer cannot be confirmed because it is obscured by slough or eschar. If slough or eschar is removed, a Stage 3 or Stage 4 pressure injury will be revealed. Stable eschar (i.e. dry, adherent, intact without erythema or fluctuance) on the heel or ischemic limb should not be softened or removed.

When the rehabilitation phase begins, emphasis is placed on mobility. More time is spent out of bed and in a wheelchair, measures like prescribing the correct wheelchair and cushion; pressure relief regime should be adopted. If a person affected by tetraplegia is unable to perform pressure relief techniques by them, a caregiver should be educated and taught how to assist in doing pressure relief (Sisto et al., 2010:32). After a pressure ulcer has developed, treatment depends on the depth and degree of the ulcer. Treatment options range from improving nutrition and increasing pressure relief, to wound debridement and surgery (Sisto et al., 2010:33).

2.13 Pain management

Pain is a common yet poorly defined occurrence in persons affected by tetraplegia. The understanding of the type and aetiology of the pain can assist to determine the correct approach for management of pain.

Pain is defined by the International Association for the Study of Pain (IASP) as an unpleasant sensory or emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Pain is classified as acute if it is shorter than 12 weeks, and chronic when longer than 12 weeks. After being affected by tetraplegia chronic pain seems to be a common occurrence (Hadjipavlou et al., 2016:264). It is reported to impact about 70% of persons affected by tetraplegia with one third of these experiencing severely intense pain impacting on mood, functioning and quality of life. The pain can be nociceptive, neuropathic or visceral (Hadjipavlou et al., 2016:264) and will be discussed below.

2.13.1 Nociceptive pain

Nociceptive pain is the most common and can be caused by the initial trauma suffered to the spinal cord, muscle and joint overuse, and injury related muscle weakness, spasms and contractures (Hadjipavlou et al., 2016:264; Sisto et al.,2010:33).

2.13.2 Neuropathic pain

Neuropathic pain can often develop acutely or after one year post-injury and often presents at or below the level of the injury (Hadjipavlou et al., 2016:264; Sisto et al., 2010:33).

2.13.3 Visceral pain

Visceral pain is most likely to originate from the abdomen, and could mainly be attributed to constipation (Hadjipavlou et al., 2016:264).

2.13.4 Management of pain in spinal cord injury

The general approach to managing pain acute or chronic is the multidisciplinary team. This team involves pain specialists, clinical psychologists, psychiatrists, physiotherapists, a spinal cord injury specialist / rehabilitation specialist, and social and occupational therapy services. The entire team is necessary to treat the biology of pain, address psychological factors, and reduce obstacles to normal life (Hadjipavlou et al., 2016:266).

The social worker acknowledges that persons affected by tetraplegia often experience some form of pain in varying degrees, and it not only has an impact on their physical well-being, but also significantly affects the emotional wellbeing and quality of life of persons with tetraplegia.

2.14 Psycho-social aspects related to tetraplegia

Spinal cord injury, specifically tetraplegia is a devastating event that not only has a physical implication, but also has psychological and social ramifications for the injured person. The psycho-social challenges that persons with tetraplegia are faced with often include depression, anxiety, and feelings of hopelessness, stress and a sense of grief (Singh, Rohilla, Siwach, Dhankar, Kaur, 2012:96; ASCoN, 2015:5; Dezarnaulds & Ilchef, 2014:2). The social challenges prominent for persons who sustained tetraplegia include sexual dysfunctions, problems of social adjustment, a sense of being a burden on their family, strained partner relationships and sleep disturbances. Other factors that often affect persons with tetraplegia is frequent rehospitalization for secondary complications, an inability to return to pre-injury occupation, immobility and lack of autonomy. These factors can often adversely affect the community reintegration and quality of life of persons with tetraplegia and significant other (Singh et al., 2012:96; ASCoN, 2015:5; Dezarnaulds & Ilchef, 2014:2).

2.14.1 Psychological impact of tetraplegia

A prominent time of psychological adjustment is evident after sustaining tetraplegia. Factors related to adjustment include depression and anxiety, losses and readjustment. These factors will subsequently be discussed.

2.14.1.1 Depression and Anxiety

In many cases, the psychological implications of tetraplegia can be as devastating as the physical changes themselves (ASCoN, 2015:5; Dezarnaulds & Ilchef, 2014:2). An estimated 20-30% of people with a spinal cord injury show clinically significant signs of depression (Orenczuk et al., 2009:1; WHO, 2017), which in turn has a negative impact on improvements in functioning and overall health (WHO, 2017). A study

conducted by Migliorini and colleagues in (Fehlings et al., 2013:205; Singh et al., 2012:95) states that 37% of a community sample of persons who sustained a spinal cord injury experienced depression, 30% anxiety, 25% experienced stress and 8.4% met the diagnostic criteria for Post Traumatic Stress Disorder (Singh, et al., 2012:95).

Adjustment to the injury is a process that proceeds gradually over an extended period of time. It is not linear in nature and is unique for each person. The psycho-social adjustment to tetraplegia is often an overwhelming process that involves all of the human emotions and coping mechanisms of the person and significant other. It typically begins at the time of injury and extends throughout the person's life, demanding new adjustments as the person progresses and faces new experiences. Over time, the person often begins to perceive the injury less of a threat and more a challenge to overcome (ASCoN, 2015:8).

Significant other often experience a variety of emotional responses after a loved one sustained tetraplegia. A study conducted in 2009 in The UK states that spouses expressed feelings of anxiety, loneliness and grieving losses while going through the rehabilitation phase (Dickson, O'Brien, Ward, Allan & O'Carrol, 2009:1103). Losses ranged from mild, to experiencing emotions that the spouse had actually passed away, as this is the severity of the finality of the experienced losses. Spouses reported feeling like they had to come to terms with a life once lived, that is now lost forever as well as adapting to significant role changes after the injury.

Mourning for the familiarity of their former lives as well as a sense of uncertainty as to what the future holds was also a central theme derived in this study. Anxiety focussed on the returning home of their spouse was also central to the emotional reactions often experienced by significant other (Dickson et al., 2010:1108).

It is further reported that spouses and significant other often experience a sense of anxiety and uncertainty in navigating the post-injury life. Often significant other report to have a sense of resentment when anticipating caring for the person who sustained tetraplegia, this feeling of resentment seems to be embedded in the significant other's sense of sacrificing their own independence and sense of freedom as well as feelings of loss of control over their own lives (Dickson et al., 2010:1107).

It was further often reported that the change in stature and loss of masculinity or femininity often associated with the physical effects of tetraplegia often negatively affected the significant other's sense of attraction and feeling towards the person who sustained tetraplegia. A sense of a one-sided relationship is often also prevalent in the feelings of significant other (Dickson et al., 2010:1107).

2.14.1.2 Losses

Experiencing losses and grieving these losses are an integral part of the emotional and psychological reactions after sustaining a spinal cord injury. Adaptation is often a life-long process after sustaining tetraplegia and personal characteristics play an important role to the often life-long process, including coping mechanisms; personality traits; cognitive styles; attitudes; values and psychological health, coupled with the social support provided by loved ones and health care professionals significantly influence adaptation and participation after sustaining the injury (Fehlings et al., 2013:207; Orenczuk et al., 2009:1; Somers, 2010:54). Persons and significant other are faced with the challenge of redefining responsibilities and redefining roles in the household. This causes a significant amount of distress for both the person and significant other (Sisto et al., 2010:114; Somers, 2010:51).

This notion is further supported by Somers (2010:54) who states that grieving losses and a life-long process of readjustment is inevitable after sustaining tetraplegia. Somers (2010:54) argued however that the level of injury is not such an important factor at play in the readjustment process. (Dickson et al., 2009: 1101; Somers, 2010:54) and (Dezarnaulds & Ilchef, 2014:2) argued that there is a relationship between psychological dimensions such as personality, behaviour and perceptions after tetraplegia, with factors such as optimism, humour, self-efficacy and solution focussed coping skills. Personal characteristics including coping mechanisms; personality, cognitive styles; attitudes, values, and psychological health coupled with social support provided by loved ones and health care professionals significantly influence adaptation and participation after sustaining the injury.

An integral part of adaptation after sustaining an injury resulting in tetraplegia according to (Somers, 2010:55 & Dickson et al., 2010:1101) is grieving what they lost and reclaiming what remains. A new identity and self-image is formed through the

grieving and adaptation process. Somers (2010:55) is confident that as the person with tetraplegia moves through this process of grieving and adaptation their identity, life goals, lifestyle and sources of satisfaction will often evolve. This is an indication of the possibility of positive psychological outcomes.

A sense of guilt for having feelings of resentment is also predominant in significant other. This seems to promote an internal turmoil about confronting their negative emotions especially related to their perception of loss of independence interchanged for a new-found caregiver role and subsequent identity (Dickson et al., 2010:1111). Significant other also often seem to experience a distinct change in their spousal identities which were unanticipated, as well as grieving losses associated with their anticipated futures (Dickson et al., 2010:1111). Significant other seem to experience that their own wellbeing becomes second and the wellbeing of the person with tetraplegia often assumes primary priority.

2.14.1.3 Readjustment

Readjustment after sustaining a spinal cord injury, especially tetraplegia could be a life-long process, encompassing working through different stages of losses and coming to a place of acceptance, as is confirmed by (Sisto et al., 2010:104) after sustaining a spinal cord injury aspects pertaining to the self-perception, locus of control and coping styles are challenged and affected. A person with tetraplegia is forced to readjust thinking and engaging with the world and needs to find alternative ways and means to engage with his world.

A variety of factors can influence the readjustment after sustaining tetraplegia, including the effect of institutionalisation; grieving the loss of life before the injury; secondary complications like chronic pain and infections, as well as emotional responses and coping mechanisms (Fehlings et al., 2013:207; Dezarnaulds & Ilchef, 2014:2). These often strong emotional reactions to sustaining tetraplegia could possibly threaten both psycho-social integration and security (Dezarnaulds & Ilchef, 2014:2).

During the rehabilitation phase, persons who sustained tetraplegia and their significant other are exposed to prolonged separation, which often evoked anxiety and uncertainties. When considering discharge after rehabilitation it seems that the change

in relationship dynamics anticipated for post-discharge appeared to be even more distressing according to the study conducted in Edenburg in the UK in 2009. A complete reversal of roles were reported, especially shifting as a significant other from depending on the injured spouse to becoming the provider and caregiver of the person affected by tetraplegia (Dickson et al., 2010:1108).

This change in roles was reported to have an influence on the feelings the spouse has towards the person affected by tetraplegia. A maternal/paternal role is almost assumed by the unaffected spouse, and their sense of identity is questioned, going from spouse to acting as a caring mother figure. Difficulties in adjusting to the role changes are often evident (Dickson et al., 2010:1109).

Other factors that could possibly affect psychological adjustment include physical factors such as medical complications including chronic pain, chronic fatigue, side effects of medication, social isolation, boredom, incontinence and dependency on family, friends and social support (Dezarnaulds & Ilchef, 2014:2).

Pre-morbid mental and emotional functioning as well as the support the person with tetraplegia experiences will significantly affect the way a person with tetraplegia approaches the readjustment after sustaining an injury. It has also been determined that pre-injury psychological characteristics such as self-concept, perceptions of control like self efficacy and coping styles are considered to be as crucial in determining adjustment to tetraplegia as are external factors like social support, socio-economic status and financial status (Dezarnaulds & Ilchef, 2014:2).

2.14.2 Social impact of tetraplegia

Social factors affected by tetraplegia are prominent, and aspects that have a social impact on the person with tetraplegia and significant other will be discussed below including: social interaction and needs; relationships and intimacy; support systems; social participation and socio-economic status.

The impact of tetraplegia and the long-lasting effects are not only limited to the person who sustained tetraplegia, but often extend to the significant other. Significant other are often faced with the inevitable stages of readjustment. In some cases pre-morbid family functioning is exacerbated by the diagnosis of tetraplegia. Drastic changes in

family roles contribute to family stress and changes in family roles. Significant other have comparable stress to that of the person with tetraplegia as changes associated with the loss of mobility and sensations may often result in persons being left incapable of mobilising independently in a variety of social settings (Sisto et al., 2010;115).

Tetraplegia and the life changes associated with the loss of mobility and sensation may often result in persons affected by tetraplegia to be unable to mobilise independently in a variety of social settings without any support or assistance. Persons affected by tetraplegia often find themselves paralysed, incontinent, immobile, dependent and isolated. They are also faced with social and physical difficulties such as isolation; stigmatization and community inaccessibility when engaging in social activities. These challenges in social participation often results in significant other also being susceptible to hostility and isolation as well as significant psycho-social consequences for all systems involved (Fehlings et al., 2013:208; Sisto et al., 2010:115; Somers, 2010:52).

The WHO (2017) stated that discrimination and isolation are evident for people with disabilities, as a group they are seen as substantially different from the rest of society. Persons with disabilities are also often perceived as less desirable than able bodied people. Discrimination is manifested in different ways including physically, emotionally and socially (ASCoN, 2015:8; WHO, 2017).

2.14.2.1 Social interaction and needs

There is often a significant change in the social interaction of persons who sustained tetraplegia. During the hospitalisation and rehabilitation phase the person is likely to experience separation from loved ones. After discharge the previous social functioning of the person is considerably different and often is accompanied by a variety of challenges. These challenges may include changes in relationships with friends and significant other; roles may be altered; patterns of communication and intimacy are likely to change; losses are prevalent after discharge, and the person and significant other are tasked with readjusting to these changes (Somers, 2010:53). Misconceptions, negative attitudes and physical barriers to basic mobility result in the exclusion of many people from full participation in society (WHO, 2017).

Another aspect affecting the social participation of persons affected by tetraplegia is their limited ability to care for themselves and move around independently after an injury. This increased need for support promotes dependence on significant other, and results in a decreased sense of autonomy for the person affected. Often other aspects exasperated by the physical and emotional effects of tetraplegia are the limited ability to engage in recreational, social educational and vocational activities. This has a significant impact on social participation which used to occupy most of their days prior to sustaining tetraplegia. This increased sense of dependence and loss of social participation often has a significant impact psychologically and socially on the persons affected by tetraplegia (Somers, 2010:53).

2.14.2.2 Tetraplegia and intimacy

A study conducted in Australia on bladder and bowel dysfunction as a complication of tetraplegia found that the altered function of the bowel and bladder changed relationships significantly due to the following factors: decreased sense of intimacy in partner relationships; strained partner relationships and role changes for family and friends. There is a sense of increased dependence on significant other for assistance to perform bladder and bowel functions, and this dependence often seem to put pressure on significant other and friends. A lack of understanding from friends about bladder and bowel management often caused frustration and imputed on social attendance (Fehlings et al., 2013:208). Dickson et al., (2009:1110) also reported that spouses often experience discomfort in taking on responsibility in facilitating the bodily functions on the behalf of the person who sustained tetraplegia including bowel and bladder management.

Persons affected by tetraplegia often experience difficulties within romantic relationships and intimacy after sustaining a spina lcord injury. A high level lesion resulting in tetraplegia has been reported to dramatically affect the ability to engage in and enjoy sexual expression. This in turn has an impact on relationship satisfaction and quality of life as a whole (Sisto et al., 2010:547; Singh, et al., 2012:95).

The neurological changes, especially those associated with high level lesions frequently result in sexual dysfunction. Such difficulties can lead to emotional distress for both the person affected as well as his romantic partner. Sexuality is

both physiological and psychological and the physical and emotional distress associated with sexual difficulty can often impact the quality of the intimate relationship negatively. Spinal trauma has a direct impact on the quality of sexual activity and intimacy between persons who sustained tetraplegia and their partners. Factors that frequently discourage persons with tetraplegia to pursue physical intimate relationships include: bowel and bladder accidents; an altered body image; autonomic dysreflexia; pain interference and spasticity (Fehlings et al., 2013:208; Leo & Orange, 2009:263).

In present society, people with disabilities are often regarded as non-sexual beings, however, if we accept sexual expression as a natural and significant part of human life, then perceptions that exclude sexuality for people with disabilities deny this basic right of expression. Perceptions of people with disabilities as non-sexual beings prevent people with disabilities from gaining equal access to information and acceptance as sexual beings (Fehlings et al., 2013:208; Leo & Orange, 2009:263).

It is further stated by the (NCISC, 2012) that considering the youthful age of most persons with spinal cord injuries, it is not surprising that most (51.7%) are single when injured. Among those who were married at the time of injury, as well as those who marry after injury, the likelihood of their marriage remaining intact is slightly lower when compared to the general population. The likelihood of getting married after injury is also reduced.

2.14.2.3 Support systems

Social support has been found to be related to psychological outcomes and adjustment after tetraplegia. The importance of social support from family and peers are emphasized during the readjustment process. It has been found that quality of life after sustaining tetraplegia is linked to secondary complications; activity limitations and barriers to participation rather than the injury itself or degrees of physical ability, the majority of people with tetraplegia however report life satisfaction. The management and support of persons with tetraplegia require various specialized resources and can place a substantial financial burden on persons, their significant other as well as the community (Singh et al., 2014:310; Fehlings, 2013:209; Somers, 2010:51).

The adaptation process to tetraplegia is a life- long process. Persons affected by tetraplegia and significant other are faced with challenges stemming from the physical impairments, which has an impact on the emotional and social functioning of both the affected person and significant other.

Fehlings et al., (2013:208) stated that social support has been found to be related to psychological outcomes and adjustment after tetraplegia. The importance of social support from family and peers are emphasised during the readjustment process (Fehlings et al., 2013:209).

As stated in the section on tetraplegia and intimacy, it seems that significant other, especially spouses, are sometimes not adept physically nor emotionally to render sustainable support to persons who sustained tetraplegia. Therefore, an alternative means of social support has been proposed. In a study conducted by Sherman and De Vinney (2004:140), the focus is on the value of peer support after sustaining tetraplegia. Sherman and De Vinney (2004:140) stated that individuals with a spinal cord injury report greater social support perceive themselves to be better adjusted to their injury and experiences less emotional distress. They also report a higher global quality of life and has significant fewer health problems, less hospital utilization and decreased mortality. They further stipulated that typically intimate confiding relations are those that best confer the beneficial effects of social support. After sustaining tetraplegia, the probability for a long-lasting relationship is significantly decreased. Sherman and De Vinney (2004: 140) proposed that alternative sources of support may significantly contribute to the adjustment after sustaining tetraplegia. Thoits (1995) as seen in (Sherman & De Vinney, 2004:140) proposes that the most effective support givers are likely to be individuals who have successfully faced the same stressful situation as the support recipient. It is further argued that this allows the support giver to provide support that best matches the emotional and practical needs of the support recipient and afford the opportunity for positive role modelling and cultivating believable hope (Borkman, 1976) as seen in (Sherman & De Vinney, 2004:140).

2.14.2.4 Social participation

Persons and significant other affected by tetraplegia are often faced with a significant change in social interaction after the injury. Trierveiler, de Souza Ramos, Schoeller,

Nogueira, da Silva Martins and Schneider (2015:993) stated that a person who sustained tetraplegia has limitations for activities which were previously simple and ordinary. Total assistance is required to perform activities like dressing, hygiene, physiological elimination and feeding. This limited capacity to perform activities interferes with independence. This notion is further confirmed by Chhabra and Batra (2016:2) who stated that a person with tetraplegia is always partially or completely dependent on someone for performing all his activities and daily routine, including initiating and participating in social interaction.

It is prevalent that social interactions are different after sustaining tetraplegia. In a study conducted by (Trierveiler et al., 2015:995) it has become apparent that family involvement can either have a functional or dysfunctional impact on the functioning and social interaction of a person who sustained tetraplegia. This study concluded that overinvolved family members can promote dependence and lack of social interaction.

Various misconceptions about tetraplegia and negative attitudes of the unaware society and individuals often lead to exclusion of many people with tetraplegia from full participation in society (Chhabra & Batra, 2016:2).

Another factor significantly affecting social interaction is the potential risk for recurrent health care complications such as urinary tract infections; pressure sores and deep vein thrombosis. The constant risk of these complications often leads to insecurity amongst people with tetraplegia and a disturbed mental state. This in turn often has the effect that family and society starts drifting away from the person with tetraplegia due to ongoing medical complications and the difficulty to engage in social interactions (Chhabra & Batra, 2016:2).

Social interactions may also often be influenced by physical access barriers within communities. Areas such as homes, schools, workplaces, hospitals and social events are often inaccessible to people who are dependent on wheelchair use for mobility. A further complication is the difficulty in procuring private or public transport suitable or accessible for a person using a wheelchair. Transport difficulty is often exasperated in rural communities and this in turn affects social participation significantly (Chhabra & Batra, 2016:2). According to Bergmark, Winograd and Koopman (2008:686) a factor that significantly affects the quality of life of persons who sustained tetraplegia is the

extent to which they are able to reintegrate into their community environments and the extent to which they perceive their social and community participation. These factors are often dependent on their residential reintegration, education, community accessibility and employment.

2.14.2.5 Socio-economic status

An integral part of the role changes associated with tetraplegia is the often loss of employment or necessity to seek alternative employment. This statement is supported by the National Spinal Cord Injury Statistical center (NSCISC, 2012) which states that more than half (57.1%) of those persons with SCI admitted to a model system reported being employed at the time of their injury. At one year after injury, 11.7% of persons with SCI are employed. By 20 years postinjury, 35.2% are employed and a similar level of employment is observed through post-injury year 35.

Singh et al., (2012: 97) also highlights the severe burden that tetraplegia could often pose on the family financially, often times the person who sustained tetraplegia was the sole earning person, or was the most responsible for the family financially. This change in the psycho-economic functioning in the household often has dire consequences pertaining to role changes, expectations and quality of life for the affected person as well as their significant other (Singh et al., 2014:310).

Another significant psycho-economic consequence of sustaining tetraplegia is the financial impact on the family to employ a full-time caregiver to assist with all activities of daily living. This has even more far reaching consequences as very often the person with tetraplegia might not be employed or earning an income after the injury (Chhabara & Batra, 2016:3).

Chhabara and Batra (2016:3) further stated that the majority of persons who sustained tetraplegia are not physically or mentally adapt to a pre-spinal cord injury work status. It is reported that the majority of persons who sustained tetraplegia do not try to procure or apply for their old jobs, and those who apply will seldom be hired.

2.15 Rehabilitation and tetraplegia

The rehabilitation process is facilitated in a multi-disciplinary team approach including services rendered by physiotherapists, occupational therapists, psychologists, social workers, medical practitioners and nursing staff. Rehabilitation is a time in which both physical and psychological growth is important. Post-discharge, it is essential for the person to have been empowered with the necessary psychological capacity to actively participate socially and vocationally in the community and in society. This includes the ability to maintain health and to direct care givers as needed in order to reduce the possibility of secondary complications. Self-management is an important asset to be mastered early in the rehabilitation process (Marino et al., 2003:50; ASCoN, 2015:9).

In order to maintain health post discharge the person is in need of sufficient emotional and social support from significant other, therefore the inclusion of significant other in the rehabilitation process is detrimental to the person's wellbeing (Singh et al., 2014:310; Fehlings, 2013:209; Somers, 2010:51; ASCoN, 2015:9).

The person and significant other should be primary members of the rehabilitation team, since significant other will most likely serve in the capacity of care givers, their input is especially important. From the onset of the in-patient rehabilitation process, it is important that significant other who will act as care givers are identified and made aware of the physical and psychological needs of the person. The significant other's own needs and concerns are to be addressed as well. Significant other need to feel comfortable to articulate their own fears, hopes and expectations without being judged (Singh et al., 2014:310; Fehlings, 2013:209; Somers, 2010:51; ASCoN, 2015:9).

This ongoing recognition of the importance of psycho-social services in Spinal Cord Injury rehabilitation has evolved gradually over time. As rehabilitation services have improved, the emphasis in Spinal Cord Injury Rehabilitation has slowly shifted from survival to quality of life. The section above indicates a growing importance of quality of life and community integration, especially as persons live for a longer period and are more active with their families and in their communities (ASCoN, 2015:6).

In a study conducted in 2010 in the United Kingdom (Back Up, 2010), the researcher investigated a variety of significant other after a person sustained a spinal cord injury and received therapy at a rehabilitation centre. A unanimous consensus was reached that there was a lack of formal support and educational services rendered to significant

other throughout the rehabilitation process, which left them feeling isolated and anxious. This lack of services also complicated the process of adaptation of the person and significant other after discharge from the rehabilitation unit. The participants exclaimed feelings of depression, anxiety, feeling alone and overwhelmed throughout the rehabilitation process because there had not been adequate services rendered to the significant other (Back Up, 2010).

The researcher agrees with the authors above that rehabilitation may be a stressful time for both the person and significant other. The researcher also fully agrees with the authors above that significant other are to be included in the rehabilitation process as they will be the person's primary support network after discharge. The researcher emphasises that significant other also experience their own sense of loss and emotional reactions to the injury and should be addressed during the rehabilitation phase of recovery. The researcher is of strong conviction that significant other are in need of psycho-social and supportive services aimed at preparation for discharge. The role of the social worker in rehabilitation is discussed in the section below.

2.16 The role of the social worker

Social work services play an important role in the acute, post-acute and rehabilitation phase. The social worker forms part of the multi-disciplinary team and focuses mainly on the psycho-social functioning of the person and significant other system. Several goals must be achieved by a social worker during these stages of in-patient rehabilitation process. These include identifying the needs of persons and significant other on admission and frequently reassess these needs throughout the rehabilitation process. The goal is to prepare the person and significant other for a safe and effective discharge by maximizing knowledge on spinal cord injury and specifically tetraplegia and identifying and addressing physical, economic, and emotional barriers to optimal community discharge. Rehabilitation social workers also regularly address emotional reactions including grief, anxiety, depression, post-traumatic stress disorder, chronic pain, and adjustment disorders (ASCoN, 2015:13; Hammond, Gassaway, Abeyta, Freeman, Primack, 2011:216; Marino et al., 2003:50).

The South African Constitution has mandated the inclusion of persons with disabilities, and is committed to ensuring inclusive and comprehensive service delivery aimed at promoting social development, social justice and social functioning of people with disabilities to bring about sustainable improvements in the wellbeing of persons, their significant other and the broader community (Department of Social Development, 2015:7) The policy on disability as outlined by The White Paper on the Rights of Persons With Disabilities (2016:21) mandated by The Constitution therefore requires that service delivery agents including social workers work towards rendering inclusive and enriching services to persons and their significant other in the medical field.

The following services are frequently rendered by the rehabilitation social worker:

- Psycho-social screening and assessment of person and significant other
- Rendering supportive counselling to person and significant other through individual counselling and group sessions
- Facilitating socio-economic services, acting as a liaison between the person and employer, educating persons and significant other about grant options, available funds and resources
- Facilitating support groups for persons and family members
- Person and family education on the psycho-social implications of sustaining a Spinal cord injury. Psycho-educational topics include self-care behaviours, coping strategies, behavioural pain management, and emotional reactions; they are addressed during individual and group sessions, with persons and significant other
- Facilitating discharge planning, which includes ensuring all the necessary systems are put into place to ensure optimal functioning and health maintenance after discharge. Systems may include identification of a carer; linking persons and significant other to community resources; linking persons and significant other with possible financial resources and funds available
- Referring persons and significant other to resources including psychologists and sexologists where necessary

(ASCoN, 2015:13; Hammond et al., 2011:216; Marino et al., 2003:50).

The researcher is of strong conviction that the role of the social worker in rehabilitation is of extreme value to the multidisciplinary team. The researcher observed in practice

that significant other are in need of the support rendered by the social worker. The researcher also agrees with the authors above that the social worker attains a variety of roles during rehabilitation according to the needs of the person and significant other.

2.17 Summary

It is evident that sustaining tetraplegia has far reaching consequences for the person who sustained tetraplegia and their significant other. When considering the Ecological Systems theory, it is evident that the interaction between the person who sustained tetraplegia and their significant other is affected on the micro-, meso-, exo-, macro and chronological levels, and all of these levels are to be included when exploring the experiences of significant other post-acute rehabilitation.

The following chapter focuses on the research methodology and findings of the study.

CHAPTER 3: RESEARCH METHODOLOGY AND EMPIRICAL FINDINGS

3.1 Introduction

This chapter aims to explore the research methodology of the study as well as the profile of the participants that participated in this study. This chapter further aims to discuss the findings that emerged from the interviews conducted to explore the psycho-social experiences of significant other of persons who sustained tetraplegia. The data from all the interviews conducted were transcribed and analysed. The research findings were presented through a thematic analysis presented through themes and sub-themes that emerged from the study, substantiated with verbatim quotes from the interviews and literature.

The goal of the study was:

The goal of this study was to explore and describe the psycho-social experiences of significant others post-acute tetraplegia in-patients after rehabilitation

The objectives that had to be strived towards to achieve the goal were:

The objectives that were reached to achieve the goal were:

- To conceptualise and contextualise the nature, treatment and rehabilitation of tetraplegia
- To explore the psycho-social experiences and needs of significant other in the care and support of the post-acute tetraplegic patient after rehabilitation
- To explore and describe the psycho-social challenges of significant other in the care and support of the post-acute tetraplegic patient post-discharge
- To make recommendations to the multidisciplinary team for improvement of post-discharge support services to significant other of tetraplegic patients.

The research question was:

What were the psycho-social experiences of significant other of post-acute tetraplegia in-patients after rehabilitation?

Subsequently the research methodology for this study will be discussed.

3.2 Research approach

The qualitative approach was used to conduct this study. Qualitative research as stated in Christensen, Johnson and Turner (2014:383) relies primarily on collection of qualitative data including non-numerical data such as words and pictures. The researcher aimed to answer questions about the complex nature of tetraplegia with the purpose of describing and understanding the phenomena from the significant other's point of view. The qualitative researcher sought a better understanding of complex situations (Fouché & Delport, 2011:64), which in this case was focussed on the psycho-social experiences of significant other after sustaining tetraplegia and completing inpatient rehabilitation.

3.3 Type of research

The type of research used in this study was applied research. Applied research was found to be appropriate as applied research aims to solve a problem in practice and is useful for projects intended to address issues that have immediate relevance to our society's current practices, procedures and policies and which can inform human decision-making about practical problems as stipulated by (Leedy & Ormrod, 2014:27; De Vos & Strydom, 2011:42). This study aimed to discover and stipulate the experiences of significant other, with the aim of improving the psycho-social and support service delivery to significant other by the multidisciplinary team. This will improve the quality of life of the person who sustained tetraplegia and significant other.

3.4 Research design

The research design applicable for this study was the case study design. Case study research is concerned with collecting extensive data on which the investigation is focussed and frequently emphasizes the environment in which the case exists (Christensen et al. 2014:396-397; Leedy & Ormrod 2014:143). The researcher was interested in exploring the perspectives of significant other after completion of acute rehabilitation, more so comparisons, categories and themes between cases and concepts and in this way theories can also be extended and validated (Mark, 1996) as seen in (Fouché & Schurink, 2011:322). The researcher found the collective case

study design applicable because the collective case study design is an instrumental case study extended to a number of cases. Cases are chosen so that comparisons can be made between the cases and concepts, and in this way theories can also be extended and validated (Mark 1996) as seen in (Fouché & Schurink, 2011:322). The purpose of this study was to gain collective information from different sources to ultimately gain an understanding of the experiences of significant other after a spinal cord injury resulting in tetraplegia.

3.5 Research methods

To guide the collective case study design, a study population had to be identified. The data collected and analysed, and a pilot study had to be done to test all aspects of the data collection process (De Vos et al., 2011:237).

3.5.1 Study Population and Sampling

A study population can be defined as individuals in the universe that hold specific characteristics (Strydom, 2011:223). The population for this study consisted of significant other who support a person with tetraplegia in the Gauteng province. The significant other did not necessarily have to be responsible for the physical care of the person with tetraplegia, but rather fulfil the role of the emotional and social companion of the person.

Sampling can be described as “a portion of measurements gathered from a population that we are attracted to and that fits our specific criteria” (Strydom, 2011:224). The sample was restricted to significant other of persons who sustained tetraplegia and completed the in-patient rehabilitation phase of recovery for at least 6 months onwards.

Non-probability sampling seeks out individuals, groups and settings where the specific processes being studied are most likely to occur (Denzin & Lincoln, 2000:370 in Strydom & Delpont, 2011:391). Purposive sampling was chosen as it uses a particular case and illustrated some feature or process that was of interest for this particular study. Strydom and Delpont (2011:392) stress the clear identification and formulation of pre-selected criteria for the selection of participants, to be of cardinal importance.

Possible participants were identified with the help of QuadPara Association of South Africa (QASA). The researcher provided QASA with an information letter of the study and QASA approached their members who met the criteria of the study and informed them about the study. If any members were interested to participate, they were requested to provide their contact details to QASA. The researcher retrieved the details of potential interested participants from QASA. The persons on the list were contacted telephonically and the first 10 participants who met the selection criteria were selected.

The selection criteria included persons who were:

- Significant other which included spouses, partners, parents or siblings of all ages of tetraplegia persons
- The person who sustained the spinal cord injury (SCI) must have completed the initial post-acute in-patient rehabilitation process and have been discharged from a rehabilitation centre for 6 months onwards
- Significant other and person with SCI had to live in Gauteng province
- Both male or female participants
- The person with SCI had to be in age group ranging from 18-50 years
- From any cultural or religious affiliation
- Fluent in English or Afrikaans

An appointment was made with these participants, either at a private venue allocated in the home of the participant or an office at Muelmed Hospital was used, whichever the participant preferred. Here the letter of informed consent was first discussed and once they signed and agreed to participate voluntarily the interview commenced.

3.5.2 Methods of Data Collection

This study utilised semi-structured face-to-face interviews as method of data collection. The letter of informed consent was read and discussed with the participant and once the letter was signed willingly the interview commenced. An interview schedule was used to collect data which was guided by appropriate predetermined questions. These were used to gain a detailed picture of the beliefs, perceptions and accounts of the participants, while allowing flexibility for participants to share more

than was predetermined in the schedule, as stipulated by (Greeff 2011:352). The duration of the interview was planned for 45 minutes and was voice recorded for transcribing purposes with the permission of the participants. This method allowed participants to share their own views, experiences and challenges based on their experiences post-rehabilitation (Greeff 2011:352). The interviews were conducted either in the home environment of the participants, or at an office at Mediclinic Muelmed in Pretoria, depending on what was most suitable for the participants.

3.5.3 Pilot study

By testing the nature of questions in the interview schedule in the pre-test of the pilot study, the qualitative researcher was able to make modifications with a view to quality interviewing during the main investigation (Strydom & Delpont, 2011:395).

In qualitative research, the pilot study is usually informal, and a few participants possessing the same characteristics as those of the main investigation can be involved in the study, merely to ascertain certain trends. The purpose is to determine whether the relevant data can be obtained from the participants (Royse, 1995:172) as seen in (Strydom & Delpont, 2011:394-395).

The researcher conducted a pilot study prior to the main study with two participants who possessed the same characteristics as mentioned above. The researcher tested the semi-structured interview schedule to make the necessary adaptations and improvements where necessary, after completion of the pilot study. The findings of the pilot study were not included with the findings of the main study but served as a tool to regulate the trustworthiness of the investigation tool, namely the interview schedule. If richness of the data in the main study was not enough, the participants from the pilot interviews could have been included in the main study.

3.5.4 Method of data analysis

Data analysis was an imperative part of this study and was approached in a circular rather than a linear manner as was stipulated by (Cresswell 2007:150-155) as seen in (De Vos, Fouché & Schurink, 2011:403). Cresswell proposed different steps that should have been utilized to analyse the data that was collected. These steps will be discussed below.

- **Preparing and organising the data**

When planning for recording the data, the researcher planned the systematic recording method of gathering information from the participants. The interview schedule was set up. This process ensured easy retrieval of data analysis as stated by De Vos, Fouché and Schurink (2011:403).

Following this process, the researcher commenced with a field visit. In this study the field visit was conducted at the home and community environment of 10 participants and their significant other, after completion of the inpatient rehabilitation phase in the Pretoria and greater Gauteng region. The researcher conducted semi-structured interviews with the sample population of 10 participants selected. The preliminary analysis of the data had already commenced in the field while the researcher was gathering the data through the interviews. After termination of the interviews, the researcher proceeded with sorting, retrieving, indexing and handling of data (De Vos, Fouché & Schurink, 2011:405-407). Managing the data entailed that the researcher took the data from the field and after the data was sorted and handled, the researcher retyped the hand-written field notes and ensured that the data was comprehensive of every aspect which the researcher was investigating. The researcher proceeded to transcribe the interviews verbatim from the voice recordings. Once this process was taken care of, the researcher wrote and read the transcripts entirely to get familiar with the details of the data (De Vos, Fouché & Schurink, 2011:408).

- **Reducing the data**

The researcher then moved on to generating categories and coding the data. During this step the researcher was in the process of noting regularities as well as identifying and labelling topics. The researcher commenced with evaluating the usefulness of the data and developed typologies to explain what is understood from the data. This included interpretation based on hunches, insights and intuitions (De Vos, Fouché & Schurink, 2011:409-416). The researcher started to get a sense of the experiences of significant other. The researcher also started making meaning of the data that was being organised into respective themes.

- **Visualising, representing and displaying the data**

The researcher concluded the research study with presenting the data, by means of concept mapping which entails the packaging what was found in the text. The researcher presented the data through visual image and explanation of the elements that were found in the study (De Vos, Fouché & Schurink, 2011:40417-418). The researcher aimed to give a representation of the experiences and needs of significant other by presenting identified themes as a whole.

3.5.5 Data quality

Lincoln and Guba (in De Vos, 2011:419) propose the following assumptions of trustworthiness in a qualitative paradigm to ensure data quality.

- **Credibility** aims at demonstrating that the inquiry was conducted in such a manner as to ensure that the subject has been accurately identified and described (De Vos, Fouché & Schurink, 2011:419). The researcher aimed to match the participants' views and the reconstruction and representation of their experiences of tetraplegia. The researcher further included verbatim quotes from the interviews in the original language to ensure meaning was protected, which was translated into English to promote credibility of the identified themes and subthemes. The researcher also ensured preparation for the interviews to obtain the richest data from the interviews. Member checking was done after the interviews as part of peer debriefing, to ensure researcher understood and captured what they were saying accurately.
- **Transferability** refers to whether the findings of the research can be transferred from a specific situation or case to another. De Vos, Fouché and Schurink (2011:419) explain that transferability can at times be seen as a weakness of the qualitative approach as difficulty arises to transfer findings of qualitative studies to other contexts or settings. The researcher however strengthened transferability of the study by making use of multiple sources of data, such as multiple cases in this study, as well as ensuring the theoretical approach was embedded in the data collection and analysis of the study. The researcher was confident that these strategies would contribute to the transferability of the findings.

- **Dependability** refers to the logical, well documented and audit of the research process (De Vos, Fouché and Schurink 2011:419). The researcher ensured the data was safely stored and that all steps of the data collection and analysis was documented, should an audit trial be done. Dependability also refers to being open to social changes of the respondents' preferences of the setting where the interviews are to take place. The researcher took into account the possible changing conditions of the design, process and setting of the research and was open to change of time and location by the respondents. The researcher also kept a journal and aimed to reflect on her experiences and feelings throughout the research process using reflexivity.
- **Conformability** refers to the need to ask whether the findings of the study could be confirmed by another. Doing so it eliminates some inherent characteristic of the researcher and place it squarely on the data itself (De Vos et al. 2011:419). A peer reviewer, such as a colleague was used to sound-board the researcher's interpretation of data and generation of themes. The researcher further conducted a literature review before commencing with data collection to ensure being embedded in the literature. The researcher also consulted literature to either confirm or contradict the findings of the study after data analysis to eliminate personal or inherent characteristics and to back the findings with literature to ensure conformability.

3.6 Ethical considerations

The ethical considerations relevant to this study were as follows:

- **Avoidance of harm**

Fundamentally social research must bring no harm to participants; subjects can be harmed physically and/or emotionally. The possibility of harm cannot be ruled out completely, leading to the weighing of risks against importance and possible benefits of the specific research project (Strydom, 2011:115). The researcher explained to every participant the letter of informed consent, containing all the important aspects of the study, including the purpose of the study, the estimated duration of the interviews, the potential impact of the study, confidentiality, the possibility of publishing the result, where after the participants were free to make an informed decision whether or not to

participate in the study (Strydom, 2011:115). The researcher used the interview schedule to guide her in the interview, so as to remain focussed and not to delve on too sensitive issues. She also conducted the interviews in an ethical manner, abiding by the interview schedule and the Code of Ethics of social workers as prescribed by the SACSSP. If any participants showed any form of emotional distress, the researcher would refer them to a social worker at Muelmed Rehabilitation Unit for counselling. This however was not needed or requested by any participants.

- **Voluntary participation**

The researcher ensured that the participants were aware at all times that their participation was voluntary and they were welcome to refuse participation in the study, or to withdraw at any time during the study, as is stipulated in (Rubin & Babbie, 2005:71) Strydom (2011:115) emphasises that participation should at all times be voluntary and no one should be forced to participate in a project. The researcher ensured clarity on voluntary participation and withdrawal of participation at any time during the study. After reading through the letter of informed consent and discussing the relevant aspects of the study, the participant had the autonomy to choose either to proceed or decline participation in the study.

- **Informed consent**

Obtaining informed consent implies all possible or adequate information on the goal of the study; the expected duration of the participants' involvement; the procedures which will be followed during the investigation; the possible advantages/disadvantages/dangers to which participants may be exposed; as well as the credibility of the researcher be rendered to potential subjects or their legal representatives. After being supplied with all the information, the potential participant, when signing consented to understanding the conditions and complied to partake in the study voluntarily (Strydom, 2011:117). The researcher supplied the participants with the letter of informed consent, including the purpose of the study, the estimated duration of the interviews, the potential impact of the study, confidentiality and protection of their identity, the possibility of publishing the results. Permission for the use of digital recorder to record the contents of the interview was sought from the participants and the fact that the data would be stored at the University of Pretoria for

the period of 15 years was also mentioned. Only after attainment of their written consent to participate in the study, did the researcher commence with the study.

- **Confidentiality**

Confidentiality indicates the handling of information in a confidential manner. The right to self-determination implies that individuals have the right and competence to evaluate available information, weigh alternatives against one another and make their own decisions (Strydom, 2011:119). The researcher explained the element of confidentiality to the participant and ensured the understanding of confidentiality. The researcher articulated that a voice recorder would be used for the transcript writing purposes and the researcher ensured confidentiality by assigning a number to every participant whereby their personal detail and identity would be protected.

3.7 Research findings

The research findings will be presented by presenting the profiles of the research participants, followed by the themes and sub-themes generated from the data. The thematic analysis will include verbatim quotes from the interviews, as well as literature control where appropriate.

3.7.1 Biographic data

The profile of the participants as well as the biographic data of the participants follows.

Table 3.1 provides a brief profile of each participant.

Table 3.1: Profiles of participants

<p>Participant XY 1</p>	<p>Participant XY 1 is the son of a male who sustained tetraplegia 17 years ago. The participant is a middle-aged man currently living on the same property as his father. He has been significantly involved in the physical, emotional and financial aftercare after his father sustained tetraplegia but no longer assumes full responsibility of his father's physical care.</p>
<p>Participant XY 2</p>	<p>Participant XY 2 is the 60+ year old mother of a middle-aged man who sustained tetraplegia. At the time of the diving accident the participant did not live with the person who sustained tetraplegia and he was not dependent on her in any way. After sustaining tetraplegia he moved in with the participant and her husband and became physically, emotionally and financially dependent on the participant. The person who sustained tetraplegia is currently unemployed, divorced and has a three year old, child to maintain.</p>

Participant XY 3	Participant XY 3 is the middle-aged father of his son who sustained tetraplegia at age 16, which happened three years ago. His son was still school-going and anticipated a future playing sport. The participant was working full time when the accident happened. The participant has scaled down his job and acts as the primary caregiver of the person who sustained tetraplegia. The person who sustained tetraplegia lives with the participant and is dependent on his physically, emotionally and financially.
Participant XY 4	Participant XY 4 is the middle-aged mother of a young adult male who sustained tetraplegia four years ago. At that time the participant was in the empty-nest phase and the person who sustained tetraplegia was not dependent on her. She became his primary caregiver after the accident and the person who sustained tetraplegia now lives with the participant and her husband.
Participant XY 5	Participant XY 5 is the wife of a middle-aged male who sustained tetraplegia 10 months ago due to an embolus in the spinal cord. The participant is currently the breadwinner in the home and manages all household tasks and activities. The participant also has a teenage daughter with the male who sustained tetraplegia.
Participant XY 6	Participant XY 6 is the middle-aged brother of a middle-aged male who sustained tetraplegia in 1996, during a rugby match. The participant does not live with the person who sustained tetraplegia and does not care for him physically or financially, but has been a source of emotional support after the accident.
Participant XY 7	Participant XY 7 is the young adult daughter of a middle-aged lady who sustained tetraplegia four years ago during a motor vehicle accident. At the time of the accident the participant was still a scholar and the person who sustained tetraplegia was the sole breadwinner of the household, providing for the participant. The participant became the primary caregiver after rehabilitation. During 2018 the family however identified caregivers and the participant is no longer the primary caregiver. She however remains a big source of emotional support for her mother.
Participant XY 8	Participant XY 8 is an elderly male who is the father of his son who sustained tetraplegia 9 years ago during a flying accident. At the time of the accident the person who sustained tetraplegia was not dependent on his father physically, emotionally or financially. After the accident the person with tetraplegia moved in with the participant and his wife and is physically, emotionally and financially dependent on the participant.
Participant XY 9	Participant XY 9 is a middle-aged mother of a young adult son who sustained tetraplegia at work. At the time the person with tetraplegia was a financially contributing member of his family and his family was dependent on his income. After his injury he became physically, emotionally and financially dependent on the participant who became his primary caregiver.
Participant XY 10	Participant XY 10 is a middle-aged wife of a middle-aged male who sustained tetraplegia during a sports accident in 2018. By the time of the injury the participant and her husband were both successful business people and the person with tetraplegia was physically active. The participant resumed full responsibility for managing the business. The participant is partly his primary caregiver.

As can be seen in table 3.1, every participant had very different circumstances, contributing to a variety of collective cases and rich and thick data.

Table 3.2 illustrates the relationship of the participant to the person with tetraplegia.

Table 3.2: Relationship of participants to person with tetraplegia

Relationship to quadriplegic patient	Number of patients
Parent	5 (50%)
Husband/wife	2 (20%)
Sibling	1 (10%)
Son/daughter	2 (20%)
Total participants	10

From table 3.2 it is evident that most participants/caregivers were parents and thereafter spouses.

Table 3.3 shows the biographic details of the participants.

Table 3:3 Biographic data of participants

Code	Gender of participant	Responsible for primary care of person with tetraplegia	Relation to the person with tetraplegia	Cause of the injury	Age at injury	Person with tetraplegia currently employed
XY 1	Male	No	Son	Motor vehicle accident	35	No
XY 2	Female	No	Mother	Diving accident	43	No
XY 3	Male	Yes	Father	Sports injury	16	No
XY 4	Female	Yes	Mother	Motor vehicle accident	25	No
XY 5	Female	Yes	Wife	Embolus in spinal cord	43	No
XY 6	Male	No	Brother	Sports injury	20	Yes
XY 7	Female	Yes	Daughter	Motor vehicle accident	42	No
XY 8	Male	Yes	Father	Aircraft accident	23	No

XY 9	Female	Yes	Mother	Work related injury	21	No
XY 10	Female	Yes	Wife	Sports injury	40	No

From table 3.3 the researcher identified that motor vehicle accidents and sports injuries were the most common cause of sustaining tetraplegia in this study. It also became clear to the researcher that 90% of the persons with tetraplegia were unemployed at the time of the interviews and are dependent on their significant other financially. The researcher further identified that 70% of the participants were at the time of the interviews acting as primary caregivers of the person with tetraplegia.

3.7.2 Thematic analysis

This section aims to present the themes and sub-themes that were derived from the interviews. Each theme and sub-theme will contain narrative accounts from the interviews, using direct verbatim quotes to support the themes. Some quotes will be provided in the language used in the interview, namely Afrikaans, which has also been translated into English thereafter. This is pivotal in capturing the participants' exact views and experiences from the interview, as a translation could alter the meaning or richness of the data slightly. For this reason, the quote is also provided in the original language used, to ensure accurateness of translation. These themes will be substantiated with literature where appropriate.

The following themes and sub-themes as shown in table 3.4 were generated from the data:

Table 3.4: Themes and sub-themes

Theme One: Understanding of SCI	Sub-themes: Knowledge of SCI Initial reactions after injury Necessity of information from the medical professionals Secondary complications
Theme two: Significant other's experience of rehabilitation	Informative Weekend pass outs Caregivers Fears regarding discharge
Theme three:	Life changing event Role changes Losses

Emotional impact of tetraplegia on significant other	
Theme four: Social changes associated with tetraplegia	Social isolation Community accessibility Social reintegration Employment
Theme five: Changes in relationship dynamics after tetraplegia	Privacy Dependency Conflict
Theme Six: Needs of significant other	Peer support Coping mechanisms of significant other

Subsequently, each theme will be discussed with its sub-themes.

3.7.2.1 Theme 1: Understanding of tetraplegia

Theme one: Understanding of Tetraplegia	Sub-themes: Knowledge of SCI Initial reactions after injury Necessity of information from the medical professionals Secondary complications
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After a traumatic injury resulting in tetraplegia it is of importance that the significant other has an understanding of the term tetraplegia and the meaning attached to the injury with regards to the prognosis and the life changing nature that has become a reality. The first point of contact is often a medical professional in the Trauma Unit or Intensive Care Unit.

3.7.2.1.1 Sub-theme 1.1: Knowledge of spinal cord injury

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY1:	<i>“Dis ‘n persoon wat die gebruik van sekere dele van sy ledemate verloor het, hy was gebonde tot ‘n rolstoel, en hy het armbeweging, nie hande nie totale immobiliteit en hy het hulp nodig”</i> Translation: <i>“This is a person that lost some use of his limbs, he was dependent on a wheelchair and has arm movement not hand movement. Total immobility and he needs help.”</i>
Participant XY 2:	<i>“Die persoon kan nie loop of kan nie sy arms gebruik met die graad van sy besering nie”</i> Translation: <i>“This person can’t walk or use his arms with the level of his injury.”</i>
Participant XY3:	<i>“The spinal cord got injured, got damaged and cause paralysis.”</i>

Participant XY4:	<p><i>“Wel aan die begin was dit vir ons onduidelik, toe het ons gaan Google en ons het agter gekom dat hy nie weer sal kan loop nie en in sy geval kan hy nie sy arms gebruik nie”</i></p> <p>Translation: <i>“Well in the beginning it was unclear, and then we Googled and we noticed that he won’t be able to walk and in his case won’t be able to use his arms.”</i></p>
Participant XY 5:	<p><i>“Dis ‘n breek in die spinale koord, of knak wat maak dat die persoon nie gebruik het van die deel van sy liggaam onder dit nie”</i></p> <p>Translation: <i>“It is a break, or bend of the spinal cord that causes a person to not have use of the part of his body below it.”</i></p>

It can be seen from the above responses that the participants have a basic knowledge of what a spinal cord injury entails, with the emphasis placed on the inability to walk, and move the arms. This knowledge of the injury was accurate as tetraplegia usually results in very distinctive physical changes, including the loss of movement and sensation in all four limbs (to varying degrees), trunk control and the pelvic muscles are also affected. (Fehlings et al., 2013:56; Marino et al., 2003:50; Medical Dictionary,2017; Sisto et al., 2010:114; Somers, 2010:52).

The researcher did not clarify the theoretical knowledge of the participants as the researcher aimed to explore the personal and authentic understanding and attachment of meaning to their understanding of the prognosis of the injury. These losses can often understandably pose significant psycho-social and socio-economic consequences for persons with tetraplegia and significant other (Somers, 2010:52).

3.7.2.1.2 Sub-theme 1.2: Initial reactions after injury

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY 10:	<p><i>“Vinning, vinning stress gekry, en verskriklik geskok, en ek vra vir hom (dokter) het hy baie seergekry, en hy se van twee uur af tot nou is hy nog nie wakker nie”</i></p> <p>Translation: <i>“Quickly, quickly I got stressed and I was shocked. I asked him (doctor) if he got hurt badly and he said he hasn’t been awake since 2PM.”</i></p>
Participant XY 5:	<p><i>“I don’t even know how to verbalise it, just hectic, basically didn’t know what was wrong. It was absolute chaos. I can’t really remember for about a week after that what happened.”</i></p>

<p>Participant XY4:</p>	<p><i>“Alles het so onwerklik gevoel, jy het gevoel dit kan nie wees nie. Jy het ook geleer om dinge dag vir dag te vat, jy moes nie vrae vra nie, daai vrae wat by jou aankom hoekom het dit gebeur en goed, maar dit sal jou mal maal. Ons het elke dag maar net dag vir dag gevat en net probeer want ek het gesukkel. Ons het nie geweet of hy dit gaan maak nie, so om net elke dag te gaan en gese hy moet net deur vandag kom”</i> Translation: <i>“Everything felt so surreal, you felt this cannot be. You also learnt to take things day by day. You should rather not ask questions, those questions like “why” this happened, it will drive you crazy. We just took everyday day by day and we tried, but I struggled because we didn’t know whether he was going to make it or not. Everyday I just said we need to get through today.”</i></p>
<p>Participant XY8:</p>	<p><i>“When you are first exposed (to the information of the injury) to that it’s rather horrifying, shocking and hard to quite grasp and understand. Doctors deal with that everyday and say this person has a C5 and what, what they have an immediate understanding of all the ramifications, but when someone says to you your son is a C5 quadriplegic you know you have absolutely no idea of how complex that is”</i></p>

When considering the quotes above, it is evident that the participants were distressed and overwhelmed with the uncertainty of the diagnosis and prognosis of the injury and what the possible ramifications might be going forward. The researcher also identified that the significant other immediately had an emotional reaction to the information provided regarding the injury.

Dezarnaulds and Ilchef, (2014:3) state that reactions that significant other experiences after being informed about the injury resulting in tetraplegia often lead to initial feelings of shock; feeling that the reality is surreal and feelings of stress. Experiencing losses is often an integral part of the emotional and psychological reactions after being informed about the injury resulting in tetraplegia. Other initial reactions often include feelings of despair and guilt, fear of losing control, helplessness and inadequacy, fatigue and lethargy, loneliness and isolation (Dickson et al., 2010:1102 ; Somers, 2010:54).

The psycho-social adjustment to tetraplegia is often an overwhelming process that involves all of the human emotions and coping mechanisms of the person affected by tetraplegia and significant other. It typically begins at the time of injury (ASCoN,

2015:8) and a significant other has comparable stress to that of the person who sustained the injury, as they are also initially faced with the implication of the loss of function associated with tetraplegia (Fehlings et al., 2013:208; Sisto et al., 2010:115; Somers, 2010:52).

3.7.2.1.3 Sub-Theme 1.3: Necessity of information from the medical professionals

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY3:	<i>“Well it took very long for us to actually understand, and looking at what you are trying to do, the biggest thing that we realised was when he got injured it took very long for someone to explain to us what this actually means, to what degree this is going to affect him. At the stage when he got hurt it seemed to us more about keeping him alive; it was the ventilator, the continuous blood checks and blood thinners that he had to take. So it was only after about five days that we actually cornered the physician.”</i>
Participant XY 8:	<i>“Ja but the explanation was very superficial because they deal with that everyday, and you have all sorts of questions that they have addressed long ago and have forgotten about them; the bowel and bladder; the lack of movement; the turning is all part of when you say C5 injury, but when you are told about it the first time you don’t even know what questions to ask and you are scared to ask questions in case the answers are not what you want to hear, so you are kind of treading on eggs, hoping that it will all go away.”</i>
Participant XY9:	<i>“Die dokter het toe vining vir my verduidelik van die (toestand) condition, en die dokter het toe vir my gesê die kind het baie seergekry en hy moet vir hom die operasie gee, en die spinal cord van die nek het seergekry.” Translation: “The doctor explained briefly about the condition and the doctor told me the child got seriously hurt and he needs to go for an operation, and the spinal cord in the neck got injured.”</i>

From the quotes above it can be gathered that the initial explanation of the medical team seems to be superficial in explaining the extent of the injury. After the initial discussion with the physician the significant other still experienced a need to gather more information and clarification on the extent and implication of the injury.

The researcher also identified a sense of frustration from the participants after the initial information was provided by the medical team. The researcher identified that most participants had the need to understand the extent and the repercussions of the

diagnosis. Spinal cord injury, specifically tetraplegia is a devastating event that has not only physical but also social and psychological ramifications for the injured person and significant other (Singh et al., 2012:96; ASCoN, 2015:5; Dezarnaulds & Ilchef, 2014:2). In many cases, the psycho-social experiences and the needs and challenges of the person with tetraplegia and significant other can be equally distressing (ASCoN, 2015:5; Fehlings et al., 2013:56). The need to understand affected the participants on a macro level, as their beliefs and ideologies of their former lives were being challenged by the news of the repercussions and ramifications of tetraplegia.

3.7.2.1.4 Sub-theme 1.4: Secondary complications

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY2:	<i>“Hy het so paar maande terug ‘n groot blaasinfeksie gehad, hulle het bepaal dis te veel suiker; te veel coke drink. Die kateter vir ‘n quadropleeg veroorsaak ook blaasinfeksies en kristalle in die blaas.” Translation: “A few months ago he had a big bladder infection. They said it’s from too much sugar, too much drinking coke. The catheter can also cause bladder infections and crystallisation in the bladder.”</i>
Participant XY1:	<i>“Ja hy het ‘n maand terug ‘n pasaangeer gekry, nie genoeg bloedsomloop nie. Hy het ‘n blaas en maagstoma gekry. Sy hart het verswak en bloedsomloop is ‘n probleem. Hy sukkel in die somer met bedsere, hy kan nie warm of koud voel nie. Dit gebeur da thy te veel sweet, beweeg rond in die stoel en skaaf. Sukkel met sweet spesefiek in November en Februarie. Hy was twee keer gehospitaliseer, maar ons probeer so ver as moontlik by die huis te doen.” Translation: “A month ago he got a pacemaker, doesn’t have enough blood circulation. He has a catheter and colostomy bag. His heart has weakened. During summer he has a challenge with pressure sores, he sweats and moves around in his wheelchair causing friction. He especially has problems with sweating in November and February. He has been hospitalised twice but mostly we try and take care of it at home.”</i>
Participant XY4:	<i>“Hy het nounet weer ‘n drukseer gehad, ons is nounet weer klaar met die drukseer.” Translation: “He just had a pressure sore, we just finished healing the pressure sore now.”</i>
Participant XY9:	<i>“Hy het nou pressure sore op sy boude, maar hulle het hom aangewerk en hy kom nou mooi.” Translation: “He has a pressure sore on his bum, but they repaired the skin and it’s healing.”</i>

It is clear from the quotes above that secondary complications including pressure ulcers and urinary tract infections seem to be very prevalent in the after care of a person who sustained tetraplegia. It has become clear that secondary complications and frequent rehospitalization is often a psycho-social challenge that significant other are faced with. This has an impact on social participation; ability to obtain and maintain a vocational position, as well as community integration.

Secondary complications are also reported to add to relationship strain between significant other and persons who sustained tetraplegia (Singh et al., 2012:96; ASCoN, 2015:5; Dezarnaulds & Ilchef, 2014:2). The researcher has come to the understanding that secondary complications and the often recurrent rehospitalization of persons with tetraplegia often has a significant impact on the psycho-social and psycho-economical functioning of significant other.

The inevitable repercussions of recurrent hospitalization are often that persons are unable to maintain a good earning job, which has financial implications on the significant other and the affected household. Another aspect which seems to be affected significantly is social participation and friends and acquaintances who often seem to steer away from engaging with persons with tetraplegia and significant other when they are constantly in the hospital. Secondary complications like chronic pain and infections could possibly threaten both psycho-social integration and security (Fehlings et al., 2013:207; Dezarnaulds & Ilchef, 2014:2).

From an Ecological systems theory, it is evident that secondary complications affect the person who sustained tetraplegia on every level, micro; meso; exo and macro levels. The interpersonal relationship with their significant other, as well as their social participation outside the home environment is affected. Not only does secondary complications affect the social interaction of the person with tetraplegia, but it also has an impact on the significant other, and their freedom to engage and interact with their home and community environment.

3.7.2.2 Theme 2: Significant other's experience of rehabilitation

<p>Theme two: Significant other's experience of rehabilitation</p>	<p>Sub-themes: Experience of significant other during rehabilitation Weekend pass outs Caregivers</p>
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After the initial stabilization and medical management of a person who sustained tetraplegia, the person is often transferred to a physical rehabilitation unit. Rehabilitation of persons with tetraplegia is often defined as a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination (WHO, 2017).

3.7.2.2.1 Sub-theme 2.1: Experience of significant other during rehabilitation

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY 4:	<i>“Dit was ook baie emosioneel om te sien hoe hy probeer om sekere goedjies te doen wat hy nie kon doen nie, uhm ek dink mens voel bly om te sien dat iets gebeur, maar jy voel ook hartseer en gebroke om hom so te sien, ‘n groot sterk man wat ewe skielik afhanklik van alles en almal is om iets te doen”</i> Translation: <i>“It was also very emotional to see him try to do certain things that he couldn’t do. Uhm I think one feels happy to see that something happens, but you also feel sad and broken to see a big strong man that suddenly has become so dependent on everything and everyone to do something”</i>
Participant XY7:	<i>“Well the first thing that came to mind was that she would probably not make it for my graduation, but either than that things just fell into place, because I had a lot of questions then when she came to rehab and I was informed about a lot of things that I didn’t know about so that helped a lot.”</i>
Participant XY 10:	<i>“Toe ons daar aankom het ons gepraat met ‘n blonde social worker, dit was eintlik die eerste keer wat ek gedink het, nou kry ons hulp. Waar voor die tyd kry ons niks nie, en geen inligting nie. Die dokter het nie gekommunikeer nie. Kommunikasie bestaan nie met dokters en matrones nie.”</i> Translation: <i>“When we got there we spoke to a blonde social worker. It was actually the first time that I thought now we are getting help, where previously we didn’t get any help and we didn’t get any information (before getting to the rehabilitation unit). The doctor didn’t communicate; communication doesn’t exist with doctors or matrons”</i>
Participant XY 5:	<i>“I think more shock and more absolute chaos in just planning; what are we going to do, how are we going to cope, just trying to gain as much information and speak to as many people as possible at that stage.”</i>

It is evident from above quotes that when a person that sustained tetraplegia is admitted in the rehabilitation unit the significant other experience a sense of relief and security. It also becomes clear that the significant other are confident that the unanswered questions addressed in the previous theme by the acute medical professionals are to be addressed during the rehabilitation period.

Significant other often experiences a variety of emotional responses after their loved one acquired an injury resulting in tetraplegia, they may often experience feelings of anxiety, loneliness and grieving losses while going through the rehabilitation phase (Dickson et al., 2010: 1103). It was identified through the interviews that rehabilitation seemed to be a beacon of hope for significant other, attributed to communication that was more prominent during this stage.

The researcher identified that participants had a need to form part of the rehabilitation process and to receive sufficient information regarding the prognosis and process. This is substantiated by (Singh et al., 2014:310; Fehlings, 2013:209; Somers,2010:51; ASCoN, 2015:9) that state that from the onset of the in-patient rehabilitation, it is important that significant other who will likely act as care givers are identified and made aware of the physical and psychological needs of the person affected by tetraplegia. The significant other's own needs and concerns are to be addressed as well. Significant other need to feel comfortable to articulate their own fears, hopes and expectations without being judged (Singh et al., 2014:310; Fehlings et al., 2013:209; Somers, 2010:51; ASCoN, 2015:9).

From the Ecological systems theory, it is evident that the rehabilitation phase has an impact on the exo-system especially, as the significant other is not actively involved and going through rehabilitation, but the events and the outcome of the rehabilitation process has an impact on the significant other. The macro system was also affected as their belief systems and ideologies were affected by the education and training provided by the rehabilitation unit.

3.7.2.2.2 Sub-theme 2.2: Weekend pass outs

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY1:	<i>"Toe my pa vir die eerstekeer naweekpas gekry het was dit nogal challenging, want hulle het nooit vir my gewys hoe om 'n</i>

	<p><i>kateter te ruil nie maar ons moes dit doen. So gelukkig kan hy nie voel nie, so as ek hom seergemaak het, het hy dit gelukkig nie gevoel nie. Emosioneel was dit baie daunting, want jy het nie mediese opleiding nie en jy moet vir jou pa 'n kateter insit, uhm jy moes latex handskoene aantrek en jou vinger indruk en sekermaak hy gaan nie deur die dag sy broek vuilmaak nie”</i></p> <p>Translation: <i>“When my dad was allowed a weekend pass out for the first time it was quite challenging, because they never showed me how to change a catheter but we had to do it. So luckily he can’t feel so if I hurt him he luckily didn’t feel it. Emotionally it was very daunting, because you don’t have medical training and you had to change a catheter. Uhm you had to put on latex gloves and put your finger up his rectum to ensure he wouldn’t soil his pants.”</i></p>
Participant XY 4:	<p><i>“Hulle het vir ons basiese goed gewys in die hospitaal van die kateter, en ons het nie 'n caregiver gehad nie, ons het dit self gedoen. Dit was baie erg, want jy is nie gewoond aan sekere goed nie en ek dink hy was baie op sy senuwees of ons iets reg maak, so daar was die heelyd spanning van sy en ons kant af ”</i></p> <p>Translation: <i>“They showed us basic things in the hospital regarding the catheter, and we didn’t have a caregiver; we had to do it ourselves. It was a lot to take in because you aren’t used to certain things. I think he (person with tetraplegia) was very nervous if we were going to do everything right. So there was pressure the whole time from his and our side.”</i></p>
Participant XY7:	<p><i>“We had a lot of those, I was the person that was trained, there wasn’t a caregiver identified. Half of the time I didn’t know what I was doing. It was a learning experience, and luckily my mom was a nurse for the past 22 years so I was lucky there, and she was there to take me through it. The biggest thing that I learnt was catheter changes, the first weekend out it leaked and I didn’t know what to do, so I changed the catheter.”</i></p>
Participant XY8:	<p><i>“Yes he had quite a few, well those weren’t too bad you know when you do it for just one night it isn’t bad at all because the next day you catch up on your sleep, but it became apparent very quickly that we would need a nigh time carer.”</i></p>
Participant XY 5:	<p><i>“That was helpful in actually realising what the tools are that we need to make it easier, I think it was really good in that sense, and I think it made him feel a little bit more human.”</i></p>

Weekend pass-outs are an integral part of the rehabilitation process. All the participants that participated in this study were exposed to at least one weekend out throughout the rehabilitation period. The main aim of weekends out seemed to be in preparation for discharge and assisting the significant other and identified caregivers

in the adjustment process of preparing for the person with tetraplegia to reintegrate into the home environment after discharge.

It is evident from the quotes above that weekends out were a positive and informative learning experience. This notion of the necessity of significant other being trained and exposed to weekend pass outs is substantiated by (Singh et al., 2014:310; Fehlings, 2013:209; Somers, 2010:51; ASCoN, 2015:9) who state that in order to maintain sustainable health post discharge the person who sustained tetraplegia is in need of sufficient emotional and social support from significant other, therefore the inclusion of significant other in the rehabilitation process is detrimental to the person’s wellbeing (Marino et al., 2003:50; ASCoN, 2015:9).

From and Ecological systems theory it is evident that weekend pass outs has an effect on all the levels of interaction of a significant other. During weekend pass outs significant other were faced with the evident changes of dynamics in the home environment, but also family, community and social interaction.

3.7.2.2.3 Sub-theme 2.3: Caregivers

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY1:	<i>“Wat ons gedoen het was die een versorger het by rehabilitasie gaan opleiding kry, nie eimand met mediese agtergrond nie. Hy het in-diensopleiding gekry en geleer hoe om ‘n transferboard te gebruik, en toe ons ander oppassers kry moes hy hulle basies leer en wys wat om te doen”</i> Translation: <i>“What we did was the initial caregiver went for training at the rehabilitation unit, he wasn’t someone with medical background. He received in-service training and learned how to use a transfer board. When we identified another caregiver, he taught them what to do and how to do it.”</i>
Participant XY8:	<i>“He is staying with us, he has four carers, one works day shift, one works night shift and they rotate over weekends. We tried to do it ourselves, but it was almost impossible.”</i>
Participant XY10:	<i>“Ons het twee caregivers, en hulle gaan in die middag huis toe, en dan sit ek hom in die bed in die aand.”</i> Translation: <i>“We have two caregivers, and they go home in the afternoon. I put him into bed in the evenings.”</i>
Participant XY 5:	<i>“We had a caregiver identified by weekend out, but those caregivers left, we went through seven caregivers in two months.”</i>

Caregiver identification is a process that usually takes place during the rehabilitation period and is often finalised before discharge. From the quotes above it has become evident that different families experience different needs and they identify caregivers accordingly. It is also evident that although a caregiver is identified and trained, significant other still remain very involved in the primary care of the person with tetraplegia.

The researcher identified through the interviews that all family systems function in a unique and authentic way, and the caregiver identification and implementation is a very subjective process parallel to the needs of a specific family system. The researcher however identified that additional assistance from a caregiver is detrimental to the successful residential reintegration after discharge.

All the participants that participated in this study utilised the support of a caregiver in some capacity. In order to maintain health post-discharge the person who sustained tetraplegia is in need of sufficient emotional and social support from significant other, therefore the inclusion of significant other in the rehabilitation process is detrimental to the patient's wellbeing (Singh et al., 2014:310; Fehlings, 2013:209; Somers, 2010:51; ASCoN, 2015:9).

It is important that significant other and care givers are identified and made aware of the physical and psychological needs of the person who sustained tetraplegia. The significant other's own needs and concerns are to be addressed as well. Significant other need to feel comfortable to articulate their own fears, hopes and expectations without being judged (Singh et al., 2014:310; Fehlings, 2013:209; Somers, 2010:51; ASCoN, 2015:9).

The necessity of a caregiver has an effect especially on the micro system between a person who sustained tetraplegia and their significant other. The interaction and dynamics in the home environment is considerably affected by an external person in the home environment on a constant basis.

3.7.2.2.4 Sub-theme 2.4: Fears regarding discharge

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY7:	<i>"I felt like I wasn't ready enough to help her, I thought I might injure her or something like that."</i>
Participant XY 5:	<i>"That he was going to die at home, or try to commit suicide at home. His emotional state is still bad and I don't think it's ever going to get better."</i>
Participant XY 3:	<i>"I had unbelievable fears; I had fears of getting him to school, I had fears of what was going to happen when he was at school because we just had a normal car."</i>

The quotes of the above participants stipulate that significant other often experience a variety of fears when faced with the imminent discharge. A specific fear identified was that significant other were experiencing anxiety and lack of confidence in their ability and capability to properly take care of the person with tetraplegia after discharge. It seems that the sense of the unknown was quite daunting for the significant other before discharge. This notion is supported by Dickson et al., (2010:1109) stating that when significant other anticipated discharge after rehabilitation, especially anticipating the new-found sense of dependence on the significant other caused extreme feelings of distress.

In a study conducted in 2010 by Back Up (2010) in the United Kingdom, they investigated a variety of significant other after a patient sustained a spinal cord injury and received therapy at a rehabilitation centre. A unanimous consensus was reached that there was a lack of formal support and educational services rendered to significant other throughout the rehabilitation process, which left them feeling isolated and anxious. This lack of services also complicated the process of adaptation of the patient and significant other after discharge of the patient. The participants experienced feelings of depression, anxiety, feeling alone and overwhelmed throughout the rehabilitation process because there had not been adequate services rendered to the significant other (Back Up, 2010).

It is therefore pivotal for significant other's own needs and concerns to be addressed as well as they have a need to feel comfortable to articulate their own fears, hopes and expectations without being judged (Singh et al., 2014:310; Fehlings, 2013:209; Somers, 2010:51; ASCoN, 2015:9). Fears surrounding discharge affects significant

other on a macro level, as their beliefs and ideologies are encompassed in these fears pertaining to the care of the person with tetraplegia.

3.7.2.2.5 Sub-theme 2.5: Significant other as caregivers

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY1:	<i>“Op hierdie stadium het hy twee oppassers wat elke twee weke ruil, maar direk na die ongeluk en rehabilitasie het ons net een oppasser gehad. Ek het by hulle in die huis gebly en ek en my ouer broer het oor naweke die oppasser afgelos. My ma het ook gehelp met van die goed”</i> Translation: <i>“At this stage he has two caregivers that rotate bi-weekly. Directly after the accident he only had one caregiver. I lived with them in the home and my brother and I relieved the caregiver over weekends. My mom also helped with some of the things.”</i>
Participant XY 4:	<i>“Op hierdie stadium het hy ‘n caregiver, en hy het ‘n meisie wat help. Ons help ook nogsteeds, ons draai hom nogsteeds in die aande en ek doen nogsteeds sy maag. Ek gaan nie dat iemand anders dit doen nie, dis baie persoonlik. Sy meisie help saam met die caregiver om hom te bad wat ek altyd gedoen het, want mens het meer as een persoon nodig om hom te bad”</i> Translation: <i>“At this stage he has a caregiver and he has a girlfriend that also assists. We also still assist him with turning during the night and I still facilitate his bowel programme. I cannot allow anyone else to do that because it is very personal. His girlfriend assists the caregiver in bathing him as it takes more than one person to bath him.”</i>
Participant XY 7:	<i>“It has affected a lot of my social life because I was very young at the time, and I can’t really say that I couldn’t go to school, but ja I couldn’t go to school because we had to like take care of her and both my sisters were working and I just finished matric at the time.”</i>
Participant XY 10:	<i>“Ek het hom altyd in die nag gedraai, maar hy draai darm nou self.”</i> Translation: <i>“I used to turn him during the night, but at least he can do that by himself now.”</i>
Participant XY 3:	<i>“He has a caregiver during the day when I have to work and the caregiver sits with him when we have to drive to Johannesburg. In the mornings the caregiver gives him his breakfast and gets him finished but in the morning I help him get dressed and transfer him into his chair and when the carer gets here he takes over.”</i>

It has become apparent to the researcher that significant other are very often still very involved in the physical care of the person who sustained tetraplegia. When considering the above quotes it is clear that the significant other seem to have to take

on the role of a physical caregiver even if an additional caregiver has been identified. The researcher also observed that different significant other experienced different needs when it came to the physical care of the person with tetraplegia, it seems that some participants felt more comfortable to maintain the responsibility for certain aspects of the care.

It was observed that caregiver identification and the care of the person who sustained tetraplegia is a very subjective process, and different families experience different needs and seems to employ help accordingly. It was evident that all the participants who participated in this study had additional assistance from a caregiver in some capacity. The researcher stresses the importance of identifying a caregiver to assist significant other.

In practice the researcher experienced that significant other often became very overwhelmed and reported that they were struggling to cope at home without an additional caregiver. It is detrimental to the wellbeing of the person with tetraplegia and the significant other to employ additional assistance and support of a caregiver. It was evident that most of the significant other were still extensively involved in the facilitation of the physical care of persons with tetraplegia.

Persons with tetraplegia become increasingly dependent on significant other for their physical care, and this new found sense of dependency on significant other as caregivers has a noteworthy psycho-social impact (Dickson et al., 2010:1109). Significant other as care givers are affected on a macro level, as their role as a caregiver is evident on the micro-, meso and macro levels. The significant other is responsible for the facilitation of daily living in the home environment, as well as responsible to facilitate interaction with friends and family and for a person with tetraplegia to access their community environment successfully.

3.7.2.3 Theme 3: The emotional impact of tetraplegia on significant other has far reaching consequences and affects them in significant ways

<p>Theme three: Emotional impact of tetraplegia on significant other</p>	<p>Sub-Themes: Life changing event Role changes Losses</p>
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The emotional impact of tetraplegia on significant other has far reaching consequences affecting them in significant ways. Significant other often experience a variety of emotional responses after their loved one experienced tetraplegia. A study conducted in 2009 in The UK states that spouses expressed feelings of anxiety, loneliness and grieving losses while going through the rehabilitation phase (Dickson et al., 2010: 1103). Losses ranged from mild, to experiencing emotions that the spouse had actually passed away, as this is the severity of the finality of the experienced losses.

3.7.2.3.1 Sub-theme 3.1: Life changing event

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY3:	<i>“Our lives have changed a lot. I now have to work from home, he goes to therapy twice a week in Sandton so that I can get him to therapy. When he was still in school the hours to drop him off and fetch him and I calculated with these things in a normal work day I was only able to work three and a half hours, and it didn’t fly well with the directors, I was a director. I had to get a job where I could work from home and also it affected our lives in other ways; sleep is now less than usual and I am getting older and need more sleep, but I’m getting less. The routine has changed completely. We have had to get a combi adapted, and this affected our budget as our car was paid off.”</i>
Participant XY 6:	<i>“Ons moes aanpas by die feit dat hy nie kon loop of enige iets vir homself kon doen nie, die goedjies wat ons gedoen het in elk geval soos vakansies wat ons gereel het moes verander na plekke wat rolstoelvriendelik is. Ons het die huis verander vir access makliker.” Translation: “We had to adjust to the reality that he couldn’t walk anymore, nor do anything for himself. The things we did like plan holidays away had to change to places that were wheelchair accessible. We also adapted the home environment to assure that it’s more wheelchair accessible.”</i>
Participant XY 5:	<i>“Well basically he now is the main centrepiece of everything. Everything we do, all the decision we make, every holiday we take is around him. Every time we go to the shops or whatever it’s around him. There is a lot of planning involved, we don’t go anywhere without planning ahead.”</i>

From the above quotes it is clear that sustaining tetraplegia has far-reaching consequences for significant other. It seems that it is an overwhelming adjustment for significant other to maintain their own lives as well as accommodate the person who sustained tetraplegia. Both the person who sustained tetraplegia and the significant

other is often faced with the reality of changing dynamics, which often leads to inevitable readjustment of roles, responsibilities and dynamics within a household. This notion is supported by Sisto et al.,(2010:114) who states that persons who sustained tetraplegia and significant other are faced with the challenge of redefining responsibilities and redefining roles in the household.

This causes an extreme amount of distress for both the person with tetraplegia and significant other. It is further stated that social challenges prominent for persons and significant other include problems of social adjustment, experiencing a sense of being a burden on their family, strained partner relationships, sleep disturbances and grief (Singh et al., 2012:96; ASCoN, 2015:5; Dezarnaulds & Ilchef, 2014:2).

Other factors that often affect persons with tetraplegia and their significant other is frequent rehospitalization for secondary complications, an inability to return to pre-injury occupation, immobility and lack of autonomy. These factors can often adversely affect the community reintegration and quality of life of persons with tetraplegia (Singh et al., 2012:96; ASCoN, 2015:5; Dezarnaulds & Ilchef, 2014:2).

It is evident that sustaining tetraplegia affects significant other on the macro level, as interaction on the micro, meso and exo levels are affected. A process of adjustment is necessary in the home environment as well as family and community environment. A person with tetraplegia is no longer able to engage in his home, community and work environments as was done prior to sustaining tetraplegia, and this has a subsequent effect on significant other and the freedom they experience to interact within their environment.

3.7.2.3.2 Sub-theme 3.2: Role changes

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY 3:	<i>"I think there was a lot of character adjustment that had to happen, uhm especially between him and myself because our relationship has changed completely. I was a lot more involved in his life than previously."</i>
Participant XY 5:	<i>"The role changes are extremely evident and also very difficult, because now I have to be the head of the house, but I can't make him feel like I'm the head of the house. I'm playing the whole time, I told my daughter the other day it feels like I am flipping between masks. Then I'm a friend; then I'm a mom;"</i>

	<i>then I'm a caregiver; then I'm a boss. It really is hard and draining to keep that going."</i>
Participant XY 8:	<i>"At the end of the day you feel guilty when you leave the house to go do something, like you feel like you are deserting him. Is he going to be alright? So there is always that like a mother leaving her child at the nursery school for the first time."</i>
Participant XY 4:	<i>"Ons verhouding het heeltemal verander, daar is nie meer die ma en kind verhouding nie." Translation: "Our relationship has changed completely. The mother-son relationship that we used to have isn't there anymore."</i>

It is clear from the quotes stated above that role changes are very significant in the relationship between a person with tetraplegia and their significant other. The researcher observed that significant other are obligated to take on more responsibility, which was previously shared with the person who sustained tetraplegia, and that the dynamics of the relationship changes significantly.

The researcher also identified that negative emotions attached to the evident role changes were prevalent in the participants of this study, it seems that these role changes and even changes in relationship dynamics causes noteworthy distress for the significant other. The marked effect of the role changes associated with tetraplegia is supported by Dickson et al., (2009:1108) who state that spouses and significant other often experience a sense of anxiety and uncertainty in navigating the post-injury life.

Often significant other report to have a sense of resentment when anticipating caring for the person who sustained tetraplegia. This feeling of resentment seems to be embedded in the significant other's sense of sacrificing their own independence and sense of freedom as well as feelings of loss of control over their own lives. They also state that the change in relationship and dynamics often generate feelings of anxiety for the significant other.

A complete reversal of roles were also reported, especially shifting as a significant other from depending on the injured spouse to becoming the provider and caregiver of the person affected by tetraplegia (Dickson et al., 2010:1108). Role changes are evident on the micro, meso and exo level, as role changes take place in the home environment, work environment and community environment. The person who

sustained tetraplegia has limited physical functionality to engage in household chores, vocational activities or family activities, thus the significant other's participation on every level is affected.

3.7.2.3.3 Sub-theme 3.3: Losses

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY 3:	<i>"For me as a father I think probably the things that we will miss out on doing together. I taught him to...his birthday was the 5th of August I had booked and planned and paid the deposit and everything for his first hunt; it didn't happen. The day he got hurt I had the cash for his motorbike in my pocket, so we were literally when he finished playing his game at TUKS we were going to drive from there to the motorbike shop and fetch his bike."</i>
Participant XY 6:	<i>"Die eerste ding waaraan ek gedink het is dat hy 'n baie belowende rugby loopbaan voor hom gehad het en toe is dit gone, ek is die jammerste vir hom daarvoor. Dis eers later wat mens agterkom dat omdat hy nie kan loop nie dat alles verander so stelselmatig." Translation: "The first thing that came to mind was that he had a very promising rugby career ahead of him, and then it was gone. I feel sorriest for him in that regard. It's only later that you realise that because he can't walk, everything has to change gradually."</i>
Participant XY 5:	<i>"Sometimes I think there is resentment not in an ugly way, it's just you kind of feel like you are not in control of your life even though you have to do everything and make all the big decisions and implement all the plans or anything that you need to, you are actually not in control. I lost my husband and gained a kid. Lost the privacy in our house."</i>

The researcher identified that significant other seem to mourn great losses after a person sustains tetraplegia. The losses seem to focus on things that they could have done or could have achieved. It also seems that a loss is experienced in activities that significant other performed with the person who sustained tetraplegia. This notion is supported by Dickson et al., (2009:1103) who state that losses experienced by significant other often ranges from mild, to experiencing emotions that the significant other had actually passed away, as this is the severity of the finality of the experienced losses.

Participants in this study reported feeling like they had to come to terms with a life once lived, that is now lost forever as well as adapting to significant role changes after

the injury. Tetraplegia and the life changes associated with the loss of mobility and sensation may often result in persons affected by tetraplegia to be unable to mobilise independently in a variety of social settings without any support or assistance.

Persons affected by tetraplegia often find themselves paralysed, incontinent, immobile, dependent and isolated. They are also faced with social and physical difficulties such as isolation; stigmatization and community inaccessibility when engaging in social activities. These challenges in social participation often results in significant other also being susceptible to hostility and isolation as well as significant psycho-social consequences for all systems involved (Somers, 2010:52; Dickson et al., 2010:1107).

Losses can be experienced on micro, meso, exo and macro levels. Necessity to care for the person who sustained tetraplegia in the home environment; loss of privacy in the home environment; loss of ability to physically engage and assist with household chores in the home environment; loss of income due to employment difficulties after sustaining tetraplegia; the loss of social participation and community accessibility all have an impact on the significant other.

3.7.2.4 Theme 4: The social implications of tetraplegia are as far reaching as the physical and psychological consequences for significant other

Theme four: Social changes associated with tetraplegia	Sub-themes Social isolation Community accessibility Employment
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3.7.2.4.1 Sub-theme 4.1: Social Isolation

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY 5:	<i>“Of course you feel isolated, your friends don’t know your real situation. They don’t see everything that happens at home, or your day or any of that. One thing that is very difficult for my husband is that he basically lost all his friends, and I don’t think he lost them because they were bad friends, but they cannot handle it. It’s not as easy or superficial or relaxed.”</i>
Participant XY 10:	<i>“Dis partykeer frustrerend dat mense sien soms net ‘n deel van die prentjie, en hulle sien nie noodwendig alles wat daar ingaan om daai persoon te kry om iets te doen nie.”</i> Translation: <i>“It is frustrating sometimes that people only see</i>

	<i>a part of the picture, and they don't necessarily see everything that goes into getting that person to do something."</i>
Participant XY 4:	<i>"Almal sal byvoorbeeld, mense wat saam met hom gewerk het of saam hom rugby gespeel het of vriende as hulle vir hom kom kuier dan sal hulle se maar hy lyk so goed, dis fantasies hoe hy verander het en hoe alles reg is. Dis maklik om 'n ou halfuur te sien en te dink alles gaan hunky dory." Translation: "Everyone for example that worked with him, or played rugby with him, or friends, when they come to visit will say that he looks so good, it's fantastic how he has changed and how everything is coming right. It's easy to see someone for half an hour and then to think everything is hunky dory."</i>
Participant XY 4:	<i>"Hy was altyd die hart en siel van die partytjie of van vriende. Hy was 'n baie sterk en onafhanklike outjie, en nou is hy afhanklik van ander om dit te bereik. Die vriende het heeltemal opgedroog wat hy altyd gehad het. Hy het al 'n nuwe vriendekring opgebou maar nie baie nie. Selfs sy vriende het vir my gese dis te veel werk om saam met hom te kuier." Translation: "He was always the heart and soul of a party or group of friends. He was a very strong and independent guy, and now he is dependent on someone else to get anything done. The friendships he used to have has dried up completely. His friends have even verbalised to me that it's too much work to socialise with him."</i>

It became clear from the above quotes that the social interaction of both the person who sustained tetraplegia and their significant other changed in a significant way after the injury. It was a common theme shared by most significant other who participated in this study that the person who sustained tetraplegia seemed to become increasingly isolated after the injury.

It seems that previous social circles are no longer engaged actively as before and friends seem to shy away from interaction with the person who sustained tetraplegia. Somers, (2010:53) and WHO, (2017) state that aspects affecting the social participation of persons affected by tetraplegia are their limited ability to care for themselves and move around independently after an injury.

This increased need for support promotes dependence on significant other and results in a decreased sense of autonomy for the person affected. Often other aspects exasperated by the physical and emotional effects of tetraplegia are the limited ability to engage in recreational, social educational and vocational activities. This has a major

impact on social participation which used to occupy most of their days prior to sustaining tetraplegia.

This increased sense of dependence and loss of social participation often has an impact psychologically and socially on the persons affected by tetraplegia. Various misconceptions about tetraplegia and negative attitudes of the unaware society and individuals often lead to exclusion of many people with tetraplegia from full participation in society (Chhabra & Batra, 2016:2; ASCoN, 2015:8; WHO, 2017). It is evident that the social implication is on a meso level.

Social isolation has an impact specifically on the macro level, as significant other are often inclined to a change in beliefs or ideologies regarding previous social interactions and norms.

3.7.2.4.1.2 Sub-theme 4.2: Community accessibility

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY 5:	<i>“Realising how inadequate South Africa is for disabled people. Every time we go on holiday there is an issue; is it wheelchair friendly, and when you get there it’s not; we have been on holiday overseas now, and we are thinking about packing up and moving because we were better geared. Difficult to book a movie ticket; can’t book online.”</i>
Participant XY 10:	<i>“Die aktiwiteite om saam hom te doen raak lastig, en as ons iewers heen wil gaan dan moet ek altyd ry, en ek is nie ‘n groot drinker nie, maar nou kan ek nie meer nie. En ek moet in die aande ry en ek ry nie goed in die aande nie. Alles vat meer beplanning as jy iewers heen wil gaan, en dit vat baie plek in die kar.” Translation: “The activities to do with him becomes effort, and if we want to go somewhere I always have to drive. I’m not a big drinker, but now I can’t drink at all anymore. I also have to drive at night, and I don’t drive well in the dark. Everything takes more planning if you want to go somewhere, and it takes a lot of space in the car.”</i>

The quotes above clearly show that wheelchair accessibility and community engagement is a concern and a source of frustration for persons who sustained tetraplegia as well as their significant other. The researcher also observed that participants commented on their responsibility to either drive the person around after

the injury, or go to great lengths to organise adequate transportation to access their community.

Trierveiler et al. (2015:993) state that social interactions may also often be influenced by physical access barriers within communities. Areas such as homes, schools, workplaces, hospitals and social events are often inaccessible to people who are dependent on wheelchair use for mobility. A further complication is the difficulty in procuring private or public transport suitable or accessible for a person using a wheelchair.

Transport difficulty is often exasperated in rural communities and this in turn affects social participation significantly (Chhabra & Batra, 2016:2). Bergmark et al. (2008:686) emphasises a factor that affects the quality of life of persons who sustained tetraplegia is the extent to which they are able to reintegrate into their community environments and the extent to which they perceive their social and community participation. These factors are often dependent on their residential reintegration, education, community accessibility and employment. Community accessibility is on meso, exo and maro levels, as significant other become subject to what is available and accessible to the person who sustained tetraplegia in their community environment.

3.7.2.4.1.3 Sub-theme 4.3: Employment

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY 5	<i>“He is not employed, hasn’t been able to work since getting injured”</i>
Participant XY 10:	<i>“Hy het aanbiedings gehad vir werk, wat hy nie kan vat nie, want hy is nog nie sterk genoeg nie. Miskien gaan hy ooit wees, ons weet nie.” Translation: “He has had work offers that he can’t take because he isn’t strong enough yet, and maybe he never will be strong enough.”</i>
Participant XY 8:	<i>“He was employed so the workman’s compensation fund (WCA) pays him a pension.”</i>

The quotes above demonstrate that employment after sustaining tetraplegia is a challenge and source of concern for persons who sustained tetraplegia and their significant other. Only two of the participants reported their significant other to be

employed after sustaining the injury. That means that 80% of the participants' significant other were never employed after their injury again.

The researcher identified however that financially some of the participants' significant other were able to still contribute financially due to policies such as workman's compensation fund, as well as the Road Accident Fund that assisted them financially. This pay out affected the quality of life of persons who sustained tetraplegia and promoted the extent to which they were able to reintegrate into their community environments promoted social and community participation.

These factors are often dependent on their residential reintegration, education, community accessibility and employment (Chhabra & Batra, 2016:2; Bergmark et al., 2008:686). An integral part of the role changes associated with tetraplegia is the often loss of employment or necessity to seek alternative employment.

This statement is supported by the National Spinal Cord Injury Statistical Center (NSCISC, 2012), which states that more than half (57.1%) of those persons with a spinal cord injury reported being employed at the time of their injury. At one year after injury, 11.7% of persons with SCI are employed. By 20 years post-injury, 35.2% are employed and a similar level of employment is observed through post-injury year 35. Singh et al., (2012: 97) also highlights the severe burden that tetraplegia could often pose on the family financially, often times the person who sustained tetraplegia was the sole earning person or was the most responsible for the family financially.

This change in the psycho-economic functioning in the household often has dire consequences pertaining to role changes, expectations and quality of life for the affected person as well as their significant other (Singh et al., 2014:310). Another significant psycho-economic consequence of sustaining tetraplegia is the financial impact on the family to employ a full-time caregiver to assist with all activities of daily living. This has even more far reaching consequences as very often the person with tetraplegia might not be employed or earning an income after the injury (Chhabara & Batra, 2016:3). Employment affects significant other on an exo level, as they are affected by the loss of income of the person who sustained tetraplegia.

3.7.2.5 Theme 5: Changes in relationship dynamics after tetraplegia

Theme five: Changes in relationship dynamics after tetraplegia	Sub-themes Privacy Dependency Conflict
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3.7.2.5.1 Sub-theme 5.1: Privacy

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY 10:	<i>“Dis nogsteeds moeilik om altyd iemand in jou huis te hê, iemand wat heeltyd jou privacy invade.”</i> Translation: <i>“It becomes difficult to always have someone else in your home, someone who constantly invades your privacy.”</i>
Participant XY 8:	<i>“No privacy in the home, not going anywhere because if you go away for a holiday the carer comes with you and you’ve got this added member of the family with you all the time, so privacy goes out the window.”</i>

The quotes above demonstrate that after sustaining tetraplegia sources of frustration for significant other are the lack of privacy and always having another person in their personal space. The researcher observed that this is something that is a concern for most of the significant other and that seems to be a big factor of adjustment after discharge.

This makes it clear that different families with different dynamics have different needs when it comes to caregivers as was discussed in the sub-theme about caregivers. The impact of tetraplegia and the long-lasting effects are not only limited to the person who sustained tetraplegia, but often extend to the significant other.

Significant other are often faced with the inevitable stages of readjustment (Sisto et al., 2010: 115). Losses are prevalent after discharge, and the person and significant other are tasked with readjusting to these changes (Somers, 2010:53). It has become clear to the researcher that the loss of privacy and the adjustment necessary to accommodate a caregiver in the home environment is at times distressing to significant other. Changes in privacy affect significant other on a micro and exo level, as interactions and dynamics within the home environment is different due to an external caregiver often present in the home.

3.7.2.5.2 Sub-theme 5.2: Dependency

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY 10	<i>“Ek het die grootste probleem daarmee dat hy ook nie verantwoordelikheid neem vir homself nie, en as hy dit nie doen nie dan is dit altyd ‘n probleem vir my. Hy weet glad nie watter pille hy drink nie, en dan het ek ‘n probleem. Ook met die dermprogram, hy neem nie verantwoordelikheid nie.” Translation: I have the biggest problem that he doesn’t take responsibility for himself, and that always becomes a problem for me. He doesn’t know the medication he has to take, and then I also have a problem. Also with the bowel programme, he doesn’t take responsibility.”</i>
Participant XY 8:	<i>“At the end of the day you feel guilty when you leave the house to go do something, like you feel like you are deserting him. Is he going to be alright?”</i>
Participant XY 4:	<i>“Ons was al op ‘n stadium waar al ons kinders uit die huis uit is, waar jy heelmaal op jou eie basies is en ewe sielik het jy iemand wat weer jou verantwoordelikheid is, hy kan nie sy eie neus blaas nie, kan homself nie hoes nie, hy kan nie self eet nie. Hy kan niks op sy eie doen nie en hy is afhanklik van absoluut alles van jou.” Translation: “We were at the stage where all of our children were out of the house, where you were basically on your own again and all of a sudden you have someone that’s your responsibility again. He can’t blow his own nose, he can’t cough himself, he can’t eat independently. He can’t do anything for himself, and he is completely dependent on you for everything.”</i>
Participant XY 2:	<i>“Die eerste ding waaraan ek gedink het toe ek gehoor het hy het sy nek gebreek is ja hy gaan afhanklik wees” Translation: “The first thing I thought about when I heard he broke his neck, is that he was going to be dependent.”</i>

The quotes above stipulate that a sense of dependency on significant other was prominent after an injury resulting in tetraplegia. Activities of daily living, as well as emotionally, socially, financially are all aspects that are affected and leads to dependence on significant other. The researcher also observed that often the person who sustained tetraplegia does not take responsibility for making decisions or managing their own health, which is a source of frustration for significant other.

Persons and significant other affected by tetraplegia are often faced with a momentous change in social interaction after the injury. Trierveiler et al., (2015:993) state that a

person who sustained tetraplegia has limitations for activities which were previously simple and ordinary. Chhabra and Batra, (2016:2) state that total assistance is required to perform activities like dressing, hygiene, physiological elimination and feeding.

This limited capacity to perform activities interferes with independence. This notion is further confirmed by (Chhabra & Batra, 2016:2) state that a person with tetraplegia is always partially or completely dependent on someone for performing all his activities and daily routine, including initiating and participating in social interaction. An increased sense of dependence often affects significant other on micro, meso, exo and macro levels. They are continuously engaged in assisting the person who sustained tetraplegia on all levels of interaction in the home, family, social, community and vocational environments.

3.7.2.5.3 Sub-theme 5.3: Conflict

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY 5:	<i>“There is a lot more, but it’s difficult because how do you fight with someone that can barely speak, is completely unreasonable, completely focussed on their needs. So half the time I fight the battles I think are important and the rest of the stuff I just let go. It is easiest this way.”</i>
Participant XY 8:	<i>“She (my wife) gets quite frustrated with him because he doesn’t make decisions, and I mean him and I have had screaming matches. I refused not to fight with him, if it is a fight issue, we fight, and we will be screaming at each other.”</i>
Participant XY 4:	<i>“Ja daar is partykeer konflik, hy voel jy het hom nie reg op die stoel gesit nie, of deur die dag is daar dalk ‘n glips, dan sê hy jy het nou nie sy maag reg gedoen nie, so dis al daai tipe goedjies. Elke dingetjie wat maar gebeur is daar half ‘n vinger wat gewys word.” Translation: “Yes there is conflict sometimes. He feels like you didn’t transfer him correctly into the chair’ or maybe during the day he had a bowel or bladder accident and then he would say but I didn’t facilitate his bowel programme correctly. It’s those types of things, everything that happens has a finger that is pointed.</i>

It is evident from the quotes above that conflict is prevalent in the relationship between the person who sustained tetraplegia and their significant other. The researcher identified that a precipitator of conflict is that the person who sustained tetraplegia

often has the expectation that things should be done for them in a very specific way. How they want it done, and when the significant other or the caregiver fails to perform tasks that meet the expectations of the person who sustained tetraplegia, conflict arises.

The impact of tetraplegia and the long-lasting effects are not only limited to the person who sustained tetraplegia, but often extend to the significant other. Significant other are often faced with the inevitable stages of readjustment. In some cases pre-morbid family functioning is exacerbated by the diagnosis of tetraplegia. Drastic changes in family roles contribute to family stress and changes in family roles. Significant other have comparable stress to that of the patient (Sisto et al., 2010:115; Dickson et al., 2010:1109). Conflict often affects significant other on a micro level, in the close interaction between significant other and person who sustained tetraplegia.

3.7.2.6 Theme 6: The identified needs of significant other

Theme Six: Needs of significant other	Sub-themes Peer support Coping mechanisms of significant other
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3.7.2.6.1 Sub theme 6.1: Peer support

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY10:	<i>“Ja waar hulle dit met pasiënte wel doen, doen hulle dit nie met die families nie, en dis definitief ‘n behoefte, peer support. Hulle het ook nooit gevra of ons sal belangstel in so iets, of dat dit daar is nie.” Translation: “Yes where they do it with patients, they don’t do it with the families, and it’s definitely a need, for peer support. They also never inquired whether we were interested in something like that or told us that there is something like that.”</i>
Participant XY1:	<i>“Ek dink baie mense is bietjie in ontkenning, so hulle moet met mense praat wat positief daardeur gegaan het. Dit is partykeer bietjie moeilik want mense dink hulle situasie is uniek, en om met mense te praat wat di took al gehad het, maar nou moet jy mense kry wat bereid is om die tyd af te staan om met daai mense te praat.” Translation: “I think a lot of people are in denial, so they have to talk to people who have gone through this in a positive way. This might be challenging as you need to find someone willing to spend the time.”</i>
Participant XY 3:	<i>“Speak to other people; speak to other families. Don’t be afraid to because I think the most help you get, well if I look at it in hindsight, it would have been a lot easier if I had another father whose son got hurt playing rugby that understands what a rugby player’s mentality is, and understand as a rugby father what you</i>

	<i>go through. If you could have somebody that could sit you down and talk to you about it and say what happened, this is the situation and explained what they have learned.”</i>
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The quotes above demonstrated the need of significant other to connect with and receive support from people who find themselves in similar situations. Typically intimate confiding relationships are those that best confer the beneficial effects of social support. After sustaining tetraplegia, the probability for a long-lasting relationship is decreased.

Sherman and De Vinney (2004, 140) proposes that alternative sources of support may contribute to the adjustment after sustaining tetraplegia in a great way. Thoits (1995) as seen in (Sherman & De Vinney, 2004:140) proposes that the most effective support givers are likely to be individuals who have successfully faced the same stressful situation as the support recipient. It is further argued that this allows the support giver to provide support that best matches the emotional and practical needs of the support recipient and afford the opportunity for positive role modelling and cultivating believable hope (Borkman, 1976) as seen in (Sherman & De Vinney, 2004:140). Peer support can have an influence on the macro system, as engaging with peers could affect the beliefs and ideologies of significant other.

3.7.2.6.2 Sub-theme 6.2: Coping mechanisms of significant other

The following quotes reflect the sub-theme:

Respondent	Verbatim quotes from participants
Participant XY 5:	<i>“I’m very glad that I didn’t stop working, my job is a little bit of an escape, or a little bit of a normalcy. I don’t have to worry about where the disability parking is and I don’t have to worry about can or can’t we get up there so that I do like. Also just between 4-5 is my hour and I go running with my dogs.”</i>
Participant XY 10:	<i>“Ek het ‘n waarskuwing gekry dat mens raak baie maklik padlangs verslaaf aan iets; of drank, of heroine of aan “gamble” en ek weet dit. Iemand het dit vir my gesê so ek is baie, ek pasop baie vir dit, want ek kan die valkuil sien. Hulle moet van goed ontslae raak, hulle moet hulle “mind” op iets anders kan sit. Ek het byvoorbeeld vir 8 maande gesukkel om te slaap, en jy weet ek moes slaap kry toe gaan sien ek die dokter na 8 maande vir slaappille.” Translation: “I received a warning that people get easily addicted to something along the way. Either alcohol, or heroine, or gambling, and I know it.</i>

	<i>Someone told me so I am very weary of things like that, and I can see the potential trap. They need to get rid of things, they need to put their minds on something else. I struggled for 8 months to sleep, where after I consulted a physician for sleeping tablets.”</i>
Participant XY 8:	<i>“I was lucky I have meditated for many years and that’s a great strength and teaches you acceptance without you even knowing it.”</i>
Participant XY 4:	<i>“Ek is op hierdie stadium op antideprisante, wat ek nooit voorheen gebruik het nie.” Translation: “I am taking antidepressants, which I never used to take.”</i>

The quotes above demonstrate that coping mechanisms are part and parcel of what is necessary in this adjustment process for significant other. It has become clear to the researcher that positive as well as negative measures are employed by significant other to cope after the injury. Mourning for the familiarity of their former lives as well as a sense of uncertainty as to what the future holds was also a central theme derived in this study.

Anxiety focussed on the returning home of their spouse was also central to the emotional reactions often experienced by significant other (Dickson et al., 2010:1108). It is evident to the researcher that feelings of anxiety and stress are prominent for significant other, and an increased sense of responsibility for the person with tetraplegia is experienced by the significant other, thus they have the responsibility to employ measures and means to cope. Coping mechanisms can affect significant other on a micro, meso, exo and macro level, as interaction on all levels can be affected by the quality of coping mechanisms that are employed.

3.8 Summary

During the course of this chapter the research methodology was discussed and themes and sub-themes that were identified through the research study were presented by means of thematic analysis. The themes identified in this study were: understanding of spinal cord injury; significant other’s experience of rehabilitation; the emotional impact of tetraplegia on significant other; social changes associated with tetraplegia; changes in relationship dynamics after tetraplegia and needs of significant other. In chapter four the summary, key findings, conclusions and recommendations are discussed.

CHAPTER FOUR: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

4.1 Introduction

This chapter aims to discuss the conclusions and recommendations determined throughout this research study, with the focus on discussing how the goal and objectives of this study were met, as well as the answer to the proposed research question.

4.2 Summary

The goal, objectives and research question will be explored and discussed in terms of how they were accomplished.

4.2.1 Goal of the study

The goal of this study was to explore and describe the psycho-social experiences of significant others post-acute tetraplegia in-patients after rehabilitation.

4.2.2 The objectives of the study

The objectives that had to be strived towards to achieve the goal were:

- To conceptualise and contextualise the nature, treatment and rehabilitation of tetraplegia
- To explore the psycho-social experiences and needs of significant other in the care and support of the post-acute tetraplegic patient after rehabilitation
- To explore and describe the psycho-social challenges of significant other in the care and support of the post-acute tetraplegic patient post-discharge
- To make recommendations to the multidisciplinary team for improvement of post-discharge support services to significant other of tetraplegic patients

4.2.3 Achievement of objectives

Each objective will be discussed individually and how it was achieved through the research study.

- **Objective 1: To conceptualise and contextualise the nature, treatment and rehabilitation of tetraplegia**

This objective was achieved through a review of the literature on tetraplegia, and how the person is affected biologically, as well as the psycho-social factors that often affect the person and significant other. This review is presented in Chapter two and includes: the definition of medical concepts; the biological aspects of tetraplegia, including; the prevalence of spinal cord injuries; the composition of the spine; the functioning of the spinal cord. The biological implications of spinal cord injuries included: the classification and symptoms of spinal cord injuries and complications, the psycho-social impact of tetraplegia on the person who sustained tetraplegia and their significant other was also discussed. Finally, the rehabilitation of the person and role of the social worker was discussed.

- **Objective 2: To explore the psycho-social experiences and needs of significant other in the care and support of the post-acute tetraplegic patient after rehabilitation**

This objective was achieved through conducting an empirical study. The researcher embarked on collecting data through the one-on-one semi-structured interviews. Rich and thick data of participant experiences, feelings and perceptions were gathered. The interviews were transcribed verbatim. Themes and sub-themes were generated from the data, revealing that tetraplegia is a life changing event, not only affecting the person who sustained tetraplegia, but also having a substantial impact on the psychological wellbeing of both the person and significant other. It often poses a challenging process of social reintegration after the injury, needing substantial support. Experiences and needs that were identified through the study included: understanding of spinal cord injury; significant other's experience of rehabilitation; the emotional impact of tetraplegia; social changes associated with tetraplegia; changes in relationship dynamics after tetraplegia and needs of significant other.

- **Objective 3: To explore and describe the psycho-social challenges of significant other in the care and support of the post-tetraplegic patient post-discharge**

This objective was also achieved through empirical research. The rich and thick data was gathered from participant interviews with regards to their experiences, feelings and perceptions. Their responses enhanced the researcher's understanding of the psycho-social challenges faced by significant other, who care for and support persons with tetraplegia. It was identified that significant other often face challenges of grieving the losses of their former lives, adjusting to a new way of life characterised by role changes, physical challenges, challenges with community accessibility, social isolation and challenges with intimacy. Theme three, four and five depict the emotional impact of tetraplegia (life changing event; role changes; losses); the social changes associated with tetraplegia (social isolation; community accessibility; social reintegration and employment) as well as the changes in relationship dynamics (privacy; dependency and conflict).

- **Objective 4: To make recommendations to the multidisciplinary team for improvement of post-discharge support services to significant other of tetraplegic patients**

This objective was achieved by means of recommendations emanating from the empirical research as discussed later in this chapter. The data collected revealed themes on the periods of hospitalisation, rehabilitation and post-discharge. The data gathered revealed the effects of the initial trauma, as well as the necessity for extensive support to the caregivers throughout the hospitalisation and rehabilitation, extending to the post-discharge period. The physical changes associated with tetraplegia, the evident losses that persons who sustained tetraplegia and significant other are faced with, as well as the biological, psycho-social and financial implication of tetraplegia provided insight into the experiences of the significant other. Recommendations are made in this chapter for social workers and acute rehabilitation centres with the focus on rehabilitation of persons with tetraplegia and their significant other.

4.2.4 Research Question

The research question was:

What are the psycho-social experiences of significant others of post-acute tetraplegia in-patients after rehabilitation?

The answer to the research question was provided in chapter three through the thematic analysis of the data and themes were generated from this study namely:

Theme one: Understanding of spinal cord injury

Theme two: Significant other' experience of rehabilitation

Theme three: the emotional impact of tetraplegia on significant other

Theme four: Social changes associated with tetraplegia

Theme five: Changes in relationship dynamics after tetraplegia

Theme six: Needs of significant other

4.2.5 Limitations of the study

- There is a scarcity of literature in the field of Social Work on this topic and as a result literature from other disciplines was consulted and adapted
- Time constraints were evident as the participants were the primary caregivers of persons with tetraplegia, and had a variety of responsibilities to attend to, thus the researcher felt pressured to keep to the time allocation of 45 minutes when conducting the interview
- Only ten participants were selected for this study, and after interviewing them a point of data saturation was reached, thus not needing to sample more participants. The findings of his study can therefore not be generalized
- Most participants knew the researcher before the study, some in capacity of social worker. This made the interviews difficult as participants had a need for support and counselling about the difficulties they were experiencing at that time. The researcher aimed to remain focussed as a researcher, but found it difficult to deal with these expectations of support and counselling, even though it was clearly stated prior to the interview that the focus was on research. The researcher addressed this in the debriefing sessions with each participant and referred them to a colleague at Mediclinic Muelmed rehabilitation unit if it was needed. No participants needed or requested counselling after the debriefing sessions.
- The researcher tried to avoid researcher bias as far as possible, as a result of the above and strived towards ensuring trustworthiness.

4.3 Key findings, conclusions and recommendations

Firstly, the conclusions regarding the literature study will be discussed, followed by the key findings, conclusions and recommendations for each theme of the research study.

4.3.1 Conclusions regarding the literature study and theoretical framework

The literature review was very helpful in assisting the researcher in understanding the phenomena of tetraplegia, and the psycho-social implication on the person who sustained tetraplegia, as well as on their significant other. The aspects revealed as the most challenging were the biological implications of spinal cord injuries, namely: the classification, symptoms and the physical complications.

The psycho-social factors that were found to be most common were depression, anxiety, feelings of hopelessness, stress and a sense of grief. Social factors included lack of autonomy, a sense of dependence on significant other physically, psycho-socially and financially. Aspects pertaining to home and community integration, community accessibility, social participation and relational difficulties were explored and found to be experienced often by persons who sustained tetraplegia as well as their significant other.

The theoretical framework, the Ecological Systems theory was meaningful in assisting the researcher to understand that tetraplegia affected the person and significant other on all levels of functioning, from the most intimate one-on-one interactions to interactions with family members, friends, community and society as a whole.

4.3.2 Key findings, conclusions and recommendations regarding the research findings

Each theme will be discussed regarding the key findings, conclusions and recommendations

4.3.2.1 Theme one: Understanding of spinal cord injury

Key findings and conclusions:

It is pivotal for the term spinal cord injury, especially tetraplegia and the effects thereof, to be understood as it is a tremendous life-changing event, that not only affects the person affected by tetraplegia, but also the significant other to a great extent.

Most of the participants had a basic understanding of what the term spinal cord injury means and what the implications of such an injury entails. During the acute phase, before being transferred to a rehabilitation unit, the participants reported that doctors were not explaining the acute diagnosis, effects and long-term prognosis efficiently and thoroughly. This lack of information often caused emotional distress and secondary trauma for the significant other, who seemed to experience feelings of uncertainty and anxiety about the future. The research findings identified a great need for the participants to be informed on the effects of tetraplegia during the acute stage after the injury.

The initial acute phase in the acute hospital was distressing to the significant other. After being informed that a loved one sustained tetraplegia, the initial reactions of significant other ranged from shock, anxiousness, stress, uncertainty and being terrified of the implications when someone has sustained tetraplegia. Participants had a distressing reaction to the initial news of the injury, feeling surreal. They were struggling to grasp the reality of the injury.

All participants reported that information had been provided to them explaining the condition of tetraplegia during multiple consultations with the assigned medical professional. The secondary trauma and shock related to the information provided about tetraplegia seemed to hamper their ability to absorb the reality of the nature of the condition, resulting in unanswered questions and feelings of ambiguity regarding prognosis and recovery.

Secondary complications were reported to be a prominent factor after sustaining tetraplegia. Pressure ulcers and urinary tract infections were reported to be the most common secondary complications associated with tetraplegia. The frequent risk of secondary complications and possible rehospitalization often caused emotional

distress to significant other. Rehospitalization has a psycho-social impact on the social reintegration, the ability to obtain and maintain a vocational position, to contribute financially to the household, as well as community reintegration. Frequent rehospitalization often exasperated the role changes, quality of relationships and the emotional support rendered to persons with tetraplegia by significant other. Social isolation was also prevalent, as persons with tetraplegia and their significant other were not able to engage with their social circles when the rehospitalization occurred for extended periods.

From the study it can be concluded that sustaining tetraplegia has far-reaching consequences for both the person who sustained the injury, as well as their significant other. It is clear that the initial acute phase in hospital is often experienced as extremely traumatic by the person and significant other. Their initial reactions after being informed about the nature of the injury were characterized by feelings of disbelief and distress. The research study identified that the significant other seemed to have a need for information and education on the nature of the condition and the effects of tetraplegia. It also became evident that secondary complications are prevalent and far reaching for both the person who sustained tetraplegia and their significant other.

Recommendations:

It is recommended that significant other receive extensive emotional support and debriefing intervention services during the acute phase after the injury. It is evident that the significant other has immense need for education and supportive counselling, so as to be able to integrate and internalise the information provided by the medical professionals about the clinical presentation of tetraplegia. It is recommended that psycho-social intervention services be rendered by social workers and psychologists in the multidisciplinary team in conjunction with the medical professionals during the acute phase.

4.3.2.2 Theme two: Significant other's experience of rehabilitation

Key findings and conclusions:

Most participants seemed to have had a positive experience during the in-patient rehabilitation process and commented that the rehabilitation team provided them with information on the condition, as well as the management of tetraplegia. Most

participants reported to experience less anxiety during the rehabilitation phase, as compared to the acute phase. Participants, however, seemed to have a need for more hands-on training regarding the nursing of the person at home, including changing catheters as well as bowel and bladder management.

Weekend pass-outs were reported to be an integral part of the rehabilitation process, and the participants mostly reported it to be a positive experience. The weekend pass-outs were also reported to be a prominent platform of preparation in the physical care, including knowledge on transfers, techniques to perform pressure relief to prevent pressure sores, bathing, toileting and management of a catheter before discharge. It was also reported to be a process of preparation emotionally for participants. They reported to be confronted with their own emotions, both positive and negative, regarding the reality of the extent of care that would be required. It was reported that some participants had positive emotional reactions to the weekend pass-outs, while for some participants the reality and adjustment to the life of living with a person who sustained tetraplegia was distressing during these pass-outs.

All participants made use of caregivers to some capacity. They were of the understanding that they would not be able to cope without an external caregiver to assist in the day-to-day care of the person with tetraplegia. The caregiver and defining the responsibilities of the caregiver is a very subjective process and was different for every significant other. Some significant other chose to still be involved in the physical nursing of the person, including bathing, dressing and managing the bowel and bladder programme. In contrast, some participants chose to only be involved in the emotional support of the person with tetraplegia. Most significant other had identified a caregiver to some degree, while still involved in the rehabilitation process. The caregiver was trained on the physical need of the person with tetraplegia and started assisting the person over weekend pass-outs.

Most participants experienced fear to some degree and feelings of anxiety, when the time for discharge came after the in-patient rehabilitation phase. They reported a lack of confidence in being able to physically take care of the person with tetraplegia in the home environment after discharge and that, the sense of the unknown caused distress for significant other.

Significant other had an overall positive experience of the in-patient rehabilitation phase. Their sense of anxiety was decreased through education and training that was rendered by the multidisciplinary team in the rehabilitation units. Rehabilitation primarily focussed on caregiver training with significant other and identified caregivers in preparation for discharge and attempts to guide and empower persons with tetraplegia on the home reintegration and management of tetraplegia after discharge. Caregiver identification and weekend pass outs were reported to be an integral part of the rehabilitation process.

Recommendations:

- The multidisciplinary team approach is pivotal in the rehabilitation phase of tetraplegia
- Emphasis should be placed on the physical care and management of tetraplegia, as well as addressing the psycho-social implications of tetraplegia during the rehabilitation phase.
- Education should be done on the necessity of external caregivers and identification and training of these caregivers before weekend pass-outs and discharge from the rehabilitation unit.

4.3.2.3 Theme three: Emotional impact of tetraplegia on significant other

Key findings and conclusions:

Significant other experienced the diagnosis of tetraplegia as a life-changing event. They experienced tetraplegia, not only affecting the person who sustained the injury, but also having a significant effect on the dynamics of their own lives. The biggest challenges faced by significant other were the reality of the person affected by tetraplegia, becoming completely dependent on an external person to perform normal day-to-day activities. This dependence ranged from physical dependence for activities of daily living such as eating, dressing, bathing, mobilising and toileting. Other aspects of dependence included becoming dependent emotionally, socially and financially on their significant other. The significant other reported a conflict in managing their own lives, while simultaneously having to adjust to having a person fully dependent on them. Both the person who sustained tetraplegia and the significant other were often faced with the reality of changing dynamics, which often lead to inevitable

readjustment of roles, responsibilities and dynamics within a household. This adjustment to life after tetraplegia often caused significant amount of distress for both the person with tetraplegia and their significant other.

Role changes were inevitable for both the person affected by tetraplegia and the significant other. Changes in relationship dynamics were evident. The dynamics between mother-son, father-son and spousal relationships, were reported to be affected in a substantial way. Not only were the role changes evident, but the role changes had an inevitable effect on the relationship dynamics between the person affected with tetraplegia and their significant other. This seemed to cause emotional distress for significant other. Feelings of anxiety, uncertainty, frustration and losing their own identity were factors reported to be associated with the role changes.

All the significant other experienced feelings of loss to some extent. Losses were focussed on the dreams and ambitions the significant other had for the person affected with tetraplegia. Promising prospects of employment; professional sports and the roles that could have been assumed, were no longer possible after sustaining tetraplegia. Significant other also seemed to mourn the losses of activities that they used to participate in with the person affected by tetraplegia. Losses associated with tetraplegia were far-reaching and affected all aspects of the significant other' lives. The severity and finality of the changes associated with tetraplegia seemed to have a negative impact on significant other.

The emotional impact of tetraplegia on significant other is far-reaching. This study provides evidence that tetraplegia is a life-changing event, affecting both the person who sustained the injury, as well as the significant other. Role changes and experiencing losses leads to an inevitable process of adjustment for the person and significant other, often having an emotional impact characterised by distress, anxiety and coming to terms with the lives that they led prior to the injury.

Recommendations

- Significant other should receive extensive psycho-social intervention services during the rehabilitation phase, aimed at education on the psycho-social implication of tetraplegia

- Education on coming to terms with losses, readjustment to different life roles, as well as coming to terms with the life-changing event are to be addressed through supportive counselling by a social worker and psychologist working in the multidisciplinary team

4.3.2.4 Theme four: Social changes associated with tetraplegia

Key findings and conclusions:

Social interaction is an area that is significantly affected after sustaining tetraplegia. Previous social acquaintances and friends seemed to step away from the person who sustained tetraplegia, as well as their significant other. This in turn leads to social isolation and the need to identify and integrate into a new social circle, which was often traumatic to the person affected with tetraplegia, as well as significant other. Social roles were also affected, with some participants reporting that they used to engage in social interaction on a regular basis before the injury. In contrast participants reported a significant deterioration in their social circle and social interaction after the injury. Significant other often experienced a sense of frustration towards their social circle's perceived perception of the responsibilities of the significant other. The participants reported that their friends were not present to see all the care that is required for the person with tetraplegia, thus their social circle of friends could not relate to obligated adjustment to this new life.

Community accessibility was another challenge faced by a variety of the participants. Community accessibility was a sense of frustration for various participants. Wheelchair accessibility and community engagement was reported to be challenging, which in turn had a negative impact on the social reintegration of the person who sustained tetraplegia and their significant other. The reality of limited community accessibility and community resources had an impact on how involved the person who sustained tetraplegia can be in their community. This obstacle in community accessibility was reported to have a psycho-social effect on the person and significant other. Leisure activities, possible vocational opportunities and community reintegration were all factors affected by the challenges of wheelchair accessibility.

Ninety percent (90%) of the persons who sustained tetraplegia were unemployed by the time of conducting the interviews. This had a significant psycho-social and socio-

economic impact, not only on the person who sustained tetraplegia, but also on significant other. The challenge associated with finding and maintaining employment after sustaining tetraplegia, often reinforced role changes and a sense of dependence on significant other. This loss of economic growth in the household due to unemployment, often strained relationships and caused concern for significant other.

The social impact of tetraplegia had far-reaching consequences for both the person who sustained tetraplegia, as well as the significant other. Changes and losses in social interaction were prominent after sustaining tetraplegia, which caused distress for both the person and significant other. Community accessibility was a topic of great frustration for significant other, as these challenges also often infringed on their ability to engage in social participation. Employment was a great area of concern, as most of the participants' significant other were not employed after sustaining tetraplegia.

Recommendations:

- Significant other and persons who sustained tetraplegia should be educated regarding the social changes associated with tetraplegia. Through education on the social factors, strategies to strengthen their support network and identifying resources in their community can be employed through supportive counselling by a social worker and psychologist working in the rehabilitation unit
- Strategies should be explored to communicate their experiences to their close friends, so as to eliminate the frustration experienced when significant other feel misunderstood by their social circle
- Guidelines should be made available to persons with tetraplegia and significant other during the rehabilitation phase, for possible temporary incapacity leave benefits, or policies that might render financial assistance.
- Possible employment opportunities should be explored and significant other should be educated on financial management, as a loss of income might be easier manageable through supportive counselling by a social worker

4.3.2.5 Theme five: Changes in relationship dynamics after tetraplegia

Key findings and conclusions:

A factor that affected persons with tetraplegia and their significant other was that a caregiver was required to be in their home environment on a regular basis to assist with the caring of the person who sustained tetraplegia. Various participants mentioned that the lack of privacy associated with the need for a caregiver, had an influence on the privacy, intimacy and dynamics of their relationships. It was also identified that participants reported they were experiencing this invasion of privacy as a loss to be mourned and a major factor in the adjustment after tetraplegia.

The sense of dependence on the significant other after sustaining tetraplegia was a prominent theme identified. Some of the participants shared frustrations with the person with tetraplegia for often not taking responsibility for their day to day care, including managing their medication and bowel and bladder programme. The dependence on significant other was evident including both a sense of physical and emotional dependence. Persons with tetraplegia also often found themselves dependent on their significant other to facilitate their activities of daily living, socially and financially.

Conflict to some degree was often a prevalent characteristic of the relationship between the person who sustained tetraplegia and their significant other. A precipitator of conflict was that the person who sustained tetraplegia, often had the expectation that things should be done for them in a very specific way, how they wanted it done, and when the significant other or the caregiver failed to perform tasks not meeting their expectations, conflict arose. The impact of tetraplegia and the long-lasting effects were not only limited to the person who sustained tetraplegia, but often extend to the significant other.

Persons with tetraplegia and their significant other experienced noticeable changes in their relationship dynamics after sustaining tetraplegia. Privacy in their home environment, and in their relationship was affected by the necessity of an external person acting as a caregiver. After sustaining tetraplegia the sense of dependency on the significant other was prominent, which caused psycho-social challenges for the significant other, contributing to challenges in adjustment after tetraplegia. Conflict was also prominent after sustaining tetraplegia and significant other reported that it often caused relationship strain.

Recommendations:

- Supportive counselling should be rendered to significant other during the rehabilitation phase, aimed at working through the losses associated with tetraplegia, and to educate them on the possible changes in relationship dynamics that might be anticipated
- Significant other should be educated and empowered to set necessary boundaries aimed at promoting a sense of privacy in their home environment after discharge. These boundaries should be discussed with the person who sustained tetraplegia, as well as the caregiver, so as to establish a routine all parties are comfortable with
- Conflict management styles should be addressed with the person who sustained tetraplegia as well as the significant other, aimed at understanding their own, as well as their significant other's conflict management styles. Education on conflict management styles are to be explored in order to promote the health of their relationships

4.3.2.6 Theme six: Needs of significant other

Key findings and conclusions:

Participants demonstrated the need for significant other to connect with and receive support from people who find themselves in similar situations.

Coping mechanisms were part and parcel of what was necessary in this adjustment process for the significant other. It became clear that positive, as well as negative measures, were employed by significant other to cope after the injury.

Two specific needs were expressed by the significant other, firstly a need for peer support, someone in a similar situation that could render support and education on aspects pertaining to tetraplegia. This need was expressed from the acute stage of the injury, throughout the rehabilitation and discharge at home phase, aimed at sharing of ideas and ways of doing things for the person with tetraplegia, as well as to be a source of emotional support for them. Support groups for significant other are thus recommended. Secondly, coping mechanisms to cope with the psycho-social impact of tetraplegia was specified as a need. Coping mechanisms employed included the

use of medication such as antidepressants, finding employment by the significant other, so as to engage in a different environment and be independent, and meditation seemed to be used to find comfort. The role of independence and meditation seemed to be various ways significant other found comfort.

Recommendations

- Peer support should be identified and utilised by significant other that have been affected by tetraplegia, including support groups of significant other in a similar situation
- The multi-disciplinary team can be of great assistance in facilitating the peer identification and assist in the process of relationship building initially.
- Positive coping strategies should be explored with significant other during the rehabilitation process, to promote positive coping strategies beneficial for themselves and the persons with tetraplegia

4.4 Recommendations

Subsequently recommendations will be made for future research, practice and policy.

4.4.1 Recommendations for future research

Further in-depth research should be conducted to explore the experiences of significant other of persons affected by tetraplegia. It is recommended that a study be focussed on the intimate relations and/or marriages of persons affected by tetraplegia and their spouses/partners as the researcher identified that this study was not aimed at exploring the changes in intimacy, sexuality and partner roles, but identified that it is an area of study where there is a gap.

4.4.2 Recommendations for practice and or policy

It is recommended that social workers embark on rendering supportive counselling in the acute phase after an individual sustained tetraplegia, aimed at crisis intervention and initial trauma counselling. It is also recommended that social workers form part of the multidisciplinary team in the acute units, so as to assist with the processing of initial information given by the medical professional after the injury. It is recommended that

a handover be provided to a social worker that is part of the rehabilitation unit's multidisciplinary team. During rehabilitation it is recommended that a social worker engage in supportive counselling with significant other aimed at educating them on the psycho-social implications of tetraplegia and to assist with the problem-solving process associated with the psycho-social factors. It is recommended that the social worker engage in intensive psycho-social counselling to ensure significant other have the necessary support throughout the rehabilitation process and are empowered to identify resources in their community for support after discharge.

4.5 Closing remarks

Recommendations were made in this chapter to address some of the difficulties identified through this study. Recommendations for practice and policy changes were made aimed at promoting the psycho-social and supportive services rendered to significant other of persons who sustained tetraplegia, by the multidisciplinary team and social workers.

The traumatic nature of sustaining tetraplegia calls for an intensified effort by social workers to engage in trauma counselling, crisis intervention and supportive counselling with significant other, aimed at education and empowerment. Support is necessary from the acute setting, throughout the rehabilitation process, and post-acute after discharge from the rehabilitation unit. It has become evident through this study that the significant other plays a key role in the coping and readjustment of the person who sustained tetraplegia. It is detrimental to take into account that the significant other experience their own sense of trauma and losses when a loved one sustains tetraplegia, thus it is necessary that the multidisciplinary team and social workers include significant other in a holistic approach of service delivery during the rehabilitation phase, as well as post-acute after rehabilitation to promote effective coping skills, readjustment and quality of life for persons who sustained tetraplegia and significant other.

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APPENDICES

APPENDIX 1: ETHICAL APPROVAL LETTER



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

26 March 2018

Dear Ms Kriel

Project: What are the psycho-social experiences of significant others of post-acute tetraplegia in-patients after rehabilitation, from an eco-systemic perspective?
Researcher: I Kriel
Supervisors: DR CL Carbonatto and Dr M Coetzee Spies
Department: Social Work and Criminology
Reference number: 12018318 (GW20180316HS)

Thank you for the application that was submitted for ethical consideration.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** at the meeting held on 22 March 2018. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely

PP.

Prof Maxi Schoeman
Deputy Dean: Postgraduate Studies and Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:tracey.andrew@up.ac.za

CC: DR CL Carbonatto (Supervisor)
Dr M Coetzee Spies (Co-Supervisor)
Prof A Lombard (HoD)

Research Ethics Committee Members: Prof MME Schoeman (Deputy Dean); Prof KL Harris; Dr L Blokland; Ms A dos Santos; Dr R Fasselt; Ms KT Govinder; Dr E Johnson; Dr C Panebianco; Dr C Puttegerill; Dr D Reyburn; Dr M Taub; Prof GM Spies; Prof E Taljard; Ms B Tsebe; Dr E van der Klashorst; Dr G Wolmarans; Mr V Sithole

APPENDIX 2: TITLE CHANGE

UNIVERSITY OF PRETORIA
DWARSVORM / LATERAL FORM
RECOMMENDATION REGARDING TITLES AND ETHICAL CLEARANCE OF THESES/DISSERTATIONS/mini-DISSERTATIONS,
SUPERVISORS/CO-SUPERVISORS

THIS FORM MUST PLEASE BE TYPED AND SUBMITTED IN DUPLICATE.

ROUTE

Please note: THE NECESSARY ETHICAL QUESTIONNAIRE AND RESEARCH PROPOSAL SHOULD BE ATTACHED TO THIS FORM.

<p>Student number: 12018318 Title: Ms</p> <p>Surname: Kriel Initials: I</p> <p>Course: MSW (Healthcare)</p> <p>Department: SOCIAL WORK & CRIMINOLOGY</p> <p>Postal address: 100 Priory Rd, Lynnwood Manor, Pretoria 0081</p> <p>Tel No: 0793543451</p> <p>Please ensure that the title is grammatically correct. Please do not type the full title in capital letters.</p> <p>For notification of the faculty board, please mention: THESIS: _____ DISSERTATION: _____ MINI-DISSERTATION: X</p> <p>OLD TITLE: What are the psycho-social experiences of significant others of post-acute tetraplegia in-patients after rehabilitation, from an ecosystems perspective?</p> <p>NEW TITLE: The psycho-social experiences of significant others of post-acute tetraplegia in-patients after rehabilitation</p>	<p>a) SUPERVISOR: Dr CL Carbonatto Please state staff number (If a person outside the University is nominated, a CV and motivation should be attached to the proposal)</p> <p>b) CO-SUPERVISOR: Dr M Coetzee-Spies Please state staff number (If a person outside the University is nominated, a CV and motivation should be attached to the proposal)</p>	<p>1. SUPERVISOR: Signature: <i>[Signature]</i> Date: 11/12/2018</p> <p>2. DEPARTMENTAL RESEARCH/POSTGRADUATE COMMITTEE: Signature: <i>[Signature]</i> Date: 11/12/2018</p> <p>3. HEAD OF DEPARTMENT APPROVED: Signature: <i>[Signature]</i> Date: 11/12/2018</p> <p>4. CHAIR OF CLUSTER: Signature: _____ Date: _____</p> <p>5. STUDENT ADMINISTRATION: (to be submitted to the Ethics Committee/Postgraduate Committee where applicable) Signature: _____ Date: _____</p> <p>6. FACULTY RESEARCH ETHICS COMMITTEE: (to approve ethical clearance) FACULTY POSTGRADUATE COMMITTEE: Where applicable (to approve research proposal; change of title; appointment of external supervisor/co-supervisor; change of supervisor/co-supervisor) Signature: <i>[Signature]</i> Date: _____</p> <p>7. RESEARCH COMMITTEE: Signature: _____ Date: _____</p>
<p>APPROVAL:</p> <p><input type="checkbox"/> Ethical clearance to be considered by the Ethics Committee</p> <p><input type="checkbox"/> Appointment of external supervisor/co-supervisor (motivation and cv attached)</p> <p><input type="checkbox"/> Change of supervisor/co-supervisor</p> <p><input type="checkbox"/> Research proposal and title to be considered by the Postgraduate Committee (where applicable)</p> <p><input checked="" type="checkbox"/> Editorial change of title</p> <p><input type="checkbox"/> Other (mention): _____</p>		

APPENDIX 3: PERMISSION LETTER QASA



PO Box 2368 Pinetown 3600
17 Hamilton Crescent Gillitts 3610
Tel: 031 7670352 / 7670348
Sharecall: 0860ROLLING
Fax: 031 7670584
Email: info@qasa.co.za
www.qasa.co.za
NPO 000 881

14/11/2017

TO WHOM IT MAY CONCERN:

This is a letter to confirm the provisional permission for the request made by Miss I Kriel to perform empirical research at Quadpara Association of South Africa (QASA) in the Gauteng region.

The **title** of the study is: **The psycho-social experiences of significant others of post-acute in-patients after rehabilitation, from an eco-systemic perspective**

The **goal** of the study is: To explore and describe the psycho-social experiences of significant others of tetraplegic patients post in-patient rehabilitation from an eco-systemic perspective

The **objectives** of the study are:

- To conceptualise and contextualise the nature, treatment and rehabilitation of tetraplegia.
- To explore the experiences and needs of significant others in the care and support of the tetraplegic patient post-discharge.
- To explore and describe the psycho-social challenges of significant others in the care and support of the tetraplegic patient post-discharge
- To make recommendations to the multidisciplinary team for improvement of post-discharge support services to significant others of tetraplegic patients

The envisaged sample for the study will include significant others which may include spouses, partners, parents or siblings of all ages of tetraplegia patients who are members of QASA. Those clients who are interested will be given an information letter by the staff at QASA and if interested will be asked to provide their contact details to the QASA staff member. The researcher will then collect these details after two weeks and contact the potential participants. Once the letter of informed consent has been discussed and signed voluntarily by the client, an appointment for an interview will be made. All information will be kept confidential and used for research purposes only. The identity of each participant will be protected by using a pseudonym, for example participant 1.

Banking details: QASA, Nedbank Pinetown Acc No: 1339 473267 Branch Code: 133 926



ROLLING
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Media monitoring by **newsclip**

Mission:-To improve lives by securing resources to advocate, educate, capacitate, support & mobilize

No **costs** will be incurred by the organization by granting this request. Possible benefits for the organization can be summarised as follows:

- Conclusions will help with understanding the experiences of significant others of tetraplegic patients.
- Recommendations will help improve the contents of services delivered to significant others of tetraplegic patients.

Hereby provisional permission is granted to Miss I Kriel to utilise the member database of QASA to identify possible participants for her study. The final permission will be granted to Miss I Kriel upon receiving her ethical clearance letter.

Kind Regards



Ari Seirlis
CEO

Banking details: QASA, Nedbank Pinetown Acc No: 1339 473267 Branch Code: 133 926



ROLLING
INSPIRATION



Media monitoring by **newsclip**

Mission:-To improve lives by securing resources to advocate, educate, capacitate, support & mobilize

APPENDIX 4: INFORMED CONSENT LETTER



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

Department of Social Work and Criminology

Researcher: Ilanie Kriel
E-mail: ilaniekriel7@gmail.com
Cell no.: 0793543451
Tel no: 012 341 1909

LETTER OF INFORMED CONSENT

Section A: Research Information

Dear participant,

Research Title: The Psycho-social experiences of significant others of post-acute tetraplegia in-patients after rehabilitation, from an eco-systemic perspective

1. Purpose of study

The purpose of this study is to explore and describe the psycho-social experiences of significant others of tetraplegic patients post in-patient rehabilitation from an eco-systemic perspective.

2. Procedures of study:

You will be expected to participate in a semi-structured interview in which you will be asked questions pertaining your experiences of your tetraplegic family member after the in-patient rehabilitation. The duration of the interview will be approximately 45 minutes. The interview will be voice recorded with your permission for data collection purposes, but will not include your name to ensure confidentiality.

Before the interviews commences, the details of the study will be explained to you. Once you agree to participate and sign the informed consent form, the interview will commence.

3. Confidentiality:

The data collection will include an interviews, voice recording of the interview and the transcription of the interview. This data will be stored in The Department of Social Work and Criminology, University of Pretoria for 15 years for archival or possible future research purposes. Your information shared will remain confidential and you will be assigned a number or pseudonym before the interview to protect your identity. Interviews will be conducted in a quiet and private room to ensure privacy and confidentiality. Furthermore the data collected will not include any information that can identify you or any participant in this study. The research report and possible article in a scientific journal will also not reveal your identity. Please note that only the researcher and supervisor will have access to the data for research purposes.

4. Voluntary participation:

Please understand that participation in this study is voluntary. You may refuse to answer any question or discontinue your involvement and withdraw at any time without incurring any negative consequences. Furthermore you can rest assured that the data you share will be destroyed should you choose to withdraw from the study.

5. Risks and discomforts:

You will not suffer any risks or discomforts, but may get tired. Debriefing will be provided by the researcher after the interview. If counselling is required, you will be referred to the social worker at the in-patient rehabilitation unit.

6. Benefits:

The researcher hopes that the study will provide a better understanding of the psycho-social experiences of significant others of tetraplegic patients post in-patient rehabilitation from an eco-systemic perspective and the findings may be used to recommend interventions in the future. There are no direct benefits for participating in this study.

7. Remuneration:

You will not receive any compensation from the researcher for your participation in the study.

8. Details of the researcher:

If you have any concerns or questions regarding the study, please do not hesitate to contact: **Ilanie Kriel** (principal researcher) at **Cell no:** 0793543451 or **Tel no:** 012 341 1909 or **E-mail:** ilaniekriel7@gmail.com

If you agree to partake in this study as explained above, please sign on the next page.

Yours sincerely,

Ms Ilanie Kriel
Principal Researcher

Section B: Informed Consent

Declaration

I, the undersigned, understand my rights as a research participant. I understand what the study is about, how I will participate and why this study is being conducted. I hereby voluntary consent to participate in this study.

Signed on _____(date)

at _____

_____(place)

Signature of participant: _____

Signature of researcher: _____

Date: _____

APPENDIX 5: INTERVIEW SCHEDULE (ENG)

INTERVIEW SCHEDULE

DEMOGRAPHICS

Gender	
Age:	
Relation to the patient:	
Cultural affiliation:	
Level of injury of loved one	
How long ago did injury occur	
Age of the loved one	

1. BIOLOGICAL ASPECTS

- What you understand by the term spinal cord injury?
- Tell me about the biggest changes in his/her body after the injury?
- How has the physical changes affected your life?
- Where is he/she living and who is caring for the patient physically at the moment?
- Is the person experiencing/struggling with any health complications at the moment?
(pressure sores, bladder infection)

2. PSYCHOLOGICAL ASPECTS

- What were your emotions the first day when you heard about the injury?
- Did you feel you wanted someone to support you emotionally at that stage?
- What emotions were you feeling when he was in the rehabilitation unit?
- Did you have a caregiver before the first weekend out?
- What emotions did you experience when he/she came home for the first weekend?
- What was the biggest thing you learned during weekends out?
- Who supported you during the rehabilitation process?
- What were your biggest fears when discharge came?
- Did you have a caregiver when he/she was going to be discharged?

- What emotion do you experience when thinking about you supporting him/her after the injury?
- What were the biggest challenges you faced after discharge?
- Explain the patient's attitude after discharge?
- Do you think his/her attitude has an impact on how the family is coping with the injury?
- Do you feel you received enough emotional support from the rehabilitation team when he/she was in rehab?
- What is the best thing that came out of him/her being a quadriplegic?
- What is the worst thing about him/her being a quadriplegic?
- Is he involved in any sport/social/leisure activities at the moment?

3. SOCIAL ASPECTS

- What is the biggest thing that you felt you had to adjust to after he/she came home after rehab?
- How did you as a family cope after he/she came home from rehab?
- Did you experience any sense of loss when thinking about him/her being a quadriplegic?
- How did the injury **bring you and him/her closer together, or drive you further apart?**
- How much conflict was there between you and him after the injury; and what did you fight about?
- What is the most frustrating part about quadriplegia?
- Do you feel that the role he/she played in the home has changed; if yes, how so?
- Has his/her personality changed at all after the injury? Does he/ she enjoy socializing with people?
- Who is your main support system?
- Was he/she able to support himself/ family financially after discharge?
- Does your loved one currently have a job?

4. ROLE OF SOCIAL WORKER

- Which multidisciplinary team members played the most meaningful role during the rehabilitation and discharge phase?
- Explain the role of the social worker during the rehabilitation phase?
- Do you feel enough services were rendered to prepare you for discharge during rehabilitation?
- Which referrals or connections to resources in the community were made?

5. RECOMMENDATIONS

- Anything you would recommend to caregivers/ family of SCI patients?
- If you could make recommendations regarding the MDT regarding the rehabilitation and discharge phase what would it be?

APPENDIX 6: INTERVIEW SCHEDULE (Afrikaans)

DEMOGRAPHICS

Geslag	
Ouderdom	
Verwantskap	
Kulturele affiliasie:	
Vlak van besering	
Hoe lank gelede het besering plaasgevind	
Geslag van geliefde	
Ouderdom van geliefde	

1. Biologiese aspekte

- Wat verstaan jy van 'n spinale koord besering
- Wat was die fisiese veranderinge na die besering
- Wie versorg die persoon fisies
- Is daar enige komplikasies met gesondheid op die oomblik?

2. Sielkundige aspekte

- Wat was jou eerste reaksie, en gedagtes toe jy hoor van die besering
- Wat was jou behoeftes to jy uitvind van die besering
- Wat was jou gevoelens en gedagtes gedurende rehabilitasie
- Wat was jou behoeftes gedurende rehabilitasie
- Wie het jou ondersteun/ bygestaan deur rehabilitasie
- Wat was jou gedagtes en vrese toe ontslag nader kom
- Wat is jou ervaring om jou geliefde te ondersteun na die besering
- Wat is die uitdagings wat jy ervaar het na ontslag
- Wat was jou behoeftes na ontslag

3. Sosiale aspekte

- Wat is die grootste verandering wat plaasgevind het na ontslag
- Hoe het die besering jou verhouding met jou geliefde geaffekteer
- Hoe het die besering die verhouding en rolverdeling in die huishouding geaffekteer

- Hoe het die interaksie met vriende, familie en die gemeenskap verander
- Was jou geliefde in staat om himself finansiell te ondersteun na die besering
- Het jou geliefde tans werk
- Hoe het kulturele of geloofsaspekte gehelp met die aanpassingsproses

4. Rol van maatskaplike werker

- Watter lid van die rehasiliasiespan het die grootste rol vir julle gespeel
- Watter rol het die maatskaplike werker in die rehasiliasieproses gespeel
- Voel jy genoeg dienste en ondersteuning was gegee om jou voor te berei vir ontslag
- Watter verwysings was gemaak vir hulpbronne in julle gemeenskap

5. Aanbevelings

- Enige aanbevelings wat jy sal maak vir SCI passiente of hulle geliefdes
- Aanbevele rakende die rehasiliasieproses

APPENDIX 7: DECLARATION OF EDITING AND PROOFREADING

BRENDA LOMBARD
PROOF READING AND EDITING
Associate member of Professional Editor's Group

Date: 25/05/2019

Invoice Number: 01/05

Invoice to:

Client name: Ilanie Kriel

Description: Editing of MSW (Health Care) thesis

Period: 24/04/2019 to 25/05/2019

Rate: R25.00/page

Amount: 112 pages x R25.00 = R2800.00

Banking details:

Bank: FNB

Branch: Greenstone (201510)

Account holder: Brenda Lombard

Account number: 62200205137

Type of account: Savings

Thank you for your support

21 Oribi Avenue, Van Riebeeck Park, Kempton Park, 1619
PO Box 8077, Birchleigh, 1621
e-mail: brenlombard@gmail.com

Telephone: 0113931577
Mobile: 0836751795
Fax: 0862055444