

**THE IMPACT OF EMOTIONAL SUPPORT
OFFERED DURING REHABILITATION ON
THE LONG-TERM QUALITY OF LIFE AND
SATISFACTION WITH LIVING OF
INDIVIDUALS WITH SPINAL CORD INJURY:
AN EXPLORATORY STUDY OF INDIVIDUALS
RE-EMPLOYED IN THE SOUTH AFRICAN NATIONAL
DEFENCE FORCE**

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The crest of the University of Stellenbosch is centered behind the author's name. It features a shield with various symbols, topped by a crown and surrounded by a decorative wreath.

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DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis is my own work and has not previously, in its entirety or in part, been submitted at any university for a degree.

Signature.....

Date.....

ABSTRACT

Many South African National Defence Force (SANDF) soldiers have suffered spinal cord injury either in the line of duty or otherwise. This injury affects all spheres of life (physical, emotional, social and psychological). Servicemen are often considered heroes of their country and are often the ones who need to set aside their emotions in order to fulfil their roles as soldiers. However, it is anticipated that a permanent impairment/disability e.g. SCI will have an impact on their quality of life (QOL) and satisfaction with living (SWL).

This study aims to explore whether emotional support offered to soldiers with spinal cord injury (SCI) during rehabilitation improve their long-term QOL and SWL.

Thirteen soldiers who have been re-employed post injury were asked to complete a self-compiled, self-administered questionnaire regarding the emotional support offered during rehabilitation and the impact thereof on long-term QOL and SWL.

The questionnaire focused on their ratings of the QOL and SWL in different areas of their lives and circumstances and asked what they would advise newly injured individuals regarding SCI and rehabilitation.

Data was analysed using a combination of qualitative and quantitative methods. Pearson's chi-square test and the M-L chi-square tests were used to analyse the data with the Statistica programme. A p-value of < 0.05 were calculated as statistically significant.

Emotional support during rehabilitation showed a significant impact on QOL ($p=0.0497$). Ninety-two percent ($n=12$) of participants rated their QOL as good or excellent while 77% ($n=10$) rated their SWL as good. Participants who were older than 26 reported a significantly higher rate of SWL than younger ones ($p=0.0292$). Furthermore, results showed that the family was the most constant source of support during rehabilitation (54%, $n=7$). Despite that, 77% ($n=10$) of participants felt that they received excellent emotional support from the rehabilitation team.

The study results are intended to facilitate growth and development in the rehabilitation process and guide professionals in the offering of emotional support.

OPSOMMING

Talle lede van die Suid-Afrikaanse Nasionale Weermag (SANW) doen ruggraatbeserings op, hetsy aan diens of elders. Dié besering raak alle aspekte van 'n persoon se lewe (fisies, emosioneel, sosiaal en sielkundig). Dienspligtiges word oor die algemeen as landshelde beskou en moet dikwels hul emosies opsy sit ten einde hul rol as soldate te kan vervul. Tog is die verwagting daar dat die lewenslange veranderinge wat met 'n permanente besering/ongeskiktheid bv. Spinaalkoord-besering gepaard gaan, 'n impak op hul lewensgehalte en lewenstevredenheid sal he.

Die doel van die studie is om te bepaal wat die langtermyn-impak van die emosionele steun, wat soldate met spinaalkoordbeserings tydens rehabilitasie ontvang, op hul lewensgehalte en lewenstevredenheid is.

Dertien soldate wat weer na hul besering in diens geneem is, is gevra om 'n self-geskepte, self-geadministreerde vraelys te voltooi rakende die emosionele steun wat hulle tydens rehabilitasie ontvang het en die impak wat dit op hul lewens en hul tevredenheid daarmee gehad het.

Die vraelys het gekonsentreer op hul evaluasie van hul lewens en hul tevredenheid daarmee ten opsigte van verskillende areas van hul lewens en omstandighede en gevra watter raad hulle aan persone wat onlangs beseer is, sou gee wat betref ruggraatbeserings en rehabilitasie.

Die data is met behulp van 'n kombinasie van kwantitatiewe en kwalitatiewe metodes ontleed. Die Pearson chi square en M-L square toetse is gebruik. 'n P waarde van < 0.05 word as statisties beduidend beskou.

Daar is bevind dat emosionele steun tydens rehabilitasie 'n beduidende impak op lewensgehalte ($p=0.497$) het. Twee en negentig persent ($n=12$) van die deelnemers het hul lewensgehalte as goed of uitstekend beskryf terwyl 77% ($n=10$) hul lewenstevredenheid as goed beskryf het. Die gerapporteerde lewenstevredenheid van deelnemers bo die ouderdom van 26 was beduidend hoër as dié van jonger deelnemers ($p=0.0292$). Daar is ook gevind dat familie die mees konstante bron van steun tydens rehabilitasie is (54%, $n=7$). Desondanks het 77% ($n=10$) van die deelnemers gemeen dat die emosionele steun wat hulle van die rehabilitasiespan ontvang het, uitstekend was.

Die doel van die studiebevindinge is om vordering en ontwikkeling in die rehabilitasieproses te fasiliteer en riglyne ten opsigte van emosionele steun aan mediese personeel te verskaf.

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DEFINITION OF KEY TERMS USED IN THE STUDY

EMOTIONAL SUPPORT: Burleson & Goldsmith (1998) defines emotional support as messages expressing care, concern and affection. These messages are communicated to bring about comfort through a trusting relationship in which feelings can be safely expressed.

QUALITY OF LIFE: According to Staquet, Hays & Fayers (1999) the term QOL defines all aspects of a persons' well-being including spiritual and economic health.

REHABILITATION: The UN Standard Rules as cited in the White Paper on an Intergrated National Disability Strategy (INDS), (1997) defines rehabilitation as a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/ or social functioning levels, thus providing them with tools to change their lives towards a higher level of independence.

SATISFACTION WITH LIVING: An individuals' global judgement of their life. Individuals weigh domains of their lives in terms of their own values (Pavot & Diener, 1993).

SPINAL CORD INJURY (SCI): A severe trauma that occurs suddenly and affects both the sensory and motor functions resulting in paraplegia or tetraplegia as complete or incomplete lesions (Hampton, 2000).

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CHAPTER 1

BACKGROUND TO THE STUDY

The South African National Defence Force (SANDF) is a government service comprising men and women across racial, cultural and religious barriers. It consists of four main arms of service (i.e. Army, Air force, Navy and SA Military Health Service (SAMHS)) and three sub-groups (i.e. Veterinary Pensioners, Military Pensioners and Reserve Force). The SANDF operates from various geographical locations in all nine provinces and neighbouring states of South Africa. For the purposes of this study, the sample was drawn from the military population in the Western Cape.

With transformation in the SANDF, the racial composition shows that the proportion of Black/African members is the largest, with the Asian intake being the smallest. Employees include professionals, operationally employed personnel as well as support staff including an array of non-professionals. The fact that all are members of the SANDF means that the sample population is made up of employed individuals (as required by the criteria for inclusion). Housing conditions of the individuals varied from Defence Force subsidised housing to shacks in townships/locations. The SANDF exposes its employees to a wide range of occupational conditions, from violence and danger to career benefits and opportunities.

Globally, and also in the South African context, rehabilitation is becoming an increasingly sought-after resource as violence escalates. Spinal cord injuries (SCI) are amongst the more common results of violence and trauma, and, as mentioned, the SANDF is an environment where members are exposed to trauma, violence and injury. The number of traumatic injuries that includes SCI in the military is steadily increasing.

SCI has an immediate effect on individuals and their support systems with unanticipated changes and unforeseen challenges, encompassing the physical, psychological and social aspects of life. Post-injury SCI individuals and their support systems are challenged to adapt.

When soldiers present with varying degrees of trauma or injuries, they are admitted to military hospitals where they undergo a rehabilitation programme that is designed to be comprehensive. One such hospital is 2 Military Hospital (2MH) in the Western Cape. 2MH has 224 beds and a rehabilitation unit with 15 beds available for patients with SCI and other injuries such as traumatic brain injuries (TBI) and strokes. A rehabilitation team consisting of medical officers, nurses, social workers, occupational therapists, physiotherapists, biokineticists, dieticians, chaplains and psychologists contribute to the rehabilitation of SCI patients. The above-mentioned professionals constitute an interdisciplinary rehabilitation team that work together to attain treatment goals such as early ambulation and reintegration into the workplace.

The implications of being restricted to a wheelchair are vast for previously active servicemen given the many restrictions of the medical classification system that is in place in the SANDF. The soldier who is a wheelchair user will never hold a rifle again, never be deployed (posted outside the borders of SA) again and never have a chance at defending his/her country in a war again. What are the psychological implications for individuals who are prepared to give their lives to defend their country? What is their satisfaction with living and quality of life post trauma? How can rehabilitation attempt to facilitate this shift in “power”, ability and image? These burning issues have motivated the researcher to investigate whether emotional support during rehabilitation has an effect on satisfaction with living and quality of life in the lives of individuals with SCI in the SANDF.

Traditionally, rehabilitation of SCI patients focused on physical issues alone rather than a combination of physical and emotional. While the physical impairment/disability is easily noticeable, the reason behind delayed recovery often baffles health care professionals (HCP), specifically when all “clinical” signs indicate an anticipated good prognosis. Although the physical impairment of the SCI individual may be an overwhelming priority, the emotional aspect of rehabilitation should not be overlooked. Diener and Diener (1995) show that culture and values are general factors that impact on SCI rehabilitation and influence satisfaction with living and quality of life, apart from the proposed impact of emotional support offered during rehabilitation. This leads us as rehabilitationists to determine which rehabilitation model is best suited. A shift towards the use of a bio-psychosocial approach is evident, also in the rehabilitation unit of 2 MH,

the setting of the current study. This merges physical and psychological goals and integrates therapies to provide a holistic approach (Judd & Brown, 1988) allowing both patient and family to learn to cope gradually. The bio-psychosocial model stands out as a holistic model for the rehabilitation of SCI individuals. Although it emphasises emotional support, the manner in which it impacts on satisfaction with living and quality of life in SCI rehabilitation needs to be explored. Even though the bio-psychosocial model is implemented at 2MH, emotional support is often still offered as a secondary part while physical rehabilitation is performed and not as a primary goal. Therefore the need exists to assess whether emotional support offered in this relatively unstructured way has an influence on long term quality of life and satisfaction with living.

The Integrated National Disability Strategy (INDS) speaks of employment of all disabled, a goal reached within the unit with the majority of its patients rehabilitated there. Since the inception of the Rehabilitation Unit in 1995, clinical records indicate that an average of 90% of the SCI patients admitted and rehabilitated at 2MH have returned to work. Of this population, 95% were men with only one female wheelchair user. Likewise, many other targets and stipulations set out by the INDS have been met in the rehabilitation of SCI (e.g. the improvement of accessibility in different Defence Force units and availability and provision of assistive devices) at the unit. The social outcome of these individuals can thus be considered excellent. However, the emotional outcome of the rehabilitation of an injury such as SCI, which is often seen as predominantly physical in nature, needs to be considered. This forms the basis for this study.

As rehabilitation is patient-driven in “ideal” situations, the interaction between patient and HCP is a dynamic process. Krishnan, Glass, Jackson and Bingley (1988) comment on the lack of research on patients’ perception of treatment received and the psychological adjustment of staff working in SCI rehabilitation units. Similarly, feedback on these issues are also lacking in the SANDF. No clear indication of the long term effect on quality of life and satisfaction with living of emotional support offered during rehabilitation is available.

As a therapist working in the rehabilitation unit, the researcher knows the importance of a team in totality offering emotional support to the patient. Often more emotions are vented as a secondary issue in therapies other than counselling sessions. Success or delay of rehabilitation can often be influenced by the emotional support available to the patient during this transition in his/her life. The diverse meanings that success might have for different individuals must, however, be kept in mind. This ties in closely with the satisfaction with living and quality of life that patients experience post injury, since these too, are different for every individual.

Successful rehabilitation as noted by Tucker (1980) is emphasised by the emotional adjustment of patient and HCP. Previous research shows that SCI individuals in rehabilitation centres felt that more support and coping strategies were received and learnt from peers in the rehabilitation centres and their families than from rehabilitation

teams (Spooner, 1995). Patients often relate that “social support” is encouraging. While studies may focus on the patients’ views and perceptions of this, no study has been done to explore the impact of emotional support on the outcome of rehabilitation. Furthermore, no research findings regarding the impact of emotional support on quality of life and satisfaction with living in the SCI individual are available. This therefore is the first study of its nature, exploring the element of emotional support and its impact on satisfaction with living and quality of life in the SCI individual.

In the military, no formal emotional outcome measure is implemented in SCI rehabilitation although a psychologist forms part of the interdisciplinary team. It is expected that emotional support will be a shared objective of the team, but to what extent does this happen in practice? Hence the study aims to explore the impact of emotional support during rehabilitation on the long-term satisfaction with living and quality of life of the SCI individual.

With the focus on a team approach and team intervention, it is essential to determine the actual source of emotional support and whether the perceptions of this source is the same for all individuals who have been rehabilitated at the unit. Pavot and Diener (1993) state that the degree of convergence between life satisfaction and emotional well-being is important since both depend on a comparison of life circumstances with one’s standards. This emphasises the focus of the study with regards to the elements of satisfaction with living and quality of life.

As a result the study aims to be significant in determining perceptions of the study population regarding the availability of emotional support and the impact it could have had on their quality of life and satisfaction with living. It will furthermore allow the researcher to gauge the general quality of life and satisfaction with living of the study population post rehabilitation and facilitate the improvement of future rehabilitation services. Should study findings point towards a lack of emotional support during rehabilitation with resultant poor quality of life and satisfaction with living the rehabilitation intervention offered by the team must be adapted to include a special focus on emotional support. Furthermore findings will improve the team's insight into the needs of SCI individuals and what form and manner of intervention they would prefer.

Overall, SCI requires an immense adjustment to live with, affecting not only the injured individuals but also their support systems. Intervention to rehabilitate the affected individual comprises the implementation of different skills to reach maximum functionality, optimally re-integrate clients into their community and adjust emotionally to the effects of the trauma in an altered body. These goals cannot be met unless the individual is emotionally stable enough. This study explores the factors that contribute to the individual reaching this level of emotional stability. It considers not only the ability of the SCI individual to respond to rehabilitation, but also the treatment offered by the health care professional and its long-term effects. This research is conducted in the interest of improved teamwork and patient care. It is in no way aimed at highlighting the strengths or weaknesses of any particular health care professional or group.

The pivotal issue of this study is the element of emotional support, whether it is offered during the rehabilitation of the SCI individual, whether it is adequate and influences their long-term quality of life and satisfaction with living. It furthermore investigates the perceptions of the individuals undergoing rehabilitation whether they see the emotional support offered as sufficient and whether the rehabilitation meets their expectations and fulfils their needs or whether the team needs to adapt its approach. The findings are intended to clarify these issues and form the basis of recommendations made to the HCP involved in rehabilitating the study population. It is furthermore proposed that findings of this study be used as the basis for further and more extensive studies regarding the topic.

This document will reflect the manner in which the researcher has explored the topic and made deductions. Chapter 2 provides an overview of the source literature used. Chapter 3 set out the methodology used to gather and interpret data and explains points such as the criteria for inclusion and exclusion in the study. Chapter 4 discusses the data analysis and provides graphical representations of the study findings and highlights significant associations that were found. In conclusion Chapter 5 contains a brief summary of the study and lists recommendations the researcher found appropriate while gathering and analysing the data.

CHAPTER 2

LITERATURE REVIEW

INTRODUCTION

Goleman (1996: pg 4) says of emotional support: “A view of human nature that ignores the power of emotions is sadly short-sighted. The very name, *Homo sapiens*, the thinking species, is misleading in light of the new appreciation and vision of the place of emotions in our lives that science now offers. As we all know from experience, when it comes to shaping our decisions and our actions, feelings count every bit as much and often more than thought”. “We, as humans, have taken the influence of intelligence almost too seriously at the expense of allowing emotions to take a back seat.” “Intelligence can count nothing when emotions hold sway” (Goleman, 1996: p4).

Sociobiologists argue that emotions serve as a guiding light for humans in situations we know we cannot face using the rationale of intellect alone (Goleman, 1996) such as painful loss that leave us in challenging life situations.

Can SCI be classified as a painful loss and can the rehabilitation be considered a life challenge?

Indeed it can, as is seen from Hellander (1992) definition of rehabilitation that describes it as a process, which involves social integration, and aims at affording the affected individual a better quality of life. It can furthermore be said that rehabilitation is a holistic process involving intervention at societal and personal level, ideally allowing the injured individual to reach optimal independence, according to his/her own standards.

However, the question as to whether rehabilitation prepares the individual to face these challenges remains. Do professionals and SCI individuals have a common understanding and agreement about the expectations of rehabilitation? Is there adequate consideration of all aspects involved in rehabilitation?

This chapter will elaborate on the concept of SCI and the trends of rehabilitation following such an injury. SCI in itself is an injury affecting individuals in a multitude of ways. A closer look is taken at the aspect of emotions that Goleman, (1996) speaks of at length. The study explores whether emotional support offered as part of the rehabilitation process has any impact. While each individual has his/her own concept of what successful rehabilitation is, all individuals need to experience quality of life and be satisfied with their lives. Essentially these two factors can gauge the success of the rehabilitation process for an individual. Therefore the researcher pays attention to factors influencing satisfaction with living and quality of life.

SCI and its effects are often either underestimated or exaggerated. To gain some clarity on the concept, a brief overview of SCI is provided below.

2.1 AN OVERVIEW OF SPINAL CORD INJURY

Social and emotional adjustment to SCI can vary considerably from person to person. Some could make satisfactory adjustments, while others remain chronically distressed. (Decker & Schulz, 1985; Nosek, Fuhrer & Potter, 1995)

SCI is an injury causing disability, a factor that has different implications for each individual. The World Health Organisation (Chase, Cornille & English, 2000: p1) defines disability as “any restriction or lack of ability to perform a function in the manner typically performed by human beings” e.g. inability to walk.

However physical impairments are barely the tip of the iceberg! The individual with the disability, his/her support systems and general community are affected by the disability. It is uncommon for us to admit to the fact that disability, whether one’s own or that of another, can evoke emotion and anxiety. This is often attributed to the fact that disability arouses a sense of vulnerability and dependency (Watermeyer, 2001). It is interesting to note that people are always eager to say that disability happens to others, never expecting to be a victim of disability themselves. While this is often our perception, statistics show that 400 to 500 South Africans sustain SCI annually (QASA, 2004). Approximately 70% of SCI are the result of trauma while the remainder are attributed to non-traumatic causes (Bromley, 1981). In the United Kingdom motor vehicle accidents account for approximately 50% of SCI (Bromley, 1981) while only 10% results from sport injuries. USA statistics correspond with the above with motor vehicle accidents accounting for

51.1% of traumatic SCI, sports injuries for 17.3% and violence for 3.1% of traumatic SCI (QASA, 2004).

In the South African context, records at a local rehabilitation hospital indicated that 90% of SCI were as a result of traumatic injuries (Hart, 2000). Motor vehicle accidents, violence and sports injuries emerged as the leading causes of traumatic SCI. Although no specific statistics are available, the incidence of SCI in South Africa is rapidly escalating, particularly in young, male adults (QASA, 2004). Where does this injury leave the affected individual and what follows?

2.1.1 What happens after SCI?

The following quotation dating back to 2500 BC is probably the earliest description of SCI: “case 31 is described as one having a dislocation in a vertebrae of his neck, while he is unconscious of his two legs and his two arms and his urine dribbles. An ailment not to be treated” (Inman, 1999: p25).

This description is typically based on the physical difficulties that present after SCI. Hampton (2000) describes SCI as a “severe traumatic disability that occurs suddenly, affecting both sensory and motor function”. This echoes the traditional medical model which focuses purely on physical (sensory and motor) function. For years, literature neglected to include elements of the individual’s functioning other than sensory and motor functions. The impairment caused by SCI produces a unique experience in disablement for each individual. To understand this experience, one needs to consider the

emotional and social factors that complement the motor and sensory aspects. This allows one to deal with a person in totality, always bearing in mind that different components are affected in varying degrees.

The bio-psychosocial model provides a more holistic approach that considers the individual as a whole, taking the person in totality into account. It includes the sensory, motor, emotional and social aspects of the individual's being. This approach views the SCI individual as part of a unit that includes the patient, his/her support system and environment, thus encompassing the individual in totality.

Nowadays rehabilitation enables most individuals with SCI to return to their pre-morbid lives. In this regard, improvement is noted in the rehabilitation of SCI individuals. The introduction of antibiotics in the 1940s improved the life expectancy of SCI individuals and today it is closer to normal life expectancy (Bromley 1981). The first to benefit from treatment with antibiotics were the SCI survivors of World War II. Like injured soldiers today, these survivors were admitted to military hospitals.

Disability in itself is influenced not only by impairment but also by contextual factors thus involving not only the person with the disability but also the context in which he/she finds themselves. Apart from physical barriers in the environment such as architectural obstacles, the attitudes of others can also contribute largely to the difficulties people with disabilities (PWD) experience in society. This is evidenced by the different approaches that different cultures follow in their acceptance of disability (Yavuzer & Ergin, 2002).

In some cultures, it is imperative to make the environment conducive to a 'normal' lifestyle for disabled individuals and in others they are shunned and considered incompetent and treated as determined fit by the community. For instance, in Turkey disabled individuals are seen as being in need of full-time care. Their abilities are completely overshadowed by their disability (Yavuzer & Ergin, 2002). This is a typically orthodox approach that echoes the traditional medical model of rehabilitation.

The situation in the SA context has clearly evolved in this regard. From casual observation, it seems evident that the rate of employment of persons with disabilities after rehabilitation is increasing gradually. Various different policies have been put in place in the SA context to assist with the respect of the persons with disabilities. (National Rehabilitation Policy, INDS, 1997)

Historically, the medical model did not allow the person with disability to have a say in the management of organisations for persons with disabilities resulting in the isolation of persons with disabilities from the rest of society. Furthermore, this medical model had fostered dependence on state support and decreased the interaction of individuals. In addition, a sense of pity was fostered. In totality, this encouraged a sense of disempowerment (White Paper on Integrated National Disability Strategy, 1997). In the eighties, persons with disabilities became more united to transform the approach to management of disability in the formation of a social model. This, then newly adopted social model was a tool of transformation to develop a more diverse environment which is more accommodating of persons with disabilities (White Paper on Integrated National Disability Strategy, 1997).

Following on this, the standard rules for the equalisation of opportunities for persons with disabilities were formulated to pay attention to issues such as awareness raising and demand the availability of rehabilitation programmes based on the individual needs of persons with disabilities and insists on the families being part of the rehabilitation team.

Other target areas for equal participation in this document include demand for accessibility of the physical environment and information of the person with disabilities; the need for proper education including the child and/ or adult with a disability; respect for their culture; maintenance of personal integrity and also the right to employment and maintenance of income (Disability Rights Charter of South Africa 1992).

In November 2000, the National Rehabilitation Policy was formulated with the objectives being to improve accessibility of rehabilitation services to all persons with disabilities; to allocate resources and encourage the optimal utilisation thereof. The National Rehabilitation Policy (2000) demands the development, implementation and maintenance of rehabilitation programmes for persons with disabilities as well as their support systems and those at risk for disability. Research into all aspects of rehabilitation also forms part of the National Rehabilitation Policy (2000).

It is essential that health care professionals and SCI individuals and their support systems work together to minimise the magnitude of the disability by addressing the impairment and contextual factors. This is only possible through comprehensive rehabilitation that addresses not only physical, but also social and emotional factors (Trieschman, 1988).

However, rehabilitation has different connotations for different individuals, both people with spinal cord injuries and health care professionals. While health care professionals in the past worked in isolation, methods have evolved, making the concept of teamwork vital.

“Few physical disabilities are as complex and challenging as spinal cord injury.” (Trieschman, 1988: p vii). Although new technology and medical expertise have to date made significant advances in the prevention of medical complications after injury as well as procedures to ensure a more normal lifespan, the severity of the psychosocial consequences remain enormous. Despite the fact that surgery and medical intervention is allowing SCI individuals to live longer, the quality of that individual’s life has not been the primary focus of concern. Therefore, Trieschman, (1998) highlights the importance of teamwork in focusing on quality of life so that medical interventions are not mere procedures but rather stepping stones to re-integration

Teamwork does not have a single universal meaning or style. Different teams choose different team styles. According to Briggs (1997) an effective team needs to have a common, clearly stated goal and mission; expertise, resources and open communication. Furthermore, each team member (patient and professional alike) needs to be committed to service delivery and show trust in one another. For teams to reach their goals, working together is vital. It is imperative to take cognisance of the fact that each team member has different responsibilities but that these can also overlap and be shared by more than one profession. This may very well be the case with the offering of emotional support.

While the psychologist traditionally is the professional known for offering emotional support, in the rehabilitation of SCI, many other professionals may share this role.

Teamwork is essential in mobilising the full integration of persons with disabilities into their pre-morbid communities. Hence the researcher has identified the need to explore different rehabilitation methods in relation to emotional aspects.

2.2. REHABILITATION TRENDS

According to Judd and Brown (1988: p419), “Rehabilitation of spinal cord injured people has traditionally emphasized physical rehabilitation and relied upon support and empathy from staff members to assist patients with their psychological and social difficulties”. The integration of physical and psychosocial therapies is essential to successful implementation of the bio-psychosocial approach (Judd & Brown, 1988). It can therefore be concluded that the need for psychosocial groups in a spinal unit could prove useful in facilitating the process of family and patient counselling intervention for both in and out patients.

Rehabilitation in general and specifically of the SCI individual is an intense process, ideally involving all role players such as professionals, the patient and his/her support system (Tucker, 1980). SCI individuals are often challenged by significant limitations that can affect all spheres of their lives such as vocational, financial and emotional situations that will require adjustments. As part of a comprehensive rehabilitation

service, it is expected of the rehabilitation team to assist the patient with overcoming these challenges, empowering them to cope (Tucker, 1980). Team members often are uncertain as to when the SCI individual has achieved this adjustment. “When is treatment successful – when the person has achieved a particular degree of neurological recovery or functional independence; when he/she earns a lot of money or when he/she has the best possible family life?” (Yavuzer & Ergin, 2002:p153).

Successful rehabilitation means different things to different people. Therefore the rehabilitation team must be clear on their goal for rehabilitation. Collaboration between professional and patient facilitates shared, realistic goal setting. Each individual has the need to adapt in his/her own way, not following predictable stages. Therefore the team needs to use an individualistic approach with every patient (Stiens, Kirschblum, Groah, McKinley & Gittler, 2002). This is often the vehicle to lessen fears the individuals have of facing their disability and inabilities which mask their potential and rob them of the drive to persevere to achieve that independence that is the goal of the rehabilitation process. This places the patient in a state of “denial” which more often than not is the result of environmental influences.

Stiens *et al.* (2002) describe the environment as the vast space around the individual, emphasising that re-integration extends beyond the actual person, promoting his/her participation in the physical and psychosocial environment. Much of the formal rehabilitation takes place in the hospital or clinical simulated setting, but the discharge environment also has to be conducive to functioning.

However, can individuals be expected to function in an inaccessible environment? Yavuzer and Ergin (2002) related that young scholars with spinal cord injury were spurred on to return to school because they believed that higher education levels facilitated better employability through productivity, but that the architectural barriers in schools presented one of the greatest hurdles in the process. The result was that after working hard to obtain a bladder and bowel regime in rehabilitation, in order to return to school the architectural barriers forced them to readjust this aspect of their rehabilitation. This poses the question whether healthcare professionals had neglected to consider the discharge environment during the rehabilitation of these individuals or whether it purely is the environment that failed.

Literature in this regard indicates that generally reintegration into the community after SCI continues to improve, partly as a result of improved acceptance, accessibility and technology for building adaptations (Stiens *et al.*, 2002).

As hypothesised in this study Decker and Schulz (1985) also emphasise the crucial need for social support (which include cognitive and affective support) to enable and encourage the impaired individual to make physical, social and cognitive life changes. This suggestion is positively in keeping with the bio-psychosocial approach to rehabilitation that entails the rehabilitation of the individual in totality.

The concept of totality in this context, without a doubt needs to include an aspect of emotional support. The author explores whether this influence the long term outcome of spinal cord injured individuals.

The International Classification of Functioning, Disability & Health (ICF, 2000) addresses this issue, taking into account the individual in totality. The ICF (2000) was mainly compiled to provide a uniform language that could describe health and health related conditions to both persons with disabilities and their support systems and not only health care professionals. This diversity of the tool is however sometimes questioned in its' ability to make it too loose and non-scientific (Bury, 2000). We however take cognisance of its' usefulness to individuals in various different domains such as epidemiology, research, policy making and statistics. The classification further defines concepts such as disability as a term which encompasses impairments, participation restrictions and activity limitations thus taking the individual into account in totality, taking note of the community and environment in which the person with disability functions. The system is thus a system which entertains the holistic management of the individual.

2.3 EMOTIONAL SUPPORT IN THE REHABILITATION PROCESS: DOES IT HAVE AN IMPACT?

Burleson & Goldsmith (1998) defines emotional support as messages expressing care, concern and affection, these are communicated to bring about comfort through a trusting

relationship in which feelings can be safely expressed. Communication is an essential element of rehabilitation. No patient will communicate completely open and freely unless a trusting relationship has been established where the patient feels safe to express him/herself and learn to deal with factors and feelings which influence the process of re-integration into his/her pre-morbid environment.

According to Goleman (1996) it is high time that the world realises the value of emotional consideration in the rehabilitation of individuals and realises that physicians need not be considered the sole providers in prevention and “cure”.

Spooner (1995), a tetraplegic herself, relates in her personal perspective that the immediate needs of SCI individuals, family and friends are for answers, advice, support and counselling throughout long-term rehabilitation. She further says that physical and psychological rehabilitation is dependant on each other, warranting a holistic approach. In her interviews with other SCI individuals, she mentions the patients’ perceptions that the nurses were much concerned about their psychological needs and long-term rehabilitation while the doctors were much more concerned with actual physical regeneration and in the process neglected the related psychological issues. A conflict of interest is evident in this scenario.

A ‘successful’ life is based on the success of different relationships individuals choose to be part of or find themselves in. The process of rehabilitation is no different. The patients and staff involved more often than not find themselves in an involuntary relationship.

Nobody pre-empted SCI and therefore nobody chooses a rehabilitation team prior to an injury. It is essential for rehabilitation staff to bear this in mind when dealing with individuals undergoing rehabilitation.

“The significant impact of the attitudes of rehabilitation staff, immediately involved with the newly injured patient, makes sense in the light of Kutner’s belief that the feeling of disability is a social fact imposed by relationships with others” (Tucker, 1980: p118). This quotation emphasises the impact of the relationships between rehabilitation staff and SCI individuals as one of the first significant post-injury relationships. This relationship can without a doubt facilitate or retard the rehabilitation process.

Kennedy and Hamilton (1999) show that the consideration of patients’ wishes leads to increased compliance with rehabilitation. This is a message that all health care professionals should take into account, an issue that spurred the researcher to explore the impact of emotional support during rehabilitation. Rehabilitation, however, is not the responsibility of any one person but needs a dedicated team to facilitate maximally beneficial results.

The researcher is herself part of a rehabilitation team where the offering of emotional support is a joint venture, however, it remains a concept which the team is not easily able to assess in terms of effectivity. The application of principles of public service delivery such as ‘Batho Pele’ as discussed in the White Paper on Public Service Delivery (1997) does however enforce issues of transparency, accountability and respect amongst others. The team uses these in an attempt to provide a holistic rehabilitation service, involving

the patient as a main stakeholder by being transparent in their intervention. This transparency in intervention allows the patient to feel comfortable with the fact that he/she forms part of all decision- making and thus fosters a trust relationship between professional and patient. Trust as seen in the quotation used earlier by Burleson & Goldsmith (1998) is an influential factor in provision of emotional support.

Decker and Schulz (1985) highlight the role of the occupational therapist as traditionally being one of assisting patients with ways of using their remaining abilities. They view this intervention as one that could be positively associated with subsequent life satisfaction as it provides the individual with a sense of control and minimises the factor of learned helplessness. It is, however, the opinion of the researcher that it is not solely the task of the occupational therapist to perform this function and that all health care professionals often use this approach indirectly.

Spooner (1995) comments on the importance of providing a service to the families of SCI individuals, highlighting that counselling and advice assist in understanding and coping with the injury and the resulting disability. In the unit where the study was conducted, their integration of the Batho Pele principles (White Paper on Public Service Delivery, 1997) in intervention, facilitates the family involvement which in turn allows them to further educate the family thus ensuring sustainable intervention to ensure maximal benefit from rehabilitation. Furthermore, Spooner (1995) notes the lack of sexual counselling during her rehabilitation as though she was not expected to engage in a

sexual relationship again because of her injury. Sexuality is often one of the most threatening issues for staff to deal with and has begun to receive more focus in rehabilitation programmes (Tucker, 1980).

In keeping with the concerns of Spooner (1995), Tucker (1980) elaborates on the emotional experiences of staff themselves. Their inability to “cure” often influences their attitude to patients in their constant driving of the patient to perform during rehabilitation. Since the staff and family, as the cornerstones of support and assistance in the SCI individual’s life, complement each other, it is imperative that they work together. Tucker (1980) views the frequent blaming that occurs between these two groups as an indirect outlet for their frustration at being unable to “cure”.

In a study by Krishnan *et al.* (1980) of the level of optimism about the achievement of rehabilitation goals, it was found that health care professionals with less experience were more optimistic regarding the potential of the patient than their more experienced counterparts. This could contribute to the patient and healthcare professional losing hope and adopting a negative approach to rehabilitation, which affects the achievement of treatment goals. In view of this, the incongruence between expectations and outcome contributes to the high staff turnover in many such units (Krishnan *et al.*, 1980).

According to Trieschmann (1988) data suggest that many rehabilitation personnel have preconceived ideas about the psychological reaction to spinal injury and the roles that

patients should play. They tend to perceive more psychological suffering than people with SCI describe.

The researcher questions whether any member of staff could ever have the physical care of the SCI individual as his/her sole responsibility and whether he/she would disagree with the view of Tucker (1980) that there is reason for the increased involvement of psychologists and social workers in SCI rehabilitation. Furthermore, it is vital that staff be given the opportunity to vent the emotional stress caused by working with such individuals. This could minimise the high turnover of staff in units serving those with long-term disabilities. It would further address the frequent feelings of helplessness experienced by staff that often transfers into aggression and frustration.

Patients are often unclear about their rehabilitation programme. Krishnan *et al.* (1988) think this is an important issue and suggest that a patient's understanding of the rehabilitation programmes and rationale should be clarified on first admission to ensure his/her commitment and co-operation. It is crucial that individuals know what is expected of them, what their needs are and what they feel threatened by. For the management of these threatening aspects, it is often the emotional support that allows the individual to survive and endure rehabilitation. The researcher, however, questions whether this emotional support in itself will have an impact on the outcome of rehabilitation. Will it positively influence quality of life and eventually afford the individual satisfaction with living?

When considering the individual in totality, life satisfaction and quality of life is a vital element which Hampton (2000) describes as an individual's cognitive assessment of his/her life. This assessment needs to form one of the key goals of rehabilitation and the goals set, should aim at enhancing quality of life.

Callahan (1995:p 48, as cited in Tate & Forcheimer, 2002: p 401) says, "Rehabilitation focuses on quality of life rather than longevity, thus, rehabilitation adds not just years to life but life to years".

Stiens *et al.* (2002) focus on employment and financial resources as attributes of successful adaptation. The criteria for inclusion for this study were designed with this in mind. The entire study population was employed at the time of conducting the study, thus ensuring that unemployment was not a complicating factor in determining the impact of emotional support on quality of life and satisfaction with living.

2.4 FACTORS INFLUENCING QUALITY OF LIFE

Throughout the study, quality of life is focussed on the individuals' well-being also taking into account both economic and spiritual well-being (Staquet, et al, 1999).

Quality of life is said to be multifactoral (Benony, Daloz, Chahraoui, Frenay & Auvin, 2002), encompassing different aspects of an individual's life including sexuality, interpersonal relationships and leisure. For many SCI individuals, limited functioning in one or more of these life domains or areas could influence quality of life negatively. Tate

and Forcheimer (2002) found a strong association between spirituality and quality of life, indicating that spirituality assists the individual to cope with weakness and limitations. This ability to cope in turn positively influences quality of life. In the same study, they found that factors such as age, marital and work status also influence quality of life. This association suggests that married individuals have greater quality of life and spiritual well-being. Again, it must be remembered that spirituality is an individual concept as is quality of life.

The attitudinal environment is often the one that positively or negatively influences the quality of life of the SCI individual. It is important for people to feel competent, an important point to remember in a rehabilitation setting where staff often are the ones praising the SCI individual and commenting on his/her abilities. (Tucker, 1980) This requires staff to be sensitive and tactful to avoid them offending the rehabilitating individual creating false impressions of progress made. Furthermore, it is essential that health care professionals show congruence in their attitudes, beliefs and practice (Krishnan, Glass, Jackson & Bingley, 1988).

Quality of life is a changing phenomenon, both from one person to another and for one person at different stages/times in his/her life. One needs to take into account the culture and spirituality as well as personal values and beliefs. Cultures differ in their standards of quality of life as can be seen in a study by Yavuzer and Ergin (2002) that leads one to consider the different attitudes that people of different cultures have to disability. This study cites the Turkish as a community that attaches strong religious connotations to

disability. Furthermore, the community considers people with disabilities as incompetent (Yavuzer & Ergin, 2002). This consequently limits the interaction, which disabled individuals have with their community, leaving them isolated and in the sole care of their families. Community integration contributes largely to an improved quality of life, thus raising concerns about the quality of life of people with disabilities in this culture. These beliefs and cultures are, however, very different from the approach taken in the Western countries. The researcher can relate that many 'black' patients at the unit were often the ones who requested to return to their homelands after the injury before commencing intensive rehabilitation. Upon re-admission after this trip, the motivation was more often than not increased. Again possibly showing that their trip to their homelands (which they report is to 'make peace with the ancestors') served useful in boosting morale and allowed them to get others to adjust to the concept of disability giving the patient an added sense of calmness and peace about their disability. A study of different cultural perspectives on disability in South Africa would be interesting.

It is important to draw a distinction between the subjective and objective quality of life of an individual. This is often influenced by the environment and often differs at different stages during his/her lifetime. Benony *et al.* (2002) refer to the objective quality of life being influenced by life conditions, environmental context and other factors such as psychological influences. On the other hand, subjective quality of life exclusively concerns the individual. It often is difficult to determine whether the quality of life indicated by individuals ever is truly subjective.

The challenge therefore is to set rehabilitation goals based on the individual's standards rather than predetermined objectives of the rehabilitation unit or personnel. The individual undergoing rehabilitation need not only experience a "good" quality of life but also needs to experience life satisfaction before rehabilitation can be considered successful.

Yet the question remains whether quality of life implies satisfaction with living. What's more, as far as the definition of rehabilitation is concerned, the concepts of quality of life and satisfaction with living may have different meanings for different individuals, in different cultures and at different life stages. The emphasis therefore should be on the fact that all individuals are different and therefore they will rate quality of life and satisfaction with living for each personally.

2.5 FACTORS INFLUENCING SATISFACTION WITH LIVING

As described by Pavot & Diener (1993), satisfaction with living as referred to in the study focuses on the individuals' global judgement of their life with each weighing their life domains according to their own values.

Research regarding the satisfaction with living of SCI individuals shows positive relationships between employment status, age of onset, marital status, level of education, social support and life satisfaction.

Decker and Schulz (1985) found that higher levels of income, education and employment had a positive bearing on life satisfaction but they also found that it was the status of being employed that contributed to higher satisfaction with living, rather than actually having an income. Successful vocational rehabilitation is seen as a contributing factor to improved satisfaction with living as a whole (Anke & Fugl-Meyer, 2003). Furthermore, higher education is related to higher life satisfaction (Dijkers, 1999). It is interesting to note that while Anke and Fugl-Meyer (2003) make the association between successful vocational rehabilitation and improved satisfaction with living, Hampton (2000) found no significant difference between employed and unemployed individuals with regard to their satisfaction with living. The majority of the literature, however, supports the hypothesis that employment status is linked to satisfaction with living (Tate & Forcheimer, 2002).

In this study, the researcher chose to include only employed individuals to be able to get a clearer indication of the effect of emotional support on satisfaction with living. She was hopeful that by including only employed individuals, no participant would have a lower satisfaction with living due to absence of income which would then have been able to 'shadow' the true effect which the emotional support or lack thereof would have had. In the study by Decker and Schulz (1985) the lack of employment among some participants may have influenced the outcome and findings of the study. Other detail in their study indicated that the level of SCI was not influential although religion was and that individuals who were more religious reported higher life satisfaction. Levels of religious involvement are, however, a subjective rating.

Dijkers (1999) found that married people reported the highest levels of life satisfaction while separated individuals reported the lowest. However, the gender of the SCI spouse in the unsatisfactory marriage was not clearly indicated. This may have enriched the ability to connect satisfaction with living to gender as evident in failed marriages but it does indicate that marital status plays an influential part in life satisfaction (Decker & Schulz, 1985). Satisfaction with family closeness and social support are factors positively related to life satisfaction of persons with physical disabilities.

While gender seems a less understood and possibly less explored factor in life satisfaction of SCI individuals, a study by Hicken *et al.* (2002) found it to be largely unrelated to satisfaction with living. Hampton (2000) found that the risk for depression after SCI were greater in women than in men. They were also more likely to experience negative feelings. Dijkers (1999), however, reports slightly higher levels of satisfaction with living in women than in men. A review of these ideas indicates that gender is an important factor but that it is not yet fully understood. This study is not intended to make any deductions related to gender issues as the gender of the study population is predominantly male.

In Hampton (2000), the tendency of poorer countries to have lower life satisfaction than more wealthy ones is related. Although this finding may be considered as a generalised statement, it would be useful to consider the effect of culture on satisfaction with living. Countries comprise individuals from different cultures, leading one to question the merit in the finding regarding the wealth of countries. Research needs to be expanded to

include the issues of culture. Hampton (2000) makes the speculative statement that a lack of social support could have a negative impact on an individual's life satisfaction.

In a study by Tate and Forcheimer (2002) participants indicated that of the success with which they performed a task rather than their actual ability to perform tasks influenced their life satisfaction. It is interesting to compare this to the findings related in Hampton, (2000) that individuals with impairments were found to have lower life satisfaction and that age had an inverse relationship to their life satisfaction.

In another study of emotional factors and subjective quality of life, Benony *et al.* (2002) report that SCI individuals generally indicate their satisfaction with living to be acceptable.

Schulz and Decker (1985) also highlight the element of self-blame as a factor that affects satisfaction with living. They noted that with time, the element of self-blame decreases and therefore is not a long-term determinant of satisfaction with living. It would be interesting to conduct a comparative study investigating the change in the effect of self-blame on satisfaction with living over the long-term.

Anke and Fugl-Meyer (2003) conducted a study on satisfaction with living after severe multi-trauma, which indicated the need for better organised, comprehensive rehabilitation services taking into consideration both social and personal factors. The connection between social support and its effect on satisfaction with living was further elaborated on by Decker and Schulz (1985) who examined the psycho-social perspective of "learned

helplessness". This concept is based on the idea that individuals experiencing a crisis that exposes them to an uncontrollable outcome such as SCI, anticipate that their future will hold uncontrollable outcomes. Rehabilitation professionals are often faced with this mind-set when patients present with cognitive, motivational and emotional deficits associated with an element of helplessness and depression. The theory of learned helplessness suggests that social support may enhance the coping mechanism of the SCI individual. If social support includes fostering a feeling of control, it could positively accelerate the feeling of competence, and thus satisfaction with living, which is vital in rehabilitation (Decker & Schulz, 1985)

2.6 CONCLUSION

Morris (1992: pg 164 as cited in Watermeyer, 2001) states: “To experience disability is to experience the frailty of the human body. If we deny this, we will find that our personal experience of disability will remain an isolated one; we will experience our differences as something peculiar to us as individuals – and we will commonly feel a sense of personal blame and responsibility”.

Disability is in itself an experience lived by both the person with the disability and those around him/her. It therefore involves not only an individual but rather an entire team and support system.

SCI and its rehabilitation is evidently an involved process. Having explored the issue, one is faced with the fact that it is not something that is to be handled in isolation by the client or health care professional but rather a journey travelled by a team. Whether traumatic or not, rehabilitation needs to focus on all spheres of life, offering a holistic approach. This is often a challenge for the professional, support system and patient for a myriad of reasons that have been the focus of this chapter. Professionals need to take cognisance of the fact that many factors influence the positive outcome of rehabilitation and that “positive” has different meanings for different individuals, depending on their cultures, values, beliefs and personal goals. Basically, rehabilitation needs to be tailored to the individual needs of every SCI patient and his/her support systems. The golden rule,

however, is that both health care professionals and patients need to have clearly defined goals and objectives for rehabilitation.

Quality of life and satisfaction with living could be seen as indicators of the success of rehabilitation. In this literature review, Tate and Forcheimer (2002) shows that the individuals' sense of spirituality and thus ability to cope with the disability as well as his/her ability re-integration into the community have a positive influence on the patients' quality of life. Furthermore, Yavuzer & Ergin, (2002) showed that culture could have either a positive or negative influence on quality of life depending on what culture one was dealing with as some encouraged independence whilst others encouraged the 'sick-role'.

The following chapters focus on the researcher's study of these elements in a military environment. Methods of data gathering and results of the study are discussed and suggestions regarding possible further studies are made.

CHAPTER 3

METHODOLOGY

INTRODUCTION

The study was predominantly quantitative in nature. The following aspects pertaining to methodology are discussed in this chapter:

- 3.1 Aim of the study
- 3.2 Objectives of the study
- 3.3 Research setting
- 3.4 Study design
- 3.5 Study population
- 3.6 Measuring instrument
- 3.7 Pilot study
- 3.8 Procedure
- 3.9 Data analysis
- 3.10 Potential bias
- 3.11 Ethical considerations

3.1 AIM OF THE STUDY

The aim of the study is to determine the impact of emotional support offered to the SCI patient (admitted to the rehabilitation unit at 2MH) during rehabilitation on his/her long-term satisfaction with living and quality of life.

3.2 OBJECTIVES OF THE STUDY

- To determine the demographic details of the participants.
- To assess the perceptions of SCI individuals re-employed in the SANDF with regard to the availability of emotional support during rehabilitation.
- To assess the perceived quality of life and satisfaction with living of the participants after their discharge and return to work.
- To analyse the gathered data for relationships between emotional support received during the in- patient rehabilitation phase and quality of life and satisfaction with living after discharge.
- To use research findings to contribute to the integration of emotional support in rehabilitation programmes for SCI individuals in the military environment as standard procedure.
- To share findings of the study with other similar rehabilitation units.

3.3 RESEARCH SETTING

The study was conducted among members of the SANDF who were rehabilitated at 2MH in the Western Cape post SCI. 2MH is a 224-bed hospital with a 15-bed rehabilitation unit for SCI and other injuries such as TBI and cerebro-vascular accidents (CVA). It is situated in the Southern suburbs of the Cape Metropole and provides a service to SANDF members residing in the Western, Eastern and Northern Cape.

A multidisciplinary team consisting of nursing staff, medical doctors, social workers, psychologists, occupational, speech and physiotherapists performs rehabilitation at the unit where the study was conducted. In addition, the team also has a permanent biokineticist as well as dietician and chaplain whom all serve the patients of this unit.

The team does implement a protocol for management of spinal cord injured individuals although it is always customised to suite the individuals' needs. The standard procedure in the unit would include a

- Six week 'bed phase' where the patient is immobilised and completely bed-bound. During this time, the occupational and physiotherapists introduce bed programmes with the emphasis often being on maintaining range of movement and muscle strengthening as well as prevention of contractures and ensuring of good pressure care principles. During this phase the entire team should ideally focus on emotionally supporting the patient however, apart

from the doctors and nursing staff, the patient is often only seen by the occupational and physiotherapists.

- On completion of the 'bed phase', the patient will, depending on his/her specific injury, commence the 'brace phase' after x-rays confirm adequate stability to progress to the use of a brace. This phase generally also lasts six weeks during which time the patients starts using a wheelchair as a means of mobility but is compelled to wear the indicated brace (eg Abco or Halo) for all periods out of the bed. During this phase, the gym programme is initiated as well as focus on performance of daily living activities such as grooming and feeding independently or with a degree of assistance.
- Once the 'brace phase' is completed (which is usually also ended after confirmation of stability through x-rays), the patient is then introduced to the 'active rehabilitation phase' which involves the major period of input from the patient. During this phase, the patient is exposed gradually to increasing demands in independence and physical activity with regards transfers and mobility. Seating needs of the patient are finalised in this time as is the need for assistive devices generally. It is also the phase which links with the more formal aspects of work assessment if the member was employed prior to the trauma. This then involves simulated work placements where possible and negotiations with employers. Once these negotiations are commenced, the patient has reached the 'final phase'.

- The ‘final phase’ of rehabilitation would focus mainly on assessment of fulfilment of goals. The employer is involved to a great extent in this phase in order to prepare the patient and employer for discharge to the working environment. This phase also includes final seating assessments as well as follow-up home visits and family meetings, as indicated.
- Once the patient is seen to cope well in this phase, discharge dates are finally set as is date for return to work. Wherever possible, it is aimed at return to work as soon as possible after discharge.
- It is policy in the unit that patients be allowed weekends at home as soon as they are able to catheterise and do pressure relief independently as well as perform car transfers with minimal to moderate amount of assistance. Where these expectations are not applicable, the patient is allowed on weekends out as soon as a caregiver has been trained in this regard.
- Furthermore, the team adopts an ‘open door’ policy with regards to requests for family meetings to assist the family and patient with the adjustment process.

The military service has a system in place which allows members a period of temporary disability leave once their sick leave has been exhausted, this period which could last up to six months or more allows prolonged admission without concern regarding loss of income.

On average, paraplegics are kept as in-patients for an average of four months of rehabilitation whilst tetraplegics often need to stay for up to eight months. The reason

behind lengthened stay is often that the patient is away from home and consequently cannot access the unit as an out patient should he/she be discharged thus forcing admission to be extended.

Members of the SANDF receive all assistive devices free of charge. Furthermore, they do not have a restriction on the medical benefit they enjoy with certain terms and conditions, which apply.

As part of the rehabilitation programme, spouses or caregivers are often allocated a temporary living quarters on the hospital grounds at a small fee to afford them the opportunity to spend time with the patient in the hospital setting and be an active part of the rehabilitation programme. The daily patient programmes are individually designed to suit the patients' needs for intervention. Furthermore, the therapist – patient ratio in this setting is approximately a third lower than in any other public service institution. The patient has access to modern, technologically advanced equipment and is assured employment if they are capable of being employed.

3.4 STUDY DESIGN

The study used a descriptive, explorative design to investigate the existence of a relationship between emotional support received during rehabilitation of the SCI patient and the subsequent satisfaction with living and quality of life of the patient.

The study was retrospective in nature and used a self-compiled questionnaire. This form of data gathering or research can also be classified as a survey. Surveys are aimed at establishing the extent of a problem or situation. Information gathered in descriptive studies can assist policy makers and service providers with the planning of services. It often gives rise to further questions leading to future studies that ensure continued research and upgrading of services (Katzenellenbogen, Joubert & Abdool Karim, 2002). In addition, retrospective studies using surveys are economical, easily executable and often form the basis for larger studies. The drawback of retrospective studies as far as this study is concerned, are that the study is done some time after the event, e.g. years after the trauma. This could impact negatively on the amount of information participants are able to remember and reflect on. Results might be influenced as participants may be unable to relate exactly what they felt at the time. Furthermore, individuals resolve issues or develop new problems over time that could influence their attitude towards the topic being researched in a positive or negative manner, depending on their state of mind at the time of research.

The researcher included a qualitative aspect in the questionnaire to ensure that participating individuals can assist with validating certain definitions such as that for depression that are important to this study. These open-ended questions were included to allow the researcher to analyse the collected data for the recurrence of themes to identify the association between emotional support and any such themes that may emerge. This should enhance findings, as emotional support is difficult to quantify.

3.5 STUDY POPULATION

The study population comprised all individuals who suffered SCI, were rehabilitated at 2MH after 1995 when the unit was started, and were re-employed by the SANDF. Their names were retrieved from the system (with permission from the hospital management). Of the 29 individuals who were tracked, 20 satisfied the criteria for inclusion. The remaining 9 were not re-employed after rehabilitation and were thus not eligible to participate in the study. The researcher approached these individuals and requested their participation in the study. One person had passed away and the researcher was unable to trace five of the others. Another had not resumed duties as yet. The final study sample therefore consisted of 13 individuals.

3.5.1 CRITERIA FOR INCLUSION:

- (i) All SCI individuals who have been rehabilitated at 2MH from 1 January 1995 to 31 December 2003 willing to participate in the study.
- (ii) All SCI individuals as stipulated in (i) who are wheelchair users but not necessarily use chairs as their sole means of mobility.
- (iii) All SCI individuals as stipulated in (i and ii) who have been re-employed in the SANDF.
- (iv) All SCI as stipulated in (i to iv) between the ages of 18 and 55.

3.5.2 CRITERIA FOR EXCLUSION:

- (i) All SCI individuals who are not members of the SANDF.
- (ii) All SCI individuals in the SANDF who were not rehabilitated at 2MH (either first phase or follow-up rehabilitation).
- (iii) All SCI individuals in the SANDF who meet the criteria for inclusion but who do not wish to participate in the study.
- (iv) All SCI individuals in the SANDF who have not been re-employed post trauma.
- (v) All SCI individuals in the SANDF who have other complicating medical diagnoses such as TBI that could influence their expression of opinion and interpretation of questions, as well as their ability to give informed consent to participate.
- (vi) All minors.
- (vii) All persons over the age of 55.
- (viii) All members who were rehabilitated before 1995.

It is important to take note of the fact that the researcher excluded all individuals who were unemployed in an attempt to control the variable of employment which according to the literature influenced quality of life and satisfaction with living (Decker & Schulz,1985).

3.6 MEASURING INSTRUMENT

Upon review of the relevant literature, the researcher decided to use a self-compiled, self-administered questionnaire as a measuring instrument for the study to allow the combination and adaptation of existing questionnaires. One of the goals of psychology is to understand unhappiness and ill-being (Pavot & Diener, 1993) which usually involves, amongst others, unpleasant emotions. This is a factor that influences satisfaction with living. Various scales have been designed to assess individuals' life satisfaction in all areas. In this study, a combination of rating scales was used to allow participants to focus more specifically on the emotional aspects of satisfaction with living and quality of life.

The questionnaire was designed to ascertain:

- (i) demographic details of all participants,
- (ii) whether any emotional support was offered to them during rehabilitation, who offered the support, and what was the impact of the support on participants' long-term satisfaction with living and quality of life.

To ascertain the points mentioned in (ii), the researcher used:

- (i) Aspects of the SWLS that, according to Diener, Emmons, Larsen and Griffin (1985) are designed to measure individuals' global judgement of their satisfaction with living rather than only specific life domains. The satisfaction with living scale is described as a measure of subjective well-being (Pavot & Diener, 1993: pg 164).

The scale is based on the rating of five statements, measured on a 7-point Likert Scale and was used in this study to gauge participants' ratings of their satisfaction with living. It focuses on the assessment of respondents' satisfaction with living as a whole rather than restricting it to specific life domains, thus allowing respondents to use their own criteria to rate their satisfaction with living. This is an important method of assessment to use in a rehabilitation setting to boost patient autonomy. The researcher chose this tool as it is brief and comprehensive enough to rate the study population (Pavot & Diener, 1993). The findings of this study in this regard will be explored later in the document. Certain elements, including sexuality, physical condition and leisure activities were, however, excluded. Life satisfaction includes an element of both cognitive and emotional well-being. As the SWLS focuses more on the cognitive well-being of the individual, it is generally suggested that the SWLS be used in conjunction with other assessment tools that focus on emotional well-being (Pavot & Diener, 1993). Therefore the researcher opted not to use the SWLS as the sole assessment scale but to include the SWLS as part of a more comprehensive questionnaire to address SWL in its totality. One other limitation of the SWLS is the fact that it provides the respondents with a broad frame of reference in their response to questions (Pavot & Diener, 1993). To narrow down

their frame of reference, the researcher clarified definitions of terms as referred to in the study to allow a common reference point amongst participants so that findings may be compared. A third limitation of the SWLS is that questions are posed in both past and future tense, allowing the respondent to shift focus from one point of reference to another (Pavot & Diener, 1993). The researcher acknowledges this limitation of the research tool but it has not been modified for this study in order to minimise the loss of validity and reliability of the scale.

This is based on the argument that individuals might rate “success in life” differently for different life domains. Considerate variability has been reported in the use of the SWLS and the scale has been used on diverse population groups. According to Pavot and Diener (1993) the SWLS has been examined for reliability and sensitivity with results showing strong internal reliability. The SWLS has been used in specific trials at different times in therapy and showed significant test-retest reliability. The scale has cross-cultural potential as well as potential across different age groups (Pavot & Diener, 1993). While much optimism exists about the SWLS, limitations do exist. These include the participants’ ability to distort what they report. It also cannot be considered a source of “emotional well-being” due to its large cognitive component. In

this study, the SWLS was used in an adapted form, making the time-frame more specific and using a 6-point instead of a 7-point Likert Scale. This was done in an attempt to decrease the choice of a “neutral” response as an easy option (Katzenellenbogen *et al.*, 2002).

- (ii) A second measuring instrument from which sections (specifically emotional factors) was used is the Osteoporosis Quality of Life Questionnaire (OQOLQ) which, according to Cook and Guyatt (1997), has “excellent reliability”. The emotional component of this questionnaire is specifically designed to establish the relationship between fear and functional disability, an issue that could also be very relevant to SCI for a long time after trauma.

Additional aspects of the questionnaire were designed by the researcher to elicit more specific information. Five open-ended questions were included and minor changes were made in the combination of the two instruments mentioned above. This was done in an attempt to refine its applicability to the research topic as it is one that, to the knowledge of the researcher, has not previously been used in this context. Being developed by the researcher this questionnaire was not in its entirety tested for reliability and validity. However the questions used from the other questionnaires such as the satisfaction with living scale were.

Participants' medical and demographic information were collected in section A of the questionnaire that represents some of the quantitative aspects of the study. Section B was used to reflect on combined quantitative and qualitative data. Common themes emerging from the answers to the open-ended questions and similarities in responses to close-ended questions will provide more specific qualitative data.

The following section provides an outline of the headings used in the questionnaire, including a brief outline of the content of the headings and the reasons why they were included in the questionnaire.

3.6.1 DESCRIPTION OF THE QUESTIONNAIRE

SECTION A: DEMOGRAPHIC DETAIL

1) Age group

The participant's age was asked to establish his/her life stage and to give a possible indication of the expected levels of activity for the respective age groups.

(2) First language

This information was requested to ascertain whether any similarities existed in the responses of different language groups, for instance, whether all individuals speaking a own language during rehabilitation and more especially during counselling.

(3) Marital status

Marital status was asked to determine one of the life roles that the participant is fulfilling. Dijkers (1999) states that married individuals reported the highest satisfaction with living and those who were separated, the lowest.

(4) Race

Race was established as an indication of the participant's culture and to establish the ratio of people with disabilities in the various race or cultural groups in the SANDF following the process of integration.

(5) Arm of service

This information was asked to establish the ratio of people with disabilities across the different arms of service in the SANDF and obtain a possible indication of the adherence to the principle of employment equity, a possible area of exploration for future research. Consistently better or worse reports of satisfaction with living and/or quality of life in a particular arm of service could also be an indication of the extent of accommodation of people with disabilities in each arm of service. This could provide grounds for further investigation.

(6) Type of housing

This information was requested to get an idea of the environment an individual came from to give an indication of how suited the physical circumstances were for living with a

SCI. It is believed that physical conditions could also influence in the individual's satisfaction with living.

(7) Religion/spirituality

This information was requested to gather further insight into the culture and beliefs of the participant as this may be influential in coping with disability by both the participant and his/her support system (Tate & Forcheimer, 2000).

(8) Level of injury (lesion)

This was requested to provide an indication of the generally anticipated or expected level of functioning which could be a factor in satisfaction with living and quality of life. Furthermore, Chase *et al.* (2000) found that individuals with paraplegia communicate more freely than those with tetraplegia.

(9) Date of injury

This was included to allow the researcher to calculate the “time since injury” in the event that a connection existed between the time since injury and the achieved satisfaction with living and quality of life (Dijkers, 1999).

The above demographic information was requested to provide a more comprehensive picture of the participant. Similarities in demographics could indicate that the sample was representative of individuals with common characteristics. This would increase the

validity of the comparison between the participants. The SANDF has a culture of its own which often cuts across the diverse range of cultures.

SECTION B: EXPLORATION OF EXPERIENCES REGARDING SATISFACTION WITH LIVING AND QUALITY OF LIFE

This section comprises a combination of open-ended and close-ended questions. The open-ended questions focused on obtaining an understanding of the participant's personal opinions on some of the key terms such as "emotional support" used in the study. This gave an idea of the point of reference from which the participants answered close-ended questions addressing similar issues.

Questions 11 and 12 focused on the participants' personal understanding of the concepts of "emotional support" and "depression". This was done to establish a baseline understanding of what the participant is referring to when answering certain questions around these concepts further on in the questionnaire. Furthermore, the responses would be scrutinised for the possible emergence of common themes.

Questions 13 to 17 focused on the participants' perception of the manner in which the news of permanent disability was related. It concentrates on the emotional support offered to the individual. This initial informational process may have long-term emotional implications for the SCI individual. The responses to these questions will be studied in association with other general responses further on in the questionnaire.

Questions 18 to 21 requested a rating of services received. This information was requested to get patients' perceptions of the service so that any shortfalls may be addressed in future staff training sessions to improve or commend service delivery.

Questions 21 to 29 explored the participants' "feelings" in different life roles. The responses to these questions could add to the rating of participants' quality of life and satisfaction with living as these are influential components.

Questions 30 to 55 focused on the participants' rating of the extent to which their impairments and disability affect their different life domains. This section explores issues such as body image and altered appearance that may be influence their willingness to socialise and fulfil their different roles.

Questions 56 to 60 is a modified version of the SWLS that sets out to measure the individuals' satisfaction with living. The Likert Scale used to score/rate this was modified to minimise the possibility of choosing of an easy response without consideration.

Questions 61 to 63 were included to allow participants the opportunity to share with peers and advise both professionals and peers. (See Appendix A.)

3.7 PILOT STUDY

Aim of the pilot study:

1. To assess the logical flow of questions, and
2. To assess whether any of the questions were unclear.

Prior to conducting the actual study, a pilot study was conducted to verify the appropriateness of the compiled questionnaire intended for use in the actual study. Owing to the limited population fitting the criteria for inclusion in the SANDF, the researcher requested permission to conduct the pilot study outside the SANDF with individuals fulfilling the rest of the criteria for inclusion. The researcher approached a social worker of another rehabilitation unit in the Western Cape to establish a possible database for prospective participants. The social worker contacted ten possibly eligible participants who were willing to consider participation. The researcher was then able to successfully contact seven of those individuals of which only four eventually participated. Reluctance was noted to enter a study of this nature, possibly because the researcher was unknown to the participants. The researcher concluded this since the actual study population did not display the reluctance. The researcher conducted one interview telephonically during the pilot study in preparation for telephonic interviews with two of the participants in the actual study.

After conducting the survey with these four individuals, one question viz. question 51 was changed as the question was not easily understandable.

Furthermore, participants were asked to report the cause of their injury.

3.8 PROCEDURE

The researcher conducted all the interviews. Permission to conduct the interviews was requested from the participants and the Medical Superintendent as well as the rehabilitation unit manager prior to conducting the interviews. The procedure, obligations and ethical issues were explained to the prospective participants before conducting the interview.

The option of having the questionnaire translated was not used by participants. No requests were made for translation of the questionnaire. The information gathered was handled with the strictest confidentiality. No participant was identified by name on his/her response sheet. The rights of the participants were explained to each one of them during the initial stage of the interview in the presence of a witness. Participants were asked to complete a written consent form to confirm their willingness to participate in the study.

Interviews were scheduled to last a maximum of one hour so that it would allow each participant the same amount of time to contribute. In the presence of a witness, the

participant was assured that participation was voluntary and that they should not feel obligated in any way to participate. They were reassured that not participating in the study would not disadvantage their continued treatment in any way as stipulated on the consent form. It was furthermore explained to the participant that the study was conducted in the interest of providing an improved rehabilitation service to both newly injured patients and to the participants themselves who still have the liberty of using the facilities. On completion of the study, it was told to the participants, the researcher would compile a document which would discuss the findings of the study. Furthermore, the findings would be presented to different involved teams and individuals. At this stage, the participant was informed that they would not each receive a copy of the document but that they were free to request this and also that they were welcome to request that the researcher present the study findings to any relevant and concerned party.

Some (two) participants chose to complete the questionnaire independently while most requested that a scribe complete the recording of the responses. Participants' responses to the open-ended questions were noted and read back to them before terminating the session. The researcher always positioned herself in the line of vision of the participant so that he/she could see the responses being recorded as they were dictated. All interviews were conducted at a venue chosen by the participant. A private area was used to conduct the interviews for the purpose of confidentiality. If the participant was accompanied by another person, they were given the choice whether they wanted that person to be present during the interview or not. All but one of the participants chose to be alone with the researcher while answering the questions.

3.9 DATA ANALYSIS

The data was collected and responses were analysed to identify associations between different variables through association of different answers. The raw data obtained from all close-ended questions were set out in an Excel spread sheet using the 'Statistica' programme with the assistance of a statistician at Stellenbosch University who verified the correctness of the captured data. The data gathered in response to close-ended questions was then analysed by using the Pearson chi square test and the M-L chi square test, to identify associations between answers to specific questions. Open-ended questions were analysed by identifying evidently common themes in an attempt to gauge the indications of a need for improvement of services as indicated by participants. Research findings were then described and clinically significant information/findings were reflected graphically later in the document.

These emerging associations were then used to make recommendations and measure whether the objectives of the study had been met.

3.10 POTENTIAL BIAS

- All respondents knew the researcher and this may have influenced their responses, although they chose the researcher as their scribe. The researcher decided to perform interviews herself after she noted that the participants in

the pilot study were reluctant to respond openly to an unknown interviewer on these questions. (The researcher did not know the participants of the pilot study.)

- Participants were predominantly male, a point that does not allow the researcher to identify any possible differences that may have evolved between men and women. One wonders whether coping skills and opinions might differ between men and women.
- The fact that participants were not interviewed in their first language except those with English or Afrikaans as their first language, could influence their ability to express themselves adequately or might have influenced their understanding of certain aspects of the questionnaire. However they chose not to utilise the services of an interpreter.

3.11 ETHICAL CONSIDERATIONS

- All participants were assured of confidentiality of the disclosed information.
- The research proposal was submitted to the Committee C of the University of Stellenbosch to ensure that the requested information was not in any way unethical to ask of any individual.
- The participants were given a written consent form to sign prior to participating in the study, this form was signed in the presence of a witness to vouch that the participant was willing to participate and also that the researcher had informed them of the conditions of the study.

- It was explained to all participants that non-participating or their answers will in no way influence future treatment.

CHAPTER 4

RESULTS AND DISCUSSION

INTRODUCTION

The results of the study are discussed in this chapter according to the objectives of the study as far as possible, under the following headings:

- 4.1 Demographic profile of participants
- 4.2 Support systems during rehabilitation
- 4.3 Participants' perceptions of services received
- 4.4 Satisfaction with living and Quality of life post discharge
- 4.5 Themes emerging from open-ended questions
- 4.6 Summary of results

The relevant findings of each section will be discussed with the inclusion of graphs as applicable.

The reader should take note of the following:

- *'No of participants' are depicted on the Y-axis of all figures in this chapter.*
- *A p value of 0.05 or less was deemed statistically significant using the Pearson's chi square test and the L-M chi square test.*
- *Definition of emotional support as used in the study: "the action of supporting, giving strength, help and encouragement to someone".*

- *Definition of depression as used in the study: “great sadness or feeling of hopelessness”.*
- *Definition of Quality of life as used in the study: “all aspects of an individuals’ well-being which encompasses spiritual and economic health as well”.*
- *Definition of Satisfaction with Living as used in the study: “an individuals’ measure of their lives, assessing each dormain of their life in conjunction with their own personal values”.*

4.1 DEMOGRAPHIC PROFILE OF PARTICIPANTS

The following factors will be discussed to address the first objective, that being to determine the demographic profile of the participants.

4.1.1 General information

4.1.2 Causes of injury

4.1.3 Gender

4.1.4 Age

4.1.5 Marital status

4.1.6 Level of injury

4.1.1 GENERAL INFORMATION

A total of 20 (twenty) individuals with SCI, treated at the rehabilitation unit of 2MH, satisfied the inclusion criteria. Of these, 13 participated in the study. Some background information on the study population is discussed as follows.

4.1.1.1 Language

Participants were asked to indicate their first language. Figure 1 depicts the distribution of participants in different language groups.

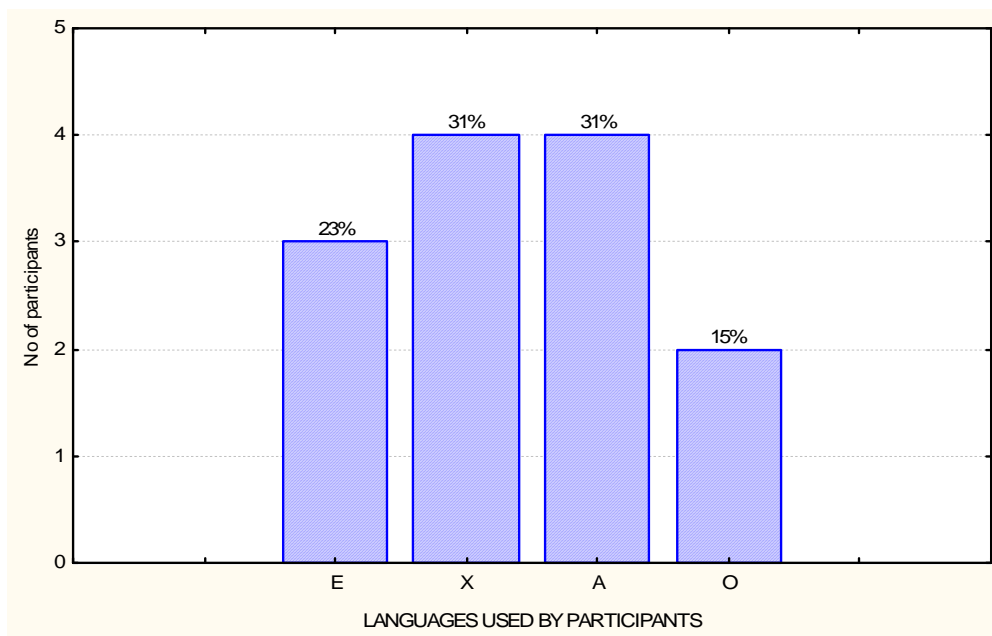


FIGURE 1: FIRST LANGUAGE OF PARTICIPANTS

KEY: X- AXIS: E = ENGLISH; X = XHOSA; A = AFRIKAANS; O = OTHER LANGUAGE

Figure 1 indicates that the first language of 31% (n=4) of participants was Xhosa and 15% (n=2) indicated a language other than English, Afrikaans or Xhosa as their first language.

The researcher noted the influence of different languages when the participants were asked to answer the open-ended questions during the interview. While the official language of the SANDF is English and all participants were able to communicate in English, those who indicated Xhosa or another language as their first language, did have some difficulty in expressing themselves when defining concepts. Therefore conducting the study in English can be seen as a limitation to the study. It should, however, be noted that all participants opted to conduct the interview in English despite having been offered a translator/translation for the interview. More detail with regard to the influence which language had will be discussed later in the chapter.

4.1.1.2 Arms of service

As indicated in earlier chapters of the document, members of the SANDF belong to different arms of service which include the SA Army, SA Navy, SA Airforce and the SA Military Health Service. The distribution of participants among these arms are depicted in Figure 2 below.

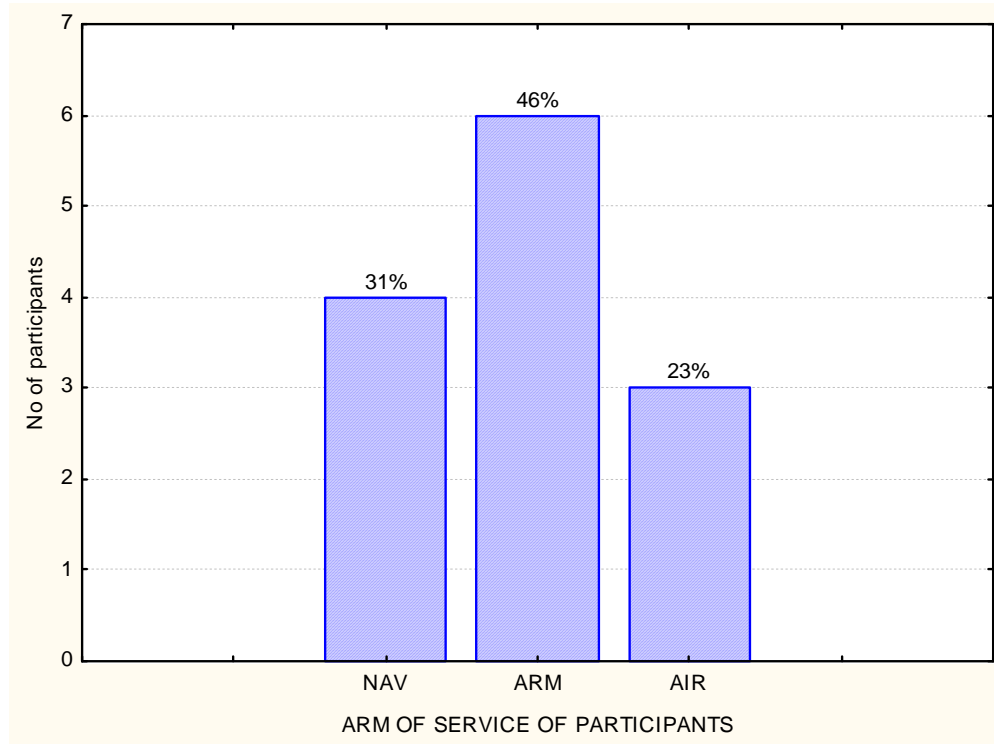


FIGURE 2: DISTRIBUTION OF PARTICIPANTS ACCORDING TO ARM OF SERVICE

KEY: X-AXIS: NAV = SA NAVY; ARM = SA ARMY; AIR = SA AIRFORCE

It is interesting to note that although none of the participants were injured during battle situations, the SA Army had the highest incidence of injuries in this population (see Figure 2). This can possibly be attributed to the fact that the SA army are the largest of the four arm of service. However the difference in actual numbers is very small and

could have been purely by chance. No participants belonged to the SA Military Health Service (thus not depicted in Figure 2).

4.1.1.3 Racial distribution

The SANDF has undergone a process of transformation and integration, resulting in the inclusion of all race groups. For the purpose of complete demographics and to substantiate associations that may be made directly or indirectly in the study, participants were asked to stipulate their racial denomination. These indications are represented in Figure 3.

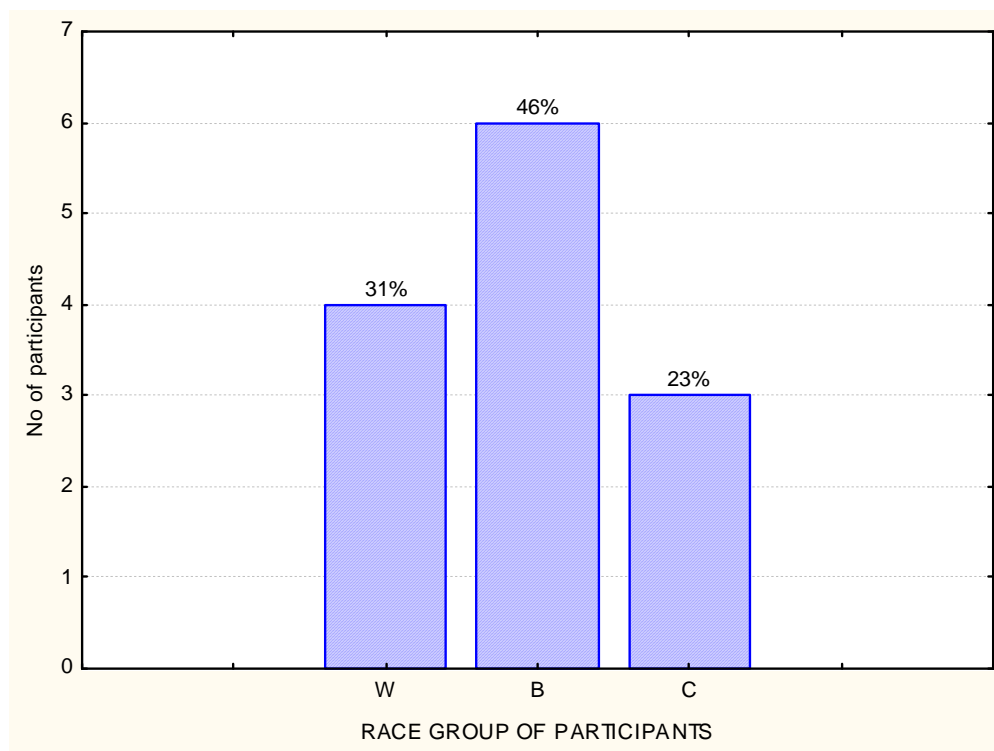


FIGURE 3: RACIAL DISTRIBUTION OF PARTICIPANTS

KEY: X- AXIS: W = WHITE; B = BLACK; C = COLOURED

Figure 3 shows that the study population comprised 46% blacks (n=6), 31% (n=4) whites and 23% (n=3) coloured. This serves as a broad indication of the population distribution of the SANDF in the Western Cape. Further discussion regarding socio-economic living conditions in this study population is also presented later in the chapter.

4.1.2 CAUSES OF INJURIES

Participants reported different causes of their injuries. A summary of these is presented in Table 1. It also indicates whether the injury was sustained on duty or not. (*Percentages in Table 1 are rounded off to the nearest integer.*)

TABLE 1: CAUSES OF INJURIES OF PARTICIPANTS

CAUSE OF INJURY	NUMBER OF PARTICIPANTS (n value)	% OF STUDY POPULATION	INJURIES ON DUTY
Sport	2	15	2
Gunshot	3	23	0
Motor vehicle accidents	5	38	1
Stabbing	1	8	0
Non-traumatic	1	8	0
Other	1	8	0

Only three participants were injured while on duty. As indicated in Table 1 92% (n=12) of the population suffered traumatic injuries that included traumas such as gunshot

wounds, motor vehicle accidents, stab injuries and sports injuries. Table 1 also indicates the frequency of each in the study population. These causes correspond with those described in the literature (QASA, 2004). Since the most injuries occurred among black participants (see Figure 3), it could be assumed that the high levels of crime they are exposed to in their neighbourhoods such as the Cape Flats and Khayelitsha, where many participants live, increased the risk factor in their case. This deduction is made despite the fact that there is no difference in the socio-economic status of the different race groups in the study population and is attributed purely to the areas where participants live. No injuries in this study population were a result of battle although some were injured on duty (see Table 1).

4.1.3 GENDER

The study population consisted of 13 participants, 12 men and 1 woman. This distribution is in keeping with the high ratio of male employees of the SANDF. Also, the general prevalence of SCI amongst women is much lower than in men. (QASA, 2004) Owing to the lack of female participants, this data could not be used to compare satisfaction with living and quality of life between male and female participants. It is recommended that this comparison is made in a future study with a more balanced study population in terms of gender distribution.

4.1.4 AGE

Figure 4 below illustrates the age distribution of the study population. All the participants were adults of working age. Ages ranged from late teens to 50.

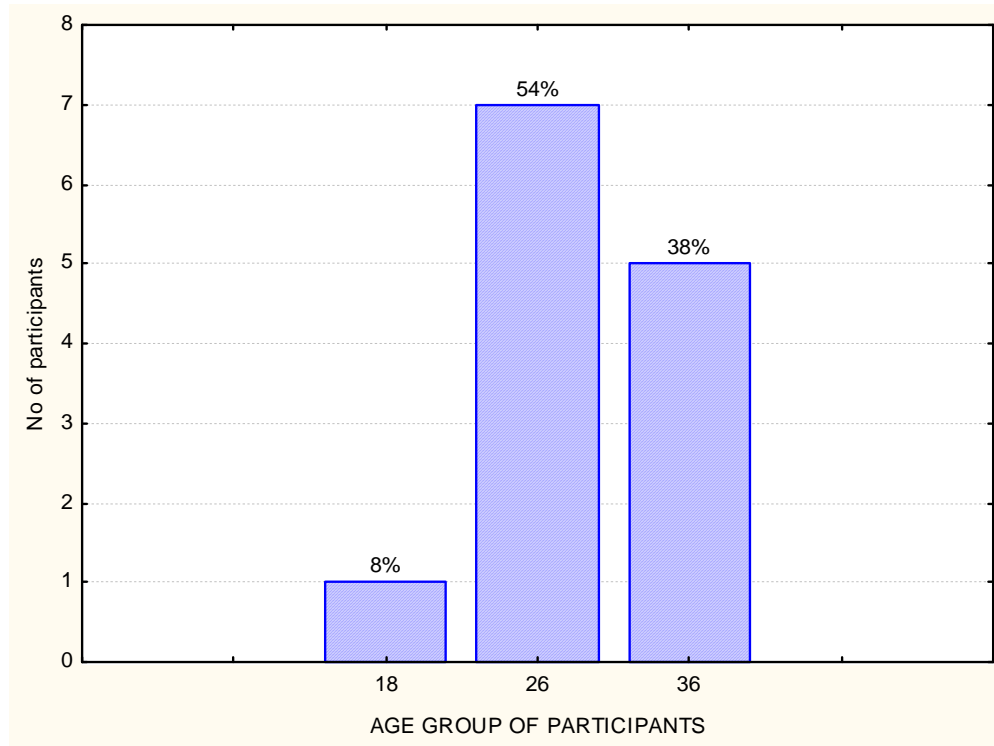


FIGURE 4: AGE DISTRIBUTION OF PARTICIPANTS

KEY: X- AXIS: 18 = Ages 18 - 25; 26 = Ages 26 - 35; 36 = Ages 36 - 50

Literature indicates that people in different age groups cope differently with trauma and disability so that age could also be a possible factor in satisfaction with living and quality of life (Tate & Forcheimer, 2000). This phenomenon will be discussed later in the chapter.

4.1.5 MARITAL STATUS

The marital status of the participants is set out in Figure 5. Participants were asked to indicate whether they were married, divorced or single.

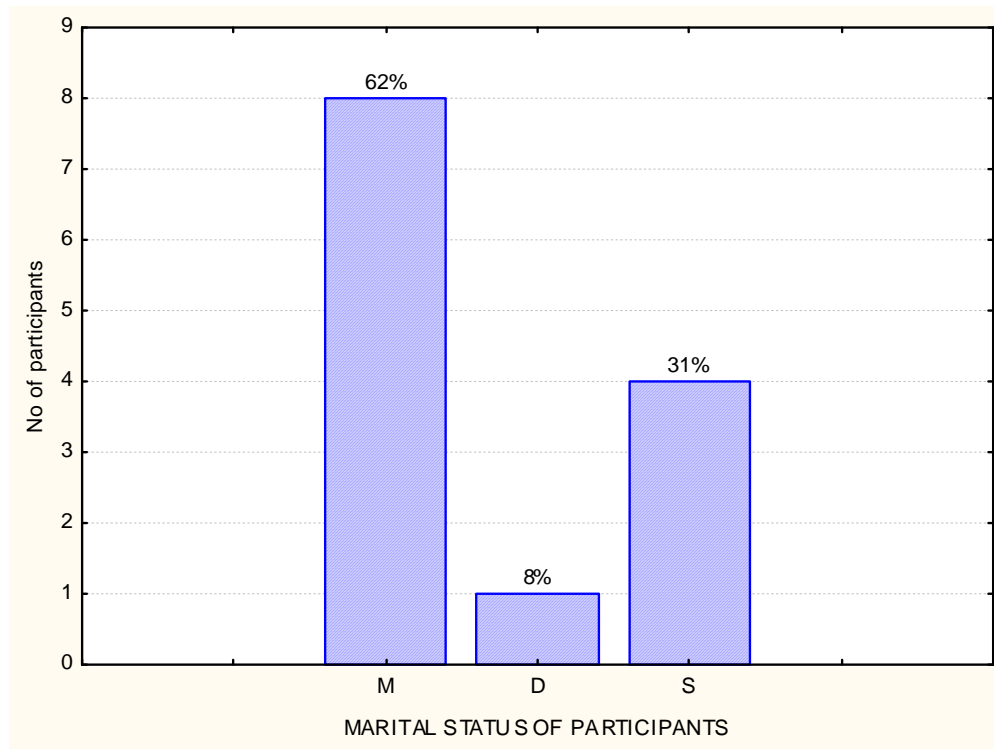


FIGURE 5: MARITAL STATUS OF PARTICIPANTS

KEY: X- AXIS: M = MARRIED; D = DIVORCED; S = SINGLE

Literature (Chase, 2000; Dijkers, 1999; Tate & Forcheimer, 2002) indicates that married individuals enjoy a stronger support system. In this study, this association was not evident ($p= 0.59141$). It was also interesting to note that even though some participants had divorced after the injury, others were married or continued dating (many with partners they met after the injury). The last two findings may be an indicator that the participants feel positive enough about themselves to foster new intimate relationships.

Where participants were divorced after the injury, it was noted that marital difficulties had existed pre-morbidly. However, this was not the focus of the research and was not investigated in detail

4.1.6 LEVEL OF INJURY

The study population consisted of both tetraplegic and paraplegic participants. Distinction was not made between complete and incomplete lesions for this study. The distribution is depicted in Figure 6.

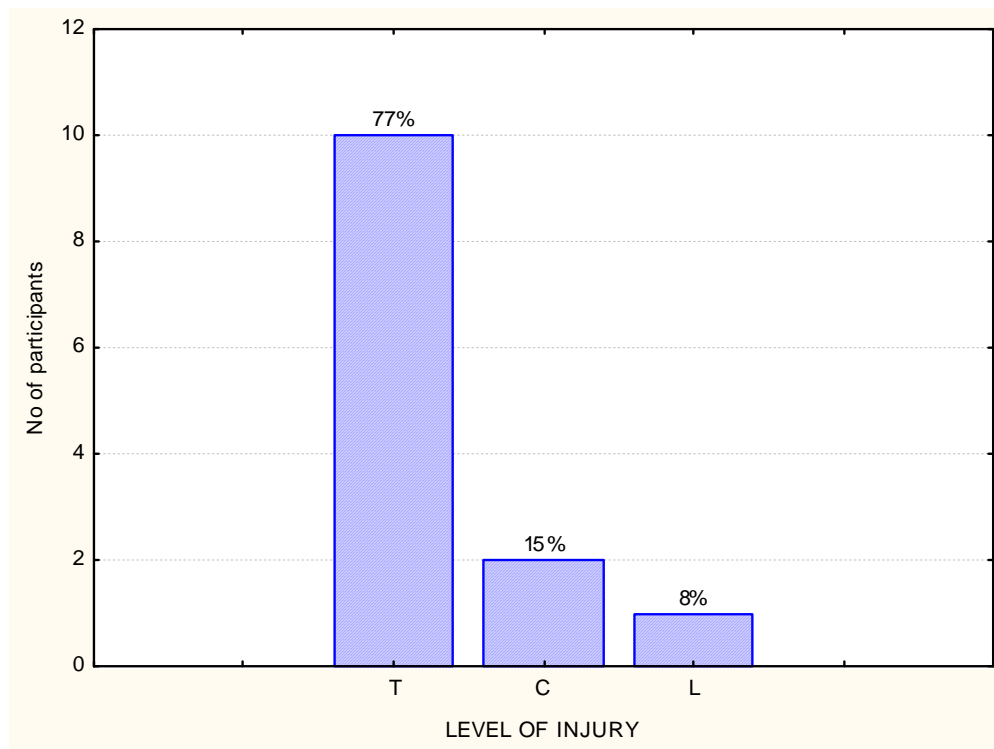


FIGURE 6: LEVELS OF INJURY OF PARTICIPANTS

KEY: X- AXIS: T = THORACIC LESION; C = CERVICAL LESION; L = LUMBAR LESION

Literature suggests that a difference exists in the communication ability and assertiveness of paraplegics in comparison with tetraplegics (Chase, 2000). This literature is suggestive

of paraplegics communicating more easily than tetraplegics. The researcher acknowledges that assertiveness, often related to communication abilities, can have an effect on satisfaction with living and quality of life. This study did not highlight such associations. It should be noted that amongst the participants with cervical lesions, one has a C3 injury and is ventilator dependant (employed full-time). Consequently, he is 100% dependant for all daily living activities and relies solely on his ability to communicate to aid his function.

It is generally expected that paraplegics are more capable of physical independence than tetraplegics. This distinction is largely based on the idea that less physical impairment facilitated increased independence training. Figure 6 serves as a gauge to estimate the level of independence of participants. Since most participants indicated that they were irritable with themselves or thought about their disability only when they needed assistance or when obstacles arose, physical independence plays an important subjective role in satisfaction with living and quality of life. The concepts of satisfaction with living and quality of life are discussed in detail as the chapter unfolds.

4.2 SUPPORT SYSTEMS DURING REHABILITATION

A second objective of the study was to assess the perceptions of the participant re-employed in the SANDF with regard to the availability of emotional support.

In order to address this objective, the different factors contributing to emotional support were investigated. Tate and Forcheimer (2002) suggest that married individuals are more likely to have a closer support system than single individuals. The study investigated

participants' satisfaction with family life, as siblings and as partners. While many indicated satisfaction in these roles and expressed closeness to their families who were seen to be a constant source of support (see Figure 7), this did not have a correlation with the marital status of the participants or the presence of a support system at all ($p=0.59141$).

Participants were also asked to indicate who provided the most constant source of emotional support for the duration of rehabilitation Figure 7 represents their responses.

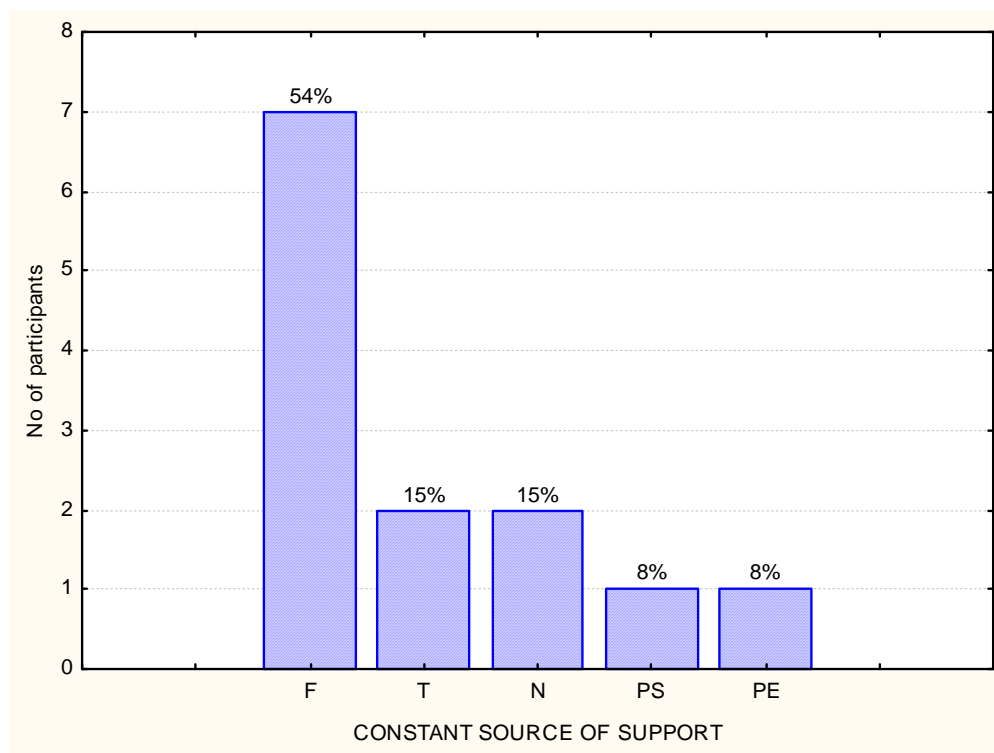


FIGURE 7: MOST CONSTANT SOURCE OF EMOTIONAL SUPPORT DURING REHABILITATION

KEY: X-AXIS: F = FAMILY; T = THERAPISTS; N = NURSES; PS = PSYCHOLOGISTS; PE = PEERS

54% (n=7) of participants indicated that they perceived their families as the most constant source of support throughout their rehabilitation (see Figure 7). It is comforting to note that families were rated highest, as they are the ones who will be a constant in the participants' lives, even after discharge. It also decreases the possibility of the participants becoming too dependent on the health care professionals. It is interesting to note that only 8% (n=1) of participants identified psychologists as their most constant source of emotional support. This could support the idea that emotions are more easily vented as a secondary aim in treatment as with nursing care (15% (n=2)) or during therapy (15% (n=2)) when the focus is not solely on emotions instead of when it is directly targeted, as one would imagine in intervention with the psychologist. The fact that the psychologist does not have contact with patients as regularly as other health care professionals on the team, may be a contributing factor in this finding.

The low level of peer support (8% (n=1)) can possibly be attributed to the fact that the unit where the study was conducted is small and does not always have many SCI individuals admitted at the same time. The participants therefore sometimes rely on the rehabilitation team to introduce a peer into the rehabilitation process. For this study, no significant association was established between the effect of exposure to a peer counsellor and its effect on satisfaction with living and quality of life ($p=0.33667$ and $p=0.42035$ respectively). A future study investigating the influence of peer support on satisfaction with living and quality of life might be useful in this regard.

“Medical practitioners/Doctors” was among the suggested responses but was not chosen by any of the respondents.

Having identified family members as their most constant source of emotional support during rehabilitation, participants were asked whether any of these members were present when the nature of their injury was related to them.

The researcher obtained results as indicated in Figure 8.

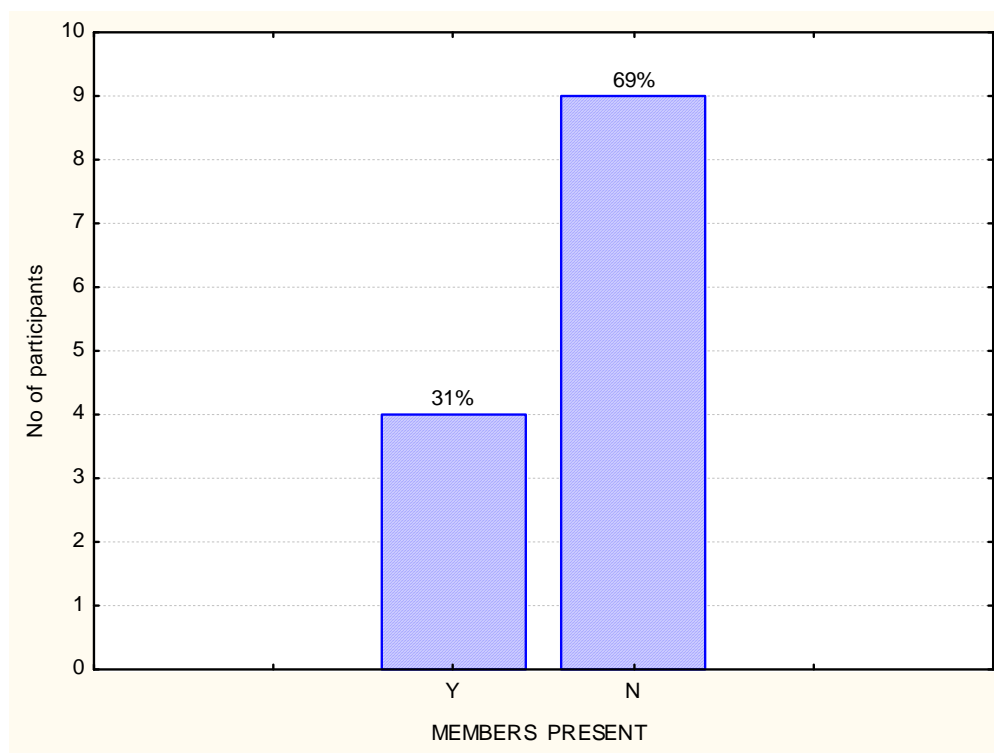


FIGURE 8: MEMBERS OF SUPPORT SYSTEM PRESENT WHEN INFORMED

KEY: X- AXIS: Y = YES; N = NO

Responses indicated that only 31% (n=4) of the participants had a member of their support system present when they were informed of the nature of their injury for the first time. The other 69% (n=9) faced the news on their own (see Figure 8). An influencing

factor in this regard may have been the fact that a percentage of the participants were injured while away from their hometowns. This was, however, not true for the majority of the cases, which arouses concern about the fact that as many as 69% (n=9) were informed without members of their support system present. Responses were analysed to establish whether participants with higher satisfaction with living and quality of life were those who had a member of their support system present when the news of their injury was related to them. A definite association was not established. In addition the researcher investigated whether participants who indicated that their family or friends were the most constant source of support during their rehabilitation showed better long-term satisfaction with living and quality of life. Findings indicated that 54% (n=7) of participants identified their families as the most constant source of support during rehabilitation (see Figure 7) but that only 31% (n=4) had a member of their family present when the news regarding the nature of their injury was related to them (see Figure 8). Satisfaction with living and quality of life, however, could not be related significantly to any of these findings ($p=0.59141$).

Evidently families played a big role in the continued rehabilitation of the participants and while some shared the initial news of the injury with participants, others were informed later.

Figure 9 indicates the distribution of the first informant of the nature of the injury as reported by participants.

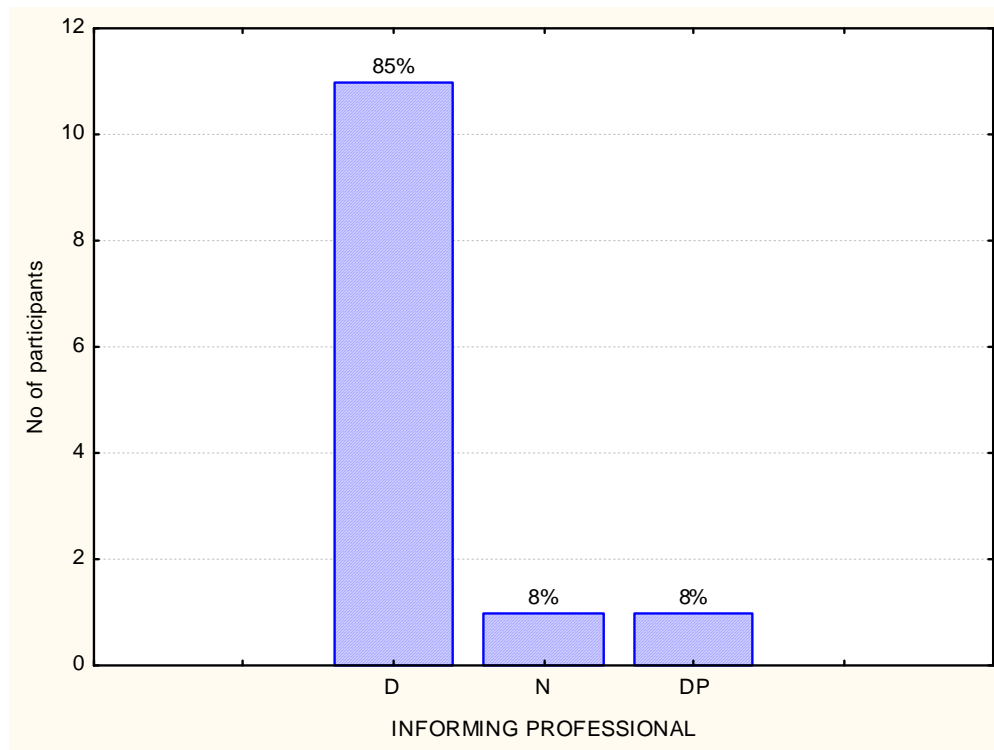


FIGURE 9: FIRST INFORMANT OF THE NATURE OF INJURY

KEY: X- AXIS: D = DOCTORS; N =NURSES; DP = DOCTORS & PSYCHOLOGISTS

This information was requested from the participants to gauge the continuity of the provision of emotional support. This is an important element in the management of a patient with a permanent injury such as SCI. Although 85% (n=11) indicated that it was the doctors who first informed them of the nature of their injury (see Figure 9) they identified their family members, therapists and nurses as their most constant source of support (see Figure 7).

One wonders whether it is acceptable for one member of a team to inform the individual of the severity of an injury and then leave the continued support to others. However, it could well be preferable as patients often attach a negative association to the individual who alerts them to their injury. In this instance it might be best for the therapists and nurses to provide continued support as they are the ones facilitating the rehabilitation process and guiding the patient towards physical improvement.

While nursing staff were identified as one of the constant sources of support (Figure 7), many participants, when responding to the open-ended questions, indicated that nursing staff needed to be more compassionate. An interesting observation in this regard is that nurses were also involved with informing the patient of their injury in 8% (n=1) of the incidents as reflected in Figure 9.

The researcher furthermore gathered an idea of participants' perceptions of whether the news was related in a supportive manner. Figure 10 reflects the results.

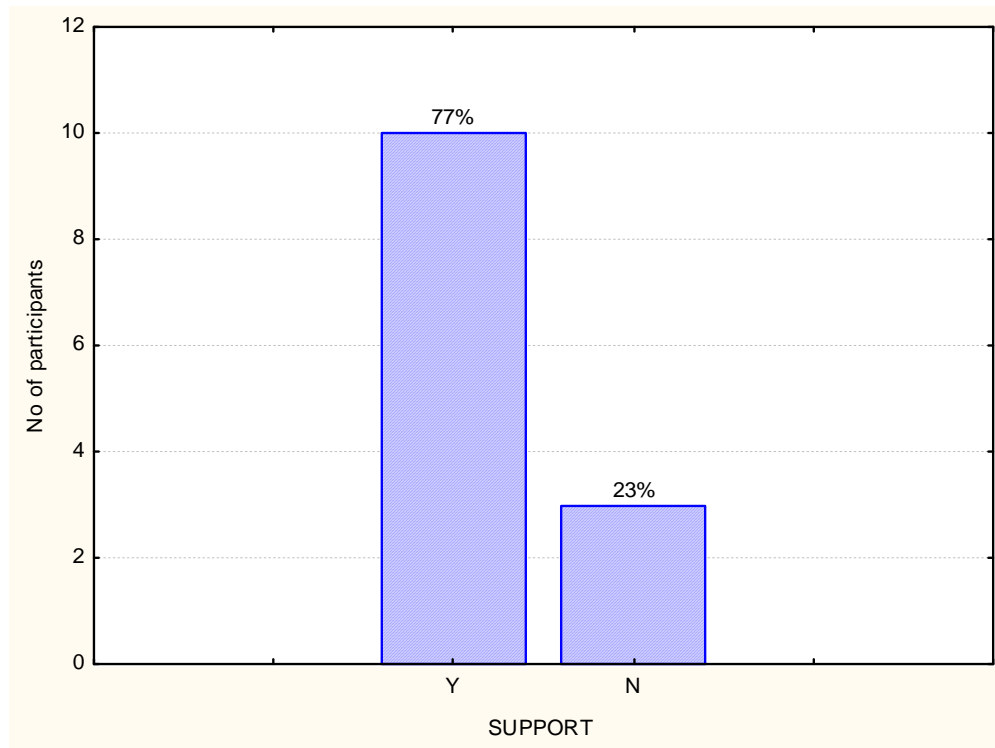


FIGURE 10: MANNER IN WHICH NEWS OF THEIR INJURIES WAS CONVEYED

KEY: X- AXIS: Y = YES; N = NO

Responses indicated that 77% (n=10) of participants felt that they were informed of the nature of their injury in a supportive manner. It was also interesting to note that during the interview many respondents found it difficult to remember the exact date of their injury, but all were able to indicate who informed them and where they were informed. Many participants reported that even though they had a feeling that their injury would be permanent even before being formally informed, they felt that they did not believe or

comprehend everything the informant was relating to them at the time. This clarifies the need for reinforcement by the health care professional.

Although the majority of participants reported being informed in a supportive way, it is imperative to also note the 23% (n=3) who did not feel supported (see Figure 10). In this case one questions whether the presence of a member of their immediate support system would have influenced the situation positively. This is another subject for future research.

It is concluded that support systems are an important element in the rehabilitation process. This echoes the workings of a rehabilitation team implementing the bio- psychosocial model where family and support systems play a pivotal role. The figures and associations made above firmly support this scenario or 'theory'.

4.3 PARTICIPANTS' PERCEPTIONS OF SERVICES RECEIVED

The study primarily focused on the offering of emotional support to individuals with SCI during rehabilitation. It was thus fitting to survey the participants' perceptions of the services they had received.

Each participant was asked to directly rate the emotional support they received from the rehabilitation team to allow the reader a subjective view. Figure 11 which follows represents their ratings.

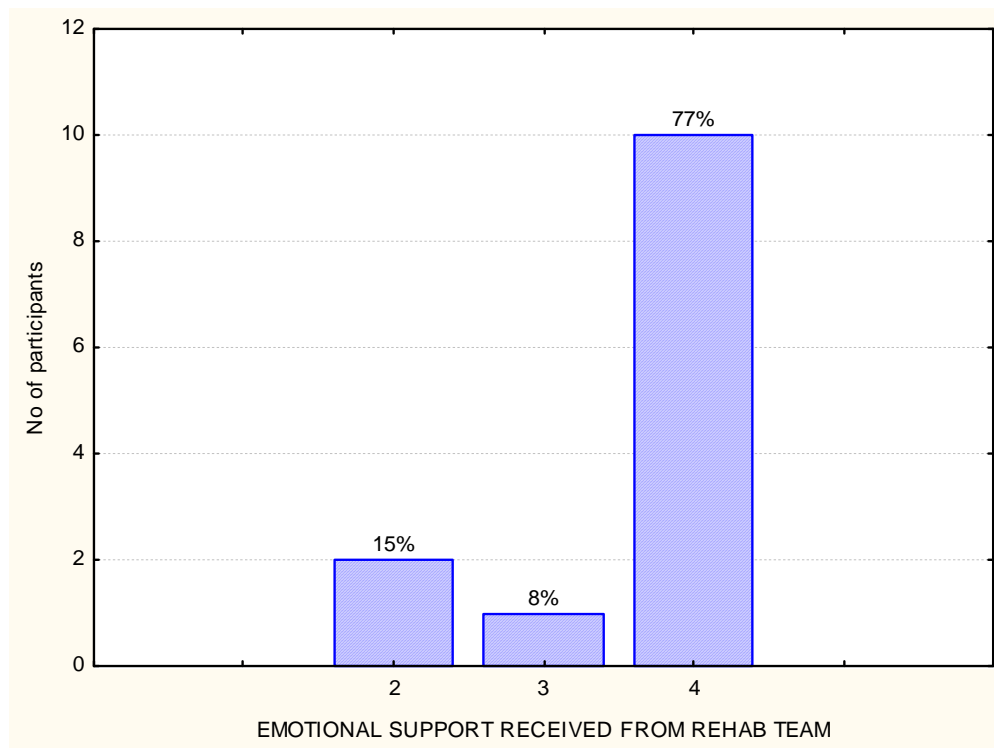


FIGURE 11: EMOTIONAL SUPPORT RECEIVED FROM THE REHABILITATION TEAM

KEY: X- AXIS: 2 = SATISFACTORY; 3 = GOOD; 4 = EXCELLENT

The majority of participants (77%, n=10) rated the emotional support received from the rehabilitation team as excellent while 8% (n=1) indicated that it was good. It was interesting to note that many of them were still able to recall the names of their therapists and relate incidents they had experienced during rehabilitation. The other response offered for this question was poor but none of the participants chose this in their rating. Although 15% (n=2) of participants felt that emotional support was merely satisfactory,

not many were able to provide concrete suggestions for the improvement of emotional support. Some participants mentioned that nurses could provide more emotional support. The participants' definitions of "emotional" support will be discussed in further detail further on in the document in the discussion of responses to the open-ended questions. In order to have an idea of the participants' overall perception of the services rendered by the unit, the researcher asked them to rate the general support received from the rehabilitation team as well. These results are set out in Figure 12.

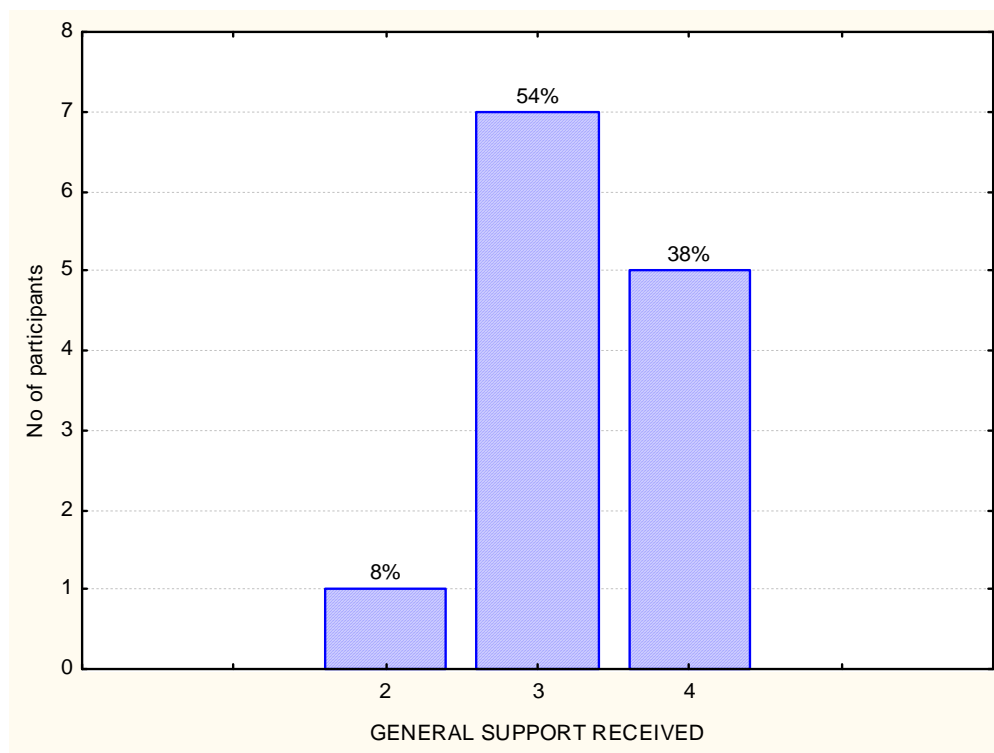


FIGURE 12: GENERAL SUPPORT RECEIVED FROM THE REHABILITATION TEAM

KEY: X-AXIS: 2 = SATISFACTORY; 3 = GOOD; 4 = EXCELLENT

In this question, participants were informed that they were required reflect on the services such as administrative issues (e.g. sick leave and financial matters). They were also free to consider issues such as the provision of assistive devices, medication, transport and general services of a more logistical nature. Whilst 38% (n=5) indicated that it was excellent, 54% (n=7) indicated that it was good with the remaining 8% (n=1) noting it to have been satisfactory. No participants rated it as poor and no serious grievances were noted regarding the general support they received. It is important to note that the hospital too is a military environment which is fitting with the military culture to which all the participants belonged. Consequently they were familiar with the setting and most delays were attributed to the military system. Participants, however, had no suggestions for improving the situation.

4.4 SATISFACTION WITH LIVING and QUALITY OF LIFE POST DISCHARGE

The study revolved around quality of life and satisfaction with living. Here the objective was set at being the assessment of the perceived quality of life and satisfaction with living of participants after discharge and return to work.

In addition, another objective of the study was set to be the analysis of the gathered data for any relationship between emotional support received during in-patient rehabilitation and quality of life and satisfaction with living post discharge.

The graphical associations, which follow, assisted the researcher in gaining information to address this objective.

Figure 13 indicates participants' subjective ratings of quality of life at the time of the study.

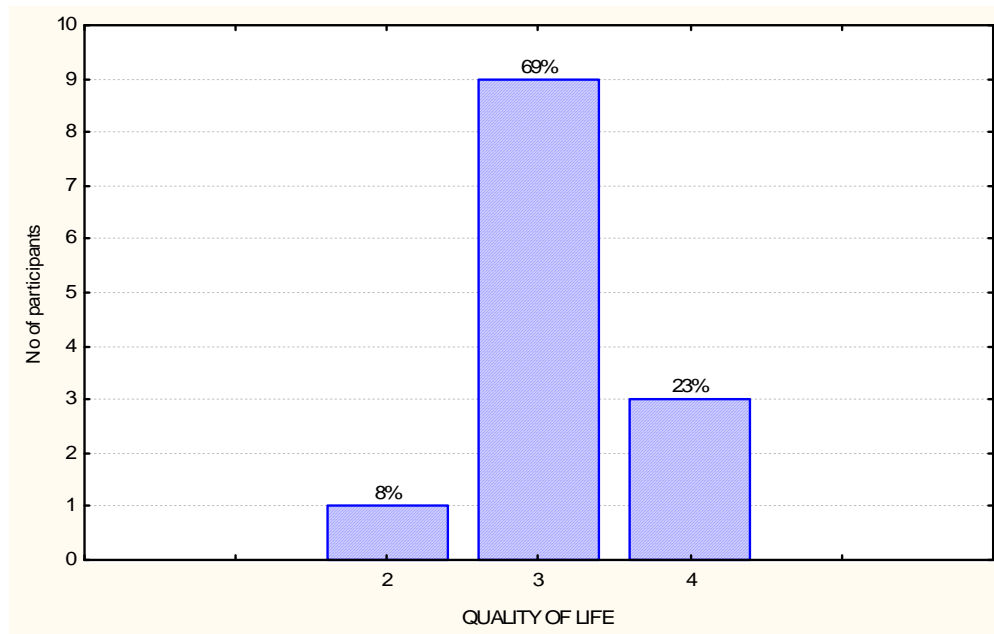


FIGURE 13: PARTICIPANTS' RATING OF QUALITY OF LIFE

KEY: X- AXIS: 2 = SATISFACTORY; 3 = GOOD; 4 = EXCELLENT

Sixty-nine percent (n=9) of participants subjectively indicated a good quality of life (QOL) while 23% (n=3) indicated an excellent QOL. Only 8% (n=1) of participants indicated a satisfactory QOL with no indications of poor QOL that was provided as a fourth option. A significant correlation between the emotional support received during rehabilitation and the QOL of participants ($p=0.0497$) points to the importance of emotional support during rehabilitation. It can therefore be noted that rehabilitation professionals and family members are seen as part of the same team. Family members were therefore guided in providing emotional support and in turn established a supportive relationship with health care professionals. The study showed no significant association

between age and QOL ($p=0.34767$). As mentioned before, the study focused on both QOL and satisfaction with living (SWL), each of which was questioned separately.

Figure 14 depicts the participants' SWL at the time of the study.

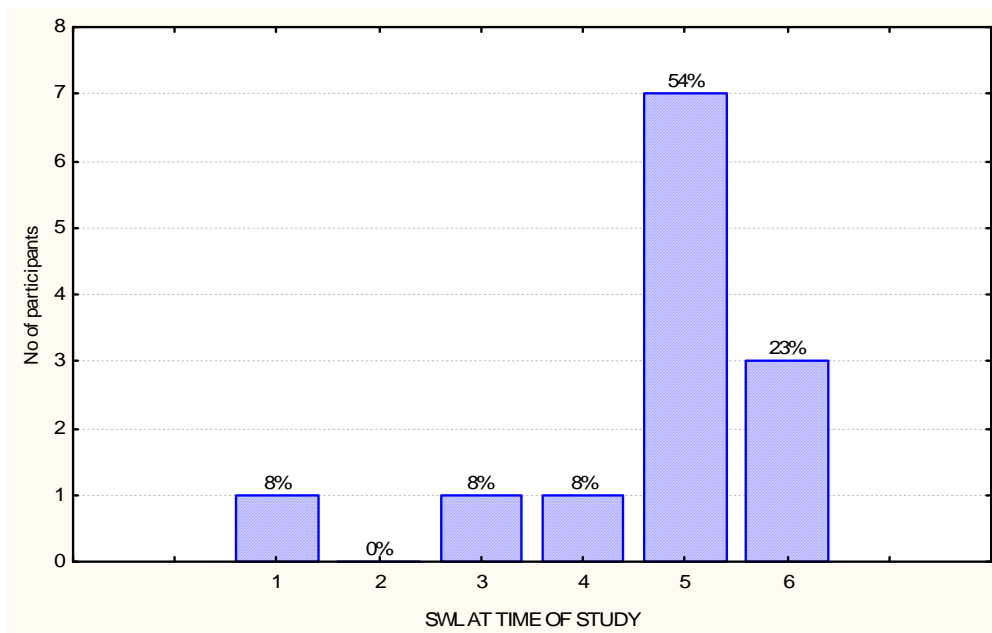


FIGURE 14: PARTICIPANTS' SATISFACTION WITH LIFE

KEY: X-AXIS: 1= STRONGLY DISAGREE; 2 = DISAGREE; 3= SLIGHTLY DISAGREE;
4 = SLIGHTLY AGREE; 5 = AGREE; 6 = STRONGLY AGREE

When the statement: "I'm satisfied with the conditions of my life now as it is" was posed to participants, the majority (54% where $n=7$) agreed that they were satisfied with the conditions of their lives as it was and 23% ($n=3$) strongly agreed with this statement. Therefore it can be concluded that 77% ($n=10$) of participants were satisfied with their lives. Only 8% ($n=1$) strongly disagreed that they were satisfied with the conditions of their lives (see Figure 14). At this point, many of them indicated the issue of fate and destiny and expressed that the injury "was meant to be". Opinions and explanations are

further elaborated on when discussing emerging themes further on in the chapter. No significant associations were made between SWL and the emotional support offered during rehabilitation ($p=0.52054$). The detailed findings regarding the elements of SWL are discussed further, later in this chapter.

A significant association was, however, made between age and the participant's satisfaction as an employee with a disability ($p=0.07521$) as well as their overall SWL ($p=0.02924$). This indicated that individuals in the age groups 26 and higher were more satisfied with their lives as employees with disabilities than those under the age of 25.

Ages of the participants were provided to indicate the approximate life stage the participant was at, which might influence their QOL and SWL.

Though beyond the scope of this study, it would be interesting to see how these scores compare to those of able-bodied people, a possible recommendation for a further study.

The study solely included re-employed participants.

Figure 15 below illustrates the feelings of participants about their roles as disabled employees.

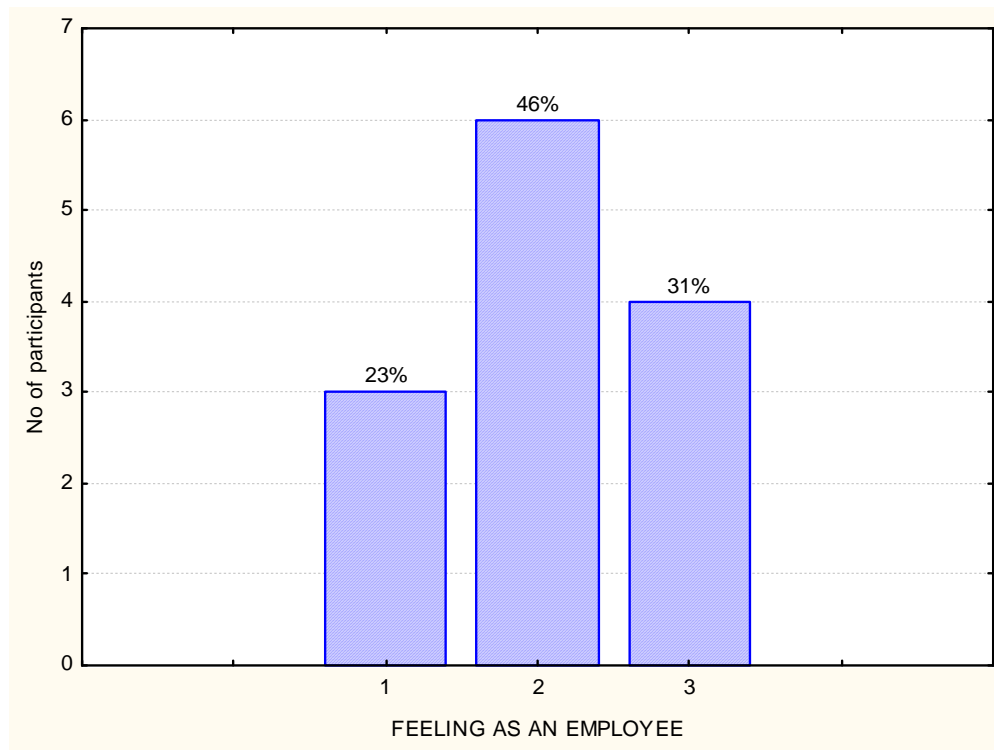


FIGURE 15: PARTICIPANTS' VIEWS OF THEIR ROLES AS EMPLOYEES

KEY: X-AXIS: 1 =NOT SATISFIED; 2 =SATISFIED; 3 =VERY SATISFIED

Employment status is often associated with higher SWL (Hampton, 2000) but one needs to look at the employee's level of happiness as an employee to decide whether any deductions can be made from this.

Viewing the participants in different life roles they were asked to rate their satisfaction with themselves as employees (see Figure 15) and then purely as a person with a disability (see Figure 16). While 77% (n=10) indicated a degree of satisfaction with their lives as employees, the remaining 23% (n=3) indicated that they were not satisfied. One

questions whether the circumstances of injury, whether on or off duty, were influential in the rating set out in Figure 15.

Figure 16 below indicates participants' feelings of satisfaction purely as people with disabilities.

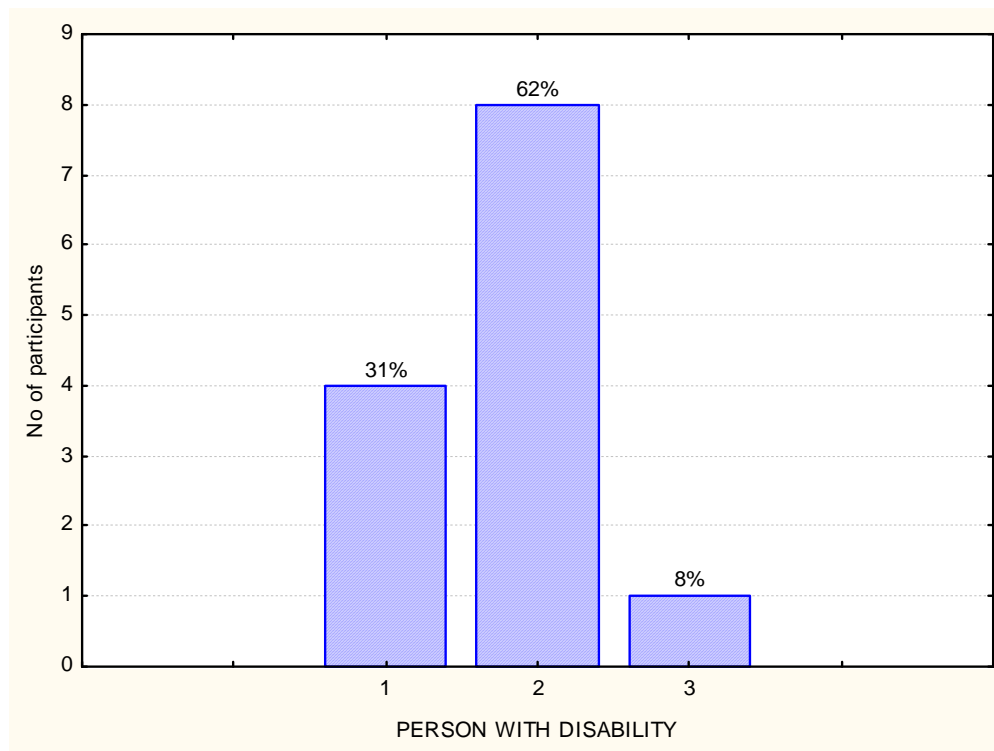


FIGURE 16- PARTICIPANTS' VIEWS OF THEMSELVES AS DISABLED

KEY: X- AXIS: 1=NOT SATISFIED; 2=SATISFIED; 3=VERY SATISFIED

It was found that, as employees with disabilities, 23% (n=3) of the study population expressed that they were not satisfied (see Figure 15) while 31% (n=4) were not satisfied when viewing themselves purely as a person with a disability (see Figure 16).

Evidently, higher percentages were yielded when participants considered themselves as employees than when they were considering themselves purely as a person with a disability (see Figures 15 and 16). For this study population it can therefore be concluded that being employed contributed positively to the participants' SWL.

It must also be noted that the general situation regarding employment in the SANDF currently is a difficult one which few individuals are entirely satisfied with. Therefore these figures might have looked different in an improved work environment.

Participants were questioned with regards to their level of satisfaction in different life roles (some of which were discussed above) as well as specific facets of life such as decision-making, episodes of depression, ability to cope with stress, thoughts about their disability, "discouragement with life" and "satisfaction with family life".

When participants were questioned about how their impairments were affecting their different life roles and more specifically how it impacted on their jobs, the results as depicted in Figure 17 below were obtained.

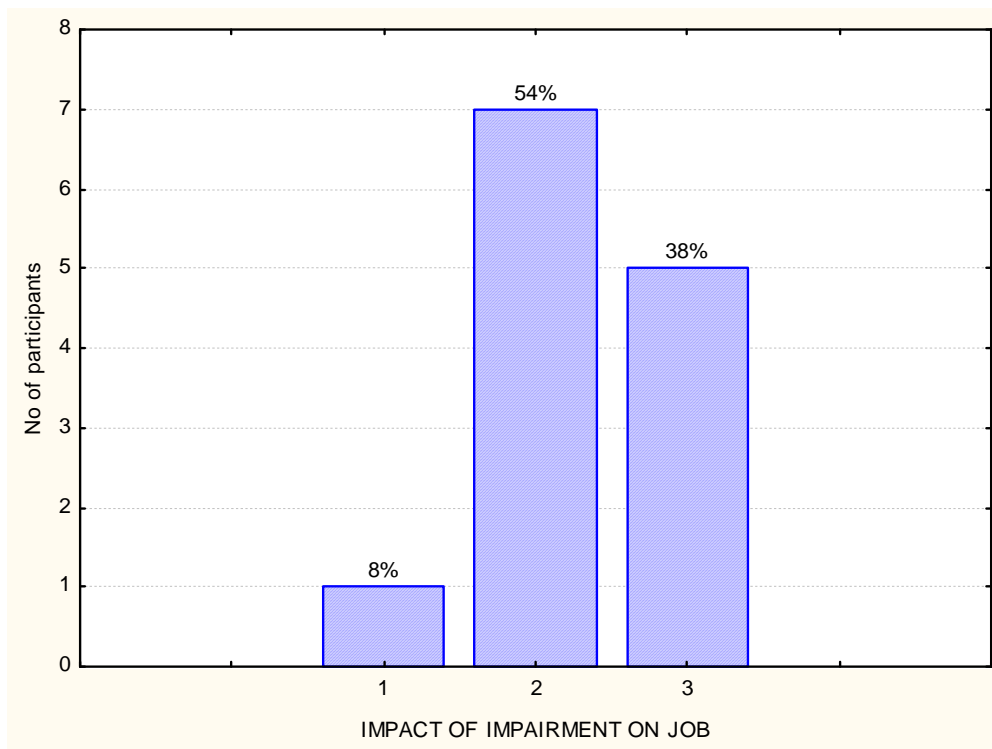


FIGURE 17: FREQUENCY OF IMPAIRMENT AFFECTING PARTICIPANTS' JOBS

KEY: X-AXIS: 1 =ALWAYS; 2 =SOMETIMES; 3 =NEVER

Fifty-four percent (n=7) of participants indicated that their impairments sometimes affected their jobs whilst 38% (n=5) felt that it never did.

Participants' satisfaction with their different life roles were compared with their rating of how often their disability affected different aspects of their lives such as their interests,

sex life, social life and occupation. Sixty-nine percent (n=9) felt that it sometimes affected their social life while 31% (n=4) felt it never did. Fifty-four percent (n=7) of participants indicated that their impairment sometimes affected their sex lives, 23% (n=3) felt it never did and 23% (n=3) indicated that it always caused difficulties.

On investigating their satisfaction with life roles as spouses and parents respectively (for those where it was applicable), it was found that 33% (n=4) of participants was not satisfied with their life role as a spouse while 33% (n=4) was very satisfied. As parents, 17% (n=2) felt that they were not satisfied while 17% (n=2) indicated that they were very satisfied. The spectrum of results could be indicative of the individuality of each participant and his/her circumstances.

Having seen how their disabilities affect different life roles, the researcher found it necessary to investigate how much the participants blamed themselves for the injury.

Figure 18 indicates how often participants attach self-blame to their disabilities.

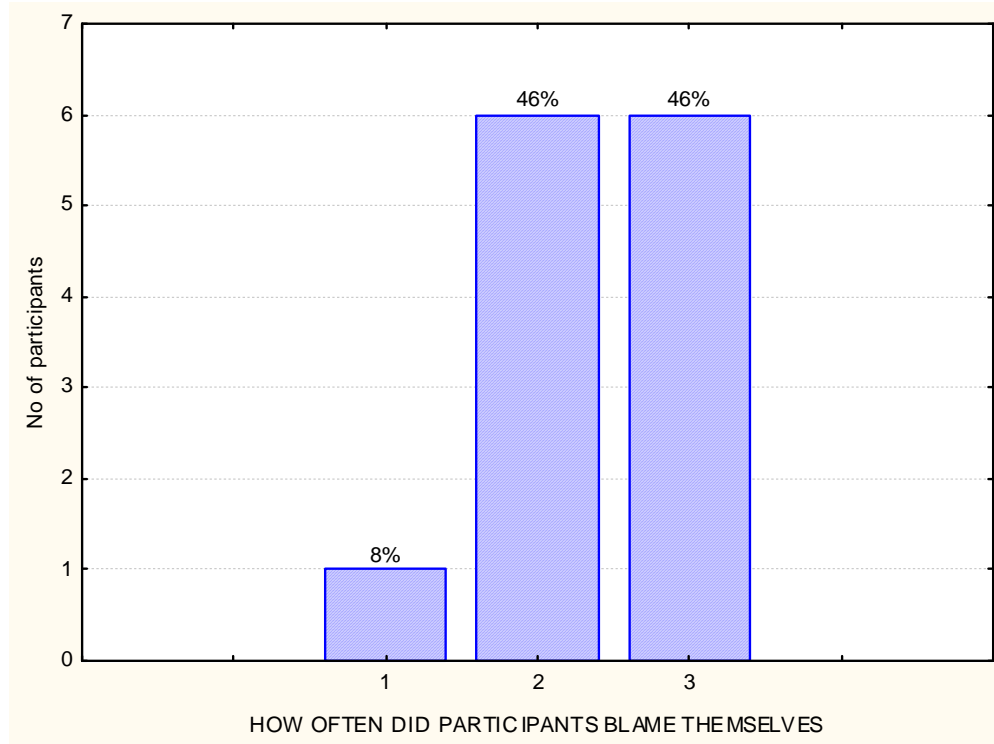


FIGURE 18: FREQUENCY OF PARTICIPANTS BLAMING THEMSELVES FOR THEIR DISABILITY

KEY: X- AXIS: 1 =ALWAYS; 2 =SOMETIMES; 3 =NEVER

This element of self-blame is often seen as a stumbling block to acceptance of the disability (Tucker, 1980). Schulz and Decker (1985), on the contrary, differentiate between the level of self-blame the individual experiences and state that those who blamed themselves and did not feel that they could have avoided their accidents, were seen to cope well. Self-blame is also seen to influence SWL and QOL.

This study found that the percentage of individuals who blamed themselves for the disability was relatively low as was the percentage of individuals who had low SWL and

QOL. Literature on this issue was thus substantiated in this study and is substantiated by a comparison of Figures 13 and 14 with Figure 18. These figures show that 8% (n=1) of individuals indicated a satisfactory QOL (as opposed to good and excellent) and 8% (n=1) indicated that they always blamed themselves for their disability. On comparison of Figures 14 and 18 it is also evident that 8% (n=1) of participants strongly disagreed that they were satisfied with their present lives. This is in keeping with the finding that 8% (n=1) of participants indicated that they always blamed themselves for their disability. The association can thus be made for this study population, but must be verified for other and on bigger population groups.

The relation of participants who blamed themselves, was compared to the frequency with which participants became irritable with themselves. The results showed that the largest percentage 46% (n=6) of individuals never or only sometimes blamed themselves and similarly, a large percentage 38% (n=5) of participants felt that they never became irritable with themselves (data extracted from study findings). These findings must be supported in future studies.

If participants attached self-blame to their disability, the researcher was interested to see how many of them would have wanted to change the situation by changing their lives. A final depiction is given of the response levels of participants to the question regarding their desire to change life if they could re-live it in Figure 19 below.

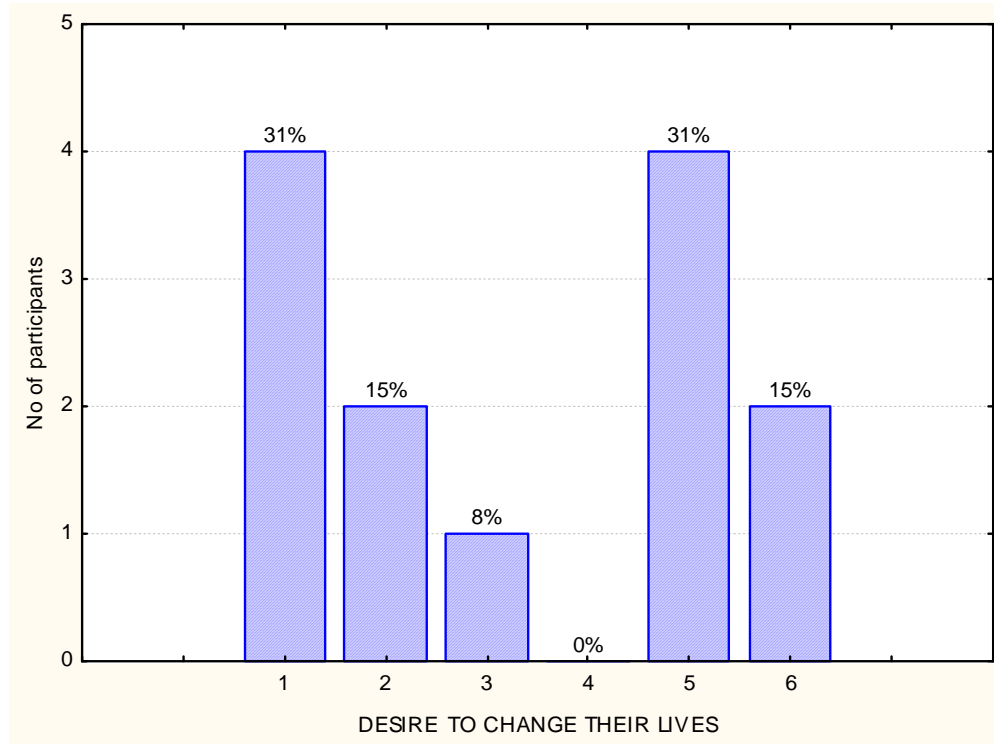


FIGURE 19: PARTICIPANTS WANTING TO CHANGE THEIR LIVES

KEY: X-AXIS: 1= STRONGLY DISAGREE, 2= DISAGREE; 3= SLIGHTLY DISAGREE; 4 =SLIGHTLY AGREE; 5 =AGREE; 6 =STRONGLY AGREE

While 31% (n=4) of participants indicated that they would change nothing in their lives if they were to live their lives over, 15% (n=2) indicated that they would want to make changes (see Figure 19). Participants were not specific as to what they would want to change. The researcher did not request that these changes be specified but did explore

other aspects in open-ended, qualitative questions. The findings are discussed in section 4.5 which follows.

4.5 THEMES EMERGING FROM RESPONSES TO OPEN ENDED QUESTIONS

As mentioned earlier, the study was explorative in nature using a self-compiled questionnaire that included both quantitative and qualitative questions. Results yielded from quantitative questions have been discussed above.

The qualitative questions were included both to ensure that all the participants had a common/similar point of reference for the definitions of key terms in the study and to clarify the quantitative results. These furthermore allowed the participants to air their views without being bound by choices. Overall, it was noticed that the participants were more comfortable when answering close-ended questions and tended to be overly brief in their response to the open-ended questions. This hesitation by the majority of participants has been attributed to the fact that the participants were familiar with the researcher and because the interview was conducted in English as observed during the interviews by the researcher.

It was expected of the participants to define the two key terms in the study, viz. “emotional support” and “depression” from their own point of reference. Although many of the definitions provided were vague, participants commonly referred to their support systems in their definitions. Figure 1 shows the language distribution of participants in the study. The use of languages other than English was seen to influence the ability of participants to define these concepts. The definitions of these key terms used by the

researcher are provided in the introductory section of this chapter. Further detail around this theme is discussed in section 4.5.1 below. In addition, participants were asked to give advice to others undergoing rehabilitation to ease the process for them and to comment on the need for improvement of services in the rehabilitation unit. The researcher concluded the interview by allowing time for participants to make additional comments.

Participants' responses reflected much about coping skills and rehabilitation services. These are discussed in more detail in sections 4.5.2 and 4.5.3.

4.5.1 SUPPORT SYSTEMS

In defining "emotional support" and "depression", many participants described emotional support as support from people who loved them and understood their frustrations. Their general definitions of depression included the use of the words 'feeling down' and 'feeling low'. All except one participant indicated that he did not know what depression was. Only one participant mentioned suicide in the description of the consequences of depression. The concept of empathy became evident in one participant's definition of emotional support and was elaborated on/further supported in another's mention of the dislike for the term "shame" which he viewed as not being supportive. Furthermore, participants spoke of coping skills as discussed in section 4.5.2.

4.5.2 COPING SKILLS

These skills became evident mainly in their advice to other rehabilitating individuals. Most commonly mentioned issues were those of “perseverance” and “spirituality”.

4.5.2.1 Perseverance

“Make peace with the fact that your life is not going to be as before and work towards the future.” This statement by one of the participants, echoed the sentiment in many of the responses. “Begin as if you are starting a new life.” These two statements, amongst others, support the general theme of perseverance with SCI individuals seeing themselves as embarking on a new life journey. A third concept that was evident was that of “belief in self”. Many participants emphasised the importance of believing in yourself. While this was a positive message, it was impossible to miss the fact that many of them believed in the possibility of miracles. This led to the identification of another theme centred around spirituality to be discussed in section 4.5.2.2: Spirituality and miracles.

4.5.2.2 Spirituality and miracles

Many advised that while one needed to work hard at rehabilitation and a new life and future, one also needed to believe that the possibility existed of proving

professionals wrong. The following quotation confirms this statement: “My advice is that you must not take advice from the doctors because the doctors will just tell you that you cannot stand up from your chair”. The integrity of professionals was not challenged but mere hopefulness was expressed.

Tying in with this hope for miracles, the importance of spiritual or religious belief became evident. The following quotation expresses this connection aptly: “To believe in the Lord strongly, to believe that He can do the impossible and make it possible, to have faith that He can move mountains”. These two quotations clearly emphasised the concept of belief in self and religious faith or faith in a superior being with hope for recovery. Having given this advice, participants still tended to emphasize their need for communicating to facilitate the rehabilitation. These findings is in keeping with literature findings on the positive effect of spirituality.

4.5.3 REHABILITATION SERVICES

Whilst the interview was mainly conducted around the set questionnaire, the researcher used the open-ended questions to allow the participant to contribute freely without being restricted by structured questions. Apart from this encouraging active partnership between service provider and the participant, it allowed the fulfilment of the objective focussed around use of research findings to contribute to the integration of emotional

support in rehabilitation programmes for SCI individuals in the military as a standard procedure.

One participant indicated that staff turnover was too high when trying to cope with his disability. He indicated the need not to have to familiarise yourself with too many new faces at such a time in your life. This was described as overwhelming when coming to terms with one's limitations. Another participant who expressed hope at recovery in the future, indicated the need of SCI individuals in rehabilitation to constantly communicate, although not specifying what communication meant to him. One participant emphasised his constant communication with others, expressing to them the high value he attached to his wheelchair without which he felt that PWD would be lost.

Other participants indicated the importance of adhering to the advice from HCP to facilitate the rehabilitation process. Another participant felt that the programme needed to include more relaxation periods to provide distraction from the constant thoughts of disability.

Three other participants highlighted the communication between doctors, nurses and patients. The general feelings expressed was that these HCP needed to be more considerate of patients' complaints even though the participants did acknowledge that some patients could be described as "lazy" and unmotivated. In this regard they felt that nurses should differentiate better between genuine complaints of discomfort or pain and not generalise that all patients are lazy.

4.6 SUMMARY OF RESULTS

Despite the fact that not all participants were able to clearly express themselves in response to the open-ended questions, which asked them to define terms such as depression, the responses provided valuable information. Participants' difficulty with defining terms was attributed to English not being their first language. Evidence of similar research is not readily obtainable.

The study population comprised 85% (n=11) paraplegics and 15% (n=2) tetraplegics (see Figure 6). Sixty-two percent (n=8) was married and 31% (n=4) single, with 8% (n=1) divorced (see Figure 5). Ninety-two percent (n=12) indicated favourable (good and excellent) QOL (see Figure 13) and 77% (n=10) agreed that their SWL (see Figure 14) was good.

Fifty-four percent (n=7) indicated that they carried some degree of blame (they always or sometimes blamed themselves) for the accident and disability (see Figure 18). Furthermore, 15% (n=2) indicated that they would want to change some element of their lives if they could live it over again (see Figure 19).

Only 8% (n=1) rated QOL and SWL as low (see Figures 13 and 14). Eighty-five percent (n=11) indicated that adequate emotional support was offered during rehabilitation and that they were satisfied with the general support received (see Figure 11). Similarly the

bulk of participants was satisfied with their lives and would not change things if they could. However, in order to obtain a more comprehensive answer to this question, the findings of the entire study needs to be seen in perspective and one must bear in mind that open-ended questions revealed dissatisfaction with certain services, as discussed earlier. Furthermore, the element of self-blame was present in some responses possibly influencing the participants' ability to utilise the emotional support as others did.

It can be deduced from the results and the emotions expressed by participants during interviews that they felt emotional support was an important element in rehabilitation and that it did impact on their long-term QOL and SWL. While a large percentage of the study population felt that emotional support was adequate and part of the rehabilitation service offered to members of the SANDF, there were others who felt that this service could be improved. The detailed discussion in this chapter gives an idea of the feelings of the participants regarding emotional support and their perceptions thereof. It was good to see that the participants were able to suggest areas needing improvement, the details of which became evident to the reader in this chapter.

Having discussed the study results, Chapter 5 will serve as a summary of the study.

CHAPTER 5

SUMMARY AND CONCLUSION

Chapters 1 to 4 highlighted the nature of the study, the literature underpinning the study, the methodology used and the results yielded. Having presented this to the reader, Chapter 5 concludes this document with a brief summary.

5.1 IMPLICATIONS OF THE STUDY

The primary objectives of the study were:

- To determine the demographic details of the participants.
- To assess the perceived quality of life and satisfaction with living of the participants after their discharge and return to work.
- To analyse the gathered data for relationships between emotional support received during the in- patient rehabilitation phase and quality of life and satisfaction with living after discharge.
- To use research findings to contribute to the integration of emotional support in rehabilitation programmes for SCI individuals in the military environment as standard procedure.
- To share findings of the study with other similar rehabilitation units.

The study population has been explained as comprising of SCI individuals re-employed in the SANDF after their rehabilitation.

Literature findings indicate a difference in the coping skills used by male and female SCI individuals (Dijkers, 1999). This study population comprised 92% male participants making the investigation of this phenomenon difficult. Furthermore, although literature by Chase (2000) suggests that married individuals have greater support systems, this finding was not confirmed in the study. These discrepancies between literature and the study findings could be the result of the limitations of the study.

While much literature regarding different aspects of the researched topic was researched, not all significant associations in the study correlated with that suggested by the literature. Chapter 4 familiarises the reader with significant associations made in the study.

Having addressed the study objectives, the research findings indicated a significant association between QOL and the availability of emotional support during rehabilitation for this particular study population ($p=0.0497$). No statistical correlation could, however, be proven between SWL and the emotional support received during rehabilitation ($p=0.52054$).

Further interpretation of data yielded a significant association between the age of participants and their ratings of their SWL, where it was evident that employees in the

age group 25 and older expressed greater satisfaction with their lives than those under 25. Chapter 4 gives the reader more detail in this regard.

Chapter 4 also includes detailed discussion of the opinions and feelings expressed by participants regarding the rehabilitation service received.

The unit where the study was conducted routinely holds family meetings during the course of the rehabilitation. The purpose of these meetings is to brief the families and patients about the aims and objectives of the rehabilitation programme, familiarise them with different staff members and their different roles and encourage the family to become an active part of the rehabilitation process. Despite these routine meetings, the element of role confusion was evident when participants answered open-ended questions. Participants showed a degree of confusion regarding the role of each professional in their rehabilitation.

The implications of this have been discussed in further detail in Chapter 4. Open-ended questions focused mainly on definitions of the basic concepts of the study, yet participants often were hesitant to respond to these. The limitations of the study are discussed in section 5.2 below.

5.2 LIMITATIONS OF THE STUDY

- The study was conducted with a very limited population and in a “unique” setting (a military environment). The results can consequently not be generalised without further investigations,
- All of the participants except one were male, preventing the researcher from making any gender-related deductions since the ratio was not proportional. One must, however, realise that the study population is a realistic reflection of a military environment where most members are male,
- The “time since their injury” differed from participant to participant. This could possibly have influenced their current experiences of SWL and QOL. It could be argued that SWL increases over time as a person with a disability improves,
- It was not established whether any of the participants had suffered from depression or related conditions pre-morbidly. A pre-morbid tendency towards these diseases could slant results,
- No distinction was made between persons with traumatic and non-traumatic injuries to study possible differences in adjustment and QOL and SWL.
- The morale of SANDF employees was generally low at the time of conducting the study. It may thus influence the response of the SCI individual negatively in their response to questioning regarding satisfaction of their role as employee/worker.

- The researcher was known to the participants. This could have prevented them from responding honestly and completely openly. It must, however, be taken into account that the researcher opted to conduct the interviews personally based on initial experiences during the pilot study where participants were reluctant to respond to most questions and were not keen to participate in the study. It was concluded that the reluctance stemmed from the fact that the participants in the pilot study did not know the researcher. This deduction is based on the fact that most participants in the pilot study agreed to participate when approached by a HCP known to them but when the researcher contacted them, showed reluctance. It was thus decided to conduct the interviews with the study population personally as they knew the researcher.
- Not all participants were of the same culture or educational background which could be considered an influencing factor owing to the fact that the less educated individual may find self expression (when providing definition of requested terms) a daunting task and may often neglect to respond to these questions.
- Not all questions were formulated to give the participant an indication of which time period he/she should be reflecting on. The questionnaire was mainly focussed on happenings before and after the injury rather than on a specific time after the injury.
- The fact that the researcher gave the participants the choice of being interviewed or completing the questionnaire by themselves could influence

reliability negatively. Participants who completed the questionnaire independently may have interpreted questions differently since questions were explained on request during the interviews.

- The questionnaire was not culture sensitive in its request for information regarding sexual relationships and partner satisfaction. This may in some cultures address topics that are preferably not discussed with ‘outsiders’.

5.3 RECOMMENDATIONS FOR THE MULTIDISCIPLINARY TEAM & HCP:

Based on the findings of the study, the following recommendations are made:

- i) An introductory session should be held with the SCI individual on admission to the unit to clarify the services available and the roles of each HCP.
- ii) The team should approach other units in the hospital (e.g. the intensive care unit) to indicate that it may be necessary for a member of the rehabilitation team to initially be present when the nature of the injury is explained to the SCI individual for the first time.
- iii) All HCPs on the rehabilitation team should become more aware of the need for emotional support as an indirect element of all treatment.
- iv) An evaluation form should be designed by the rehabilitation unit for completion by the SCI individual on discharge. This will allow the team to rate the quality of service and support rendered. It would also identify those individuals who have a need for continued support post discharge.

- v) Many participants reported that nursing staff sometimes showed a lack of empathy. The implementation of an introductory session on admission can also help avoid this impression of the nursing staff's attitude by clarifying the practices and expectations of SCI individuals in the rehabilitation unit at the outset.
- vi) Bearing in mind that this study was conducted in a very small population, it would be useful to execute the same study in units where conditions are similar and later units that are very different. This would allow teams to evaluate the effect that their intervention style has on their patients.
- vii) As family members were identified as the most constant source of emotional support, they should be encouraged by the team to maintain involvement whilst at the same time acquaint themselves with techniques to maintain their health as well.

5.4 RECOMMENDATIONS FOR FURTHER RESEARCH:

- i) Further research comparing the opinions of patients and staff regarding the topic would be useful in guiding staff to recognise the strengths and weaknesses of their service delivery.

- ii) Another associated topic for discussion on this subject could be the comparison of staff working in units where patients report a more emotionally supportive environment to those where emotional support is still primarily lacking.

5.4 IN CONCLUSION

The findings of this research study will be presented to the rehabilitation team at 2MH and further recommendations will be invited from the team members to attempt the implementation of an improved service delivery to SCI individuals encompassing a programme in which emotional support is an integrated part. The researcher furthermore intends to publish an article in a rehabilitation journal regarding the key issues and findings of the study. The research findings will also be presented to the study population with a view of involving them in the rehabilitation process as peer councillors in future.

In addition, the researcher also intends to suggest the implementation of these recommendations at 2MH as a 'pilot' programme with the aim of expanding it to other rehabilitation units in the future. Once fully implemented and running over a period of some time a research project of a similar nature must be done to assess its effectiveness.

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APPENDIX A

SECTION A - DEMOGRAPHIC DETAIL

PLEASE INDICATE YOUR ANSWER BY PLACING A TICK IN THE APPROPRIATE BLOCK BELOW

1. Which age group do you belong to:

- 18-25 26-35 36-50 51-55

2. First language:

- English Afrikaans Xhosa Other If other, specify.....

3. Marital Status:

- Single Married Divorced Living Together

4. Race:

- Black White Coloured Asian Other

If Other, Specify

5. Arm of Service:

- SA Army SA Air force SA Navy
 SAMHS MPO VPA SAP

6. Type of Housing:

- Private Military Housing Informal Settlement Other

If other, Specify

7. Religion/ Spirituality

8. Please write down your lesion of SCI (eg. T6 ,C5)

9. Date of Injury

10. Who was the first to inform you about the nature of your injury?

(Please tick the appropriate block/s)

- Family Peers /other patients Therapists
 Doctors Nurses Psychology Other

If other, Please Specify.....

SECTION B:

11. Explain 'emotional support' as you understand it.

.....
.....
.....
.....

12. What does depression mean to you?

.....
.....
.....

PLEASE TICK THE APPROPRIATE BLOCK

13. Was the news about your injury related to you in a supportive manner?

- Yes No

14. Were any of the members of your support system present when you were informed of the nature of your injury for the first time?

- Yes No

15. Did you have sufficient 'emotional support' from the rehabilitation team when the nature of your injury was explained to you? YES NO

16. Were you offered a peer counsellor (a session with another person with a similar injury as yourself) during rehabilitation? YES NO

If YES, what did you find more comfortable?

Relating to a peer Relating to a professional

17. What was the most constant source of 'emotional support' during your rehabilitation?

Family *Peers /other patients* *Therapists* *Doctors*
 Nurses *Psychology* *Other*

If other, Please Specify _____

18. Rate the 'emotional support' you received during rehabilitation

Excellent Good Satisfactory Poor

19. Which service/s in the rehabilitation unit do you think needs improvement regarding offering of emotional support?

Ward Doctors *Nursing* *Social Work* *Psychology*
 Physiotherapy *Occupational Therapy* *Biokinetics*
 Dieticians *Chaplains* *Other*

If other, please specify _____

20. Why do you think this improvement is necessary?

.....

21. Rate the general support you received (eg. Nursing, Work related matters, Social matters)

- Excellent Good Satisfactory Poor

PLEASE INDICATE YOUR PERSONAL OPINION BY TICKING THE APPROPRIATE BLOCK BELOW:

22. Since discharge, I have:

- had good relationships and support from at least one family member/ friend.
 received limited support from family and friends
 received support from family/ friends only when necessary
 received no support

23. After the injury, relationships with partners have been :

- impossible
 satisfying for my partner only
 satisfying for me only
 very good
 I have not had a partner since the injury

24. Since the injury, I make:

- Fewer decisions regarding my life and household than before
 the same amount of decisions as before
 decisions are made for me by others without my input.

25. After the accident, how often do you feel depressed?
- Never
 - Sometimes (at least once a month)
 - All the time
 - As often as before the accident
 - More often than before the accident
26. How well do you cope with everyday stress?
- Not well
 - Well enough to avoid depression
 - Very well
 - Better than before the accident
 - As well as before the accident
27. How often do you think about your disability?
- All the time
 - Only when others remind me of it
 - Only when obstacles arise
 - Only when people stare at me
 - Never
28. How often do you feel discouraged about life?
- Never
 - When I need assistance with personal care (eg bathing, toileting)
 - All the time
 - As often as before the injury
 - More often than before the injury

29. How satisfied are you with family life (relations with spouse, partner, siblings, parents,etc) after the injury in comparison to before the injury?

- Very satisfied
 Satisfied
 Not satisfied
 I do not have any family life/ not applicable

30. Rate your quality of life after the injury (Your idea of what your overall life is like)

- Excellent Good Satisfactory Poor

31. As a person with a disability, I feel :

- Very Satisfied Satisfied Not Satisfied

32. As a spouse I feel:

- Very Satisfied Satisfied Not Satisfied Not applicable

33. As a sibling, I feel:

- Very Satisfied Satisfied Not Satisfied Not applicable

34. As a parent, I feel:

- Very Satisfied Satisfied Not Satisfied Not applicable

35. As a friend, I feel:

- Very Satisfied Satisfied Not Satisfied Not applicable

36. As an employee (a worker), I feel:

- Very Satisfied Satisfied Not Satisfied

37. Things are getting me down after the injury
 Sometimes Always Never
38. I feel lonely even when I'm in company
 Sometimes Always Never
39. My impairment is affecting my job
 Sometimes Always Never
40. My impairment is affecting my social life
 Sometimes Always Never
41. My impairment is affecting my interest, sport or hobbies
 Sometimes Always Never
42. My impairment is affecting my sex life
 Sometimes Always Never
43. I blame myself for the injury
 Sometimes Always Never
44. I feel that people stare at me
 Sometimes Always Never
45. I have lost interest in my appearance
 Not at all All together
46. I received sexual counselling during my rehabilitation
 Not at all Only briefly Yes, it was adequate

47. After the injury, people still consider me an adult.
 Sometimes Always Only when I stand up for myself
 Never
48. I isolate (avoid contact with) myself from family/ friends
 Often Most of the time Occasionally Never
 As much as before the injury More than before the injury
49. I am impatient or irritable with myself
 Often Most of the time Occasionally Never
 As much as before the injury More than before the injury
50. I still enjoy the same things as before the accident
 Mostly Not as much as before As much as before Not at all
51. I feel that there is no change in my appearance
 Yes No Not Really
52. I feel that the change in my appearance is minor
 Yes No
53. My appearance bothers me but I remain active
 Yes No Most of the time
54. I feel significantly disfigured and as a result I limit my activities
 Yes No Most of the time
55. I avoid people due to my appearance
 Yes No Most of the time

56. In most ways my life after the accident is close to ideal
 Strongly Disagree Disagree Slightly Disagree
 Strongly Agree Agree Slightly Agree
57. The conditions of my life after the accident are excellent
 Strongly Disagree Disagree Slightly Disagree
 Strongly Agree Agree Slightly Agree
58. I am satisfied with life as it is now
 Strongly Disagree Disagree Slightly Disagree
 Strongly Agree Agree Slightly Agree
59. So far I have gotten the most important things I want in life after the accident
 Strongly Disagree Disagree Slightly Disagree
 Strongly Agree Agree Slightly Agree
60. If I could live my life over, I would change almost nothing
 Strongly Disagree Disagree Slightly Disagree
 Strongly Agree Agree Slightly Agree

BRIEFLY ANSWER THE QUESTIONS BELOW

61. What advice would you give to other patients undergoing rehabilitation to make it easier for them?

.....
.....
.....
.....

62. What suggestions would you like to make to the rehabilitation team regarding improvement of services?

.....
.....
.....
.....

63. Additional Comments

.....
.....
.....
.....

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE IN THE INTEREST OF IMPROVED REHABILITATION!!!

APPENDIX B**PARTICIPANTS CONSENT FORM**

I, hereby consent to participate in the study as explained to me. I understand that the study is investigating the “impact of ‘emotional support’ during rehabilitation of Spinal Cord Injured individuals on ‘Satisfaction with Living’ and ‘Quality of Life’.

It has been explained to me that:

- I am not compelled to participate in the study.
- I may withdraw from the study at any time without any obligation.
- I am not compelled to answer any questions I do not wish to answer.
- all information which I may divulge during this study will be confidential.
- I may request that the questions be translated into Afrikaans or Xhosa for me should this aid my understanding thereof.
- I may request a scribe (nominate any other to write my answers as I instruct) should I be unable to physically complete the questionnaire.
- The results of this study is intended to improve understanding and approach of rehabilitationists towards their patients.
- No payment (financial or other) is due to me for participation.

Signed on

Translator used YES NO

If a translator has been used, please indicate

Name of Translator.....

Translated into: AFRIKAANS ENGLISH

Scriber Used YES NO

Name of Scriber.....

WITNESS NAME:.....

I, the above signed hereby confirm that the above named participant has been informed of the conditions of the study and that they have consented to use of the above signed translator and/ or scriber where applicable.

APPENDIX C

STATEMENT BY THE RESEARCHER

I, Shabnim Parker hereby confirm that,

- I have explained information in this document to
- I have made myself available to answer any questions or uncertainties he/ she may have.
- The conversation was conducted in English / Afrikaans.
- The participant chose to use a translator / no translator & a scribe / no scribe.

Signed at..... on

Researcher (S. Parker)

Witness

IMPORTANT:

Dear Participant, Thank you for your participation in this study. Your co-operation is appreciated. Please contact me should you have any queries or uncertainties arising from the study at:

(021) 7996301/ 6420 (w) or
0828640550 (cell)

Thank you

(Ms) Shabnim Parker