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Life after spinal cord injury in South African rugby: Carer and the injured individual perspective

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Life after spinal cord injury in South African rugby: Carer and the injured individual perspective.

Joshua Sandler

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Physiotherapy

Johannesburg, 2015

DECLARATION

I, Joshua Sandler, declare that this research report is my own work. It is being submitted for the degree of Master of Science in Physiotherapy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

_____

Joshua Sandler

_____ day of _____ 2015

Dedication

To my fiancé and family for all their love and support and for helping me through this process. To my boss Richard Feher for making this all possible for me.

Abstract

Introduction

Spinal cord injuries (SCI) are infrequent in rugby, however, the implications of such injuries are catastrophic and far reaching. These injuries not only affect the individual who sustains the injury but also their families, their caregivers, their community and the economy. The affected individual and their caregivers' quality of life can be negatively affected by SCI. The effect of SCI on individuals and their caregivers has not been established in South Africa before. The main aim of this study was therefore to establish the quality of life (QOL) of rugby players and their caregivers post SCI. The specific objectives were to describe the demographic details for individuals who suffered a SCI while playing rugby, to determine the individuals' QOL and their level of community re-integration post SCI. The study also sought to establish if a relationship exists between community re-integration and QOL following SCI. Lastly the study sought to determine the quality of life and the strain on the caregiver caring for an individual post SCI that was sustained during rugby.

Method

A nationwide survey was performed using questionnaires that were sent to individuals who sustained SCI while playing rugby and their caregivers. The questionnaires were sent either via the postal service or were completed online using Survey Monkey. The questionnaires that were used in this study were: a demographic questionnaire, the WHOQOL-BREF, the Modified Reintegration to Normal Living Index and the Modified Caregiver Strain Index. The questionnaires were self-administered.

Results

The decades that accounted for the most spinal cord injuries were the 1980's and 1990's. The mean age at time of injury was 20.3 (± 5) years, the spinal levels most commonly affected were the C_4-C_6, the positions that the SCIs most commonly occurred were the prop (32%) and the hooker (29%). The majority of SCIs occurred at school boy rugby level (48%). Individuals with SCI and their carers had impaired QOL, with the carers scoring worse than the SCI individuals, 243.8(±48.1) and 238.3(±54.9) respectively. The sample experienced a fairly good reintegration back

in to the community with a mean score of 75.7 (± 16.0). The QOL for the SCI individual had a positive correlation with the community reintegration they experienced ($r = 0.65$, $p<0.001$) .The carers in this study experienced a moderate level of strain with a mean score 9.1 (± 4.6).

Conclusion

Both the SCI individuals and their carers experience an impaired QOL post SCI in rugby. It is important to incorporate both the SCI individuals and their carers into the rehabilitation process to improve QOL and community reintegration. The reintegration for this sample was fairly good and the positive correlation between QOL and level of community re-integration emphasises the importance of optimising the rehabilitation process. The carers in this study experienced moderate strain, the rehabilitation process should address the source of caregiving stress to ensure optimal QOL for both the caregiver and the SCI individual.

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Chapter 1

1. Background and Need

1.1 Introduction

Rugby is a full contact sport and as with all contact sports there is a risk of injury. When focussing on injuries associated with the sport, one doesn't immediately think of spinal cord injuries (SCI). As stated by Fuller (2008), even though rugby has a high risk of injuries it actually has a relatively low risk of fatal and catastrophic ones. When you also consider the number of individuals playing rugby worldwide, the frequency of SCIs is low (Quarrie et al., 2002). Various studies have identified the prevalence of these injuries and the various factors that are associated with these injuries (Hermanus et al., 2010; Dunn and van der Spuy, 2010; Bohu et al., 2009; Fuller et al., 2008; Berry et al., 2006; Carmody et al., 2005; Haylen, 2004; Quarrie et al., 2002). From these and many other studies, invaluable data was collected and various prevention programmes were initiated worldwide to reduce the incidence of SCIs in rugby.

When SCIs occur in rugby the most commonly affected area is the cervical spine at the levels of $C_{4\text{-}6}$ (Berry et al., 2006, Quarrie et al., 2002). Considering that an injury to the spinal cord at these levels would leave the individual with head, neck, shoulder and minimal upper limb movement, these injuries leave the individuals severely disabled and more often than not, wheelchair bound for life (Dunn and van der Spuy, 2010). Spinal cord injuries are thus the leading cause of morbidity and mortality in rugby (Hermanus et al., 2010).

Those who survive these catastrophic injuries will have to face many potential physical, psychological and social consequences for the rest of their lives (Kennedy et al., 2006). These individuals will have to manage the potential physical complications such as urinary tract infections, pressure sores, contractures, fractures, and many other life threatening complications such as autonomic dysreflexia (Mckinley et al.,1999). Along with these physical complications, are the possible psychosocial consequences of the injury, namely anxiety and depression (Hoffman et al., 2011; Kennedy et al., 2006; Faber, 2005), loss of independence

(Franceschini et al., 2003), unemployment (Boschen et al., 2003; Krause et al., 1999), inadequate re-integration and participation in the community (Carpenter et al., 2007; Scelza et al., 2007).

When assessing the consequences of a SCI holistically, one can't just focus on the individual but have to consider their caregivers as well. Caring for an incapacitated individual can worsen health; impair social and family life and increase stress, anxiety and depression (Jones and Peters, 1992). The percentage of caregivers that present with depression symptoms may be as high as that observed among persons with SCI (Dreer et al., 2007). With this in mind, one has to identify the strain experienced by their caregivers and family members when determining the quality of life (QOL) post SCI (Dreer et al., 2007; Rees et al., 2001and Jones and Peters, 1992).

1.2 Problem Statement

While there is some literature on the prevalence, incidence or survival rates post SCI in rugby, there is virtually no information about how these injuries impact on the lives of the individuals that sustain these injuries. It is important for us to establish the QOL of these individuals and their carers. According to the World Health Organisation (WHO), appropriate and effective rehabilitation for disabled individuals must focus on all the different domains of the International Classification of Functioning, Health and Disability (ICF). By applying this definition to rehabilitation, one should ensure community re-integration and optimal QOL for the individual and their carers. We need to address the dearth of literature on the functioning and QOL of these individuals and their families post SCI.

1.3 Research Question

What is the QOL of rugby players and their caregivers post SCI?

1.4 Aim of study

The aim of this study was to establish the QOL of rugby players and their caregivers post SCI.

1.4.1 Objectives of the study

The objectives for this study were to:

- describe the demographic details for individuals who suffered SCI while playing rugby.
- determine the QOL for the individual that sustained SCI while playing rugby.
- determine the level of community re-integration for the individual who sustained SCI while playing rugby.
- establish if a relationship exists between community re-integration and QOL following SCI that was sustained while playing rugby.
- determine the quality of life of and the strain on the caregiver caring for an individual post SCI while playing rugby.

1.5 Significance of study

In 2006, a prevention programme named BokSmart was started to address the high incidence of head, neck and SCIs in South African rugby. As vital as this prevention programme is, it is important to not only focus on decreasing the incidence of these injuries but also to optimise the QOL of those who have already sustained the injury. This study identified the QOL post SCI for the individual and their caregivers. By doing this study, one can see if enough is being done for these individuals post injury and if not, the study may highlight some of the measures that should be taken into consideration to improve their QOL.

Chapter 2

2. Literature Review

2.1 Introduction

The purpose of this literature review is to have a more in depth understanding of SCIs in rugby and what the implications are of these injuries, on the individual and their carer. This literature review will look at current literature that identifies the prevalence and incidence of SCIs in rugby in South Africa and compare it to other rugby playing nations worldwide. It will also look at life after the SCI, firstly looking at the QOL and community reintegration of the SCI sufferer, secondly the life of the carer, focussing on their QOL and the strain they experience. The majority of the articles are from the last 10 years (2004-2014) however various relevant studies that are older have been included (from the late 1990s). The articles were identified mostly using Scopus and collected via the University of Witwatersrand electronic database. The key words used were: spinal cord injuries in rugby, incidence and prevalence of SCI in rugby, financial implications following SCI, QOL following a SCI, QOL and community reintegration, community reintegration following a SCI, employment and SCI, marital status and SCI, QOL of carers, QOL of carers of neurological patients, caregiver strain for carers of neurological patients, caregiver strain and SCI, CSI and QOL.

2.2 Spinal cord injuries in rugby

Worldwide rugby is the third most popular full contact team sport (Kaplan et al., 2008). As in all contact sports there is a risk of sustaining an injury when participating however rugby has been noted as having a relatively high risk when compared to other sports (Fuller 2008; Shelly et al., 2006). Of these injuries spinal cord injuries (SCIs) are the most catastrophic that can be sustained by the players and can cause permanent disability or even death (Shelly et al., 2006). When considering the number of individuals playing rugby globally, the frequency of SCIs is relatively low (Kuster et al., 2012; Fuller, 2008; Quarrie et al., 2007; Berry et al., 2006; Quarrie et al., 2002). Regardless of the frequency, the effects of such a catastrophic injury can have devastating ramifications not only on the individual but

also their carers, family members and their communities (Ning et al., 2011; Quarrie et al., 2007; Berry et al., 2006; Carmody et al., 2005; Quarrie et al., 2002)

Spinal cord injuries that occur in rugby are largely traumatic in nature. A traumatic SCI can be defined as " the occurrence of an acute, traumatic lesion of neural elements in the spinal canal (spinal cord and cauda equina) resulting in temporary or permanent sensory deficit, motor deficit or bladder/bowel dysfunction"(Ning et al., 2011) .

When looking at SCI in rugby, the majority occur in the cervical spine (Zahir & Ludwig, 2010; Hermanus et al., 2010; Banerjee et al., 2004; Quarrie et al., 2002). It can therefore be stated that a "catastrophic cervical spine injury can be defined as a structural distortion of the cervical spinal column associated with actual or potential damage to the spinal cord"(Banerjee et al., 2004).

2.2.1 Cervical spine anatomy and susceptibility to injuries

Clinically the portion of the spine most commonly injured and that is most vulnerable or susceptible to SCI in sport is the cervical spine (Dennison et al., 2012; Kuster et al., 2012; Ning et al., 2011; Carll et al., 2010; Hermanus et al., 2010; Zahir and Ludwig, 2010; Kaplan et al., 2008; Shelly et al., 2006; Banerjee et al., 2004).

The cervical spine is the most mobile region of the spinal column. It is at its most stable in the lordotic position. In this position forces can be evenly distributed through the paraspinal neck muscles and the ligaments (Zahir and Ludwig, 2010).

The cervical spine is made up of seven vertebrae and can be conceptually divided into an upper and lower region. These two regions differ in function and anatomical structure (Banerjee et al., 2004). The upper region consists of the occiput and the first two cervical vertebrae. The atlantooccipital joint plays a major role with movement in the sagittal plane. This joint is where approximately 40% of all cervical flexion-extension and 5º-10º of lateral flexion occurs (Banerjee et al., 2004). The next joint in the upper cervical spine, the atlantoaxial joint/complex, is responsible for about 60% of the cervical rotation. The lower portion is thus made up of vertebrae C_3-C_7 and this region is where the remaining arc of movement occurs (Banerjee et al., 2004).

The figure below illustrates the anatomy of the cervical spine and the cervical vertebrae.

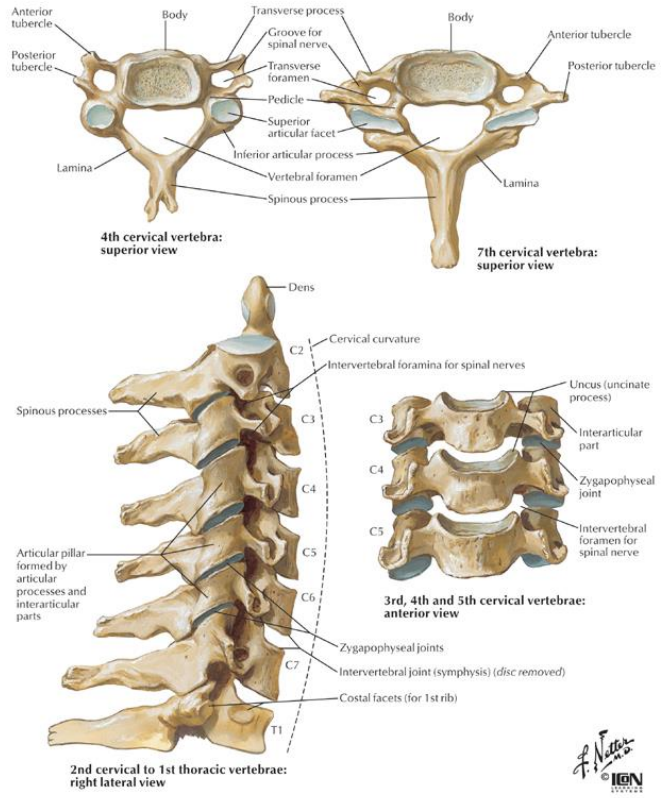


Figure 1.1: Cervical spine and vertebrae (Netter, 2003).

Certain features of the cervical spine have been identified in literature to be the causes of the high risk of injury to this area of the spine. Research by Secin et al. (1999) and Shelly et al. (2006) indicate why the cervical spine is at such a high risk of injury when compared to the rest of spinal column. The studies showed that the cervical spine was at a high risk or susceptibility to injury due to certain anatomical structures or features in this region. These features will now be discussed. Firstly it was identified that the cervical spine(c-spine) has greater mobility than other sections of the spine, with greater mobility can come lesser stability. Banerjee et al. (2004) stated that the c-spine derives most of its stability from the anterior spinal elements (vertebral bodies and the intervertebral discs). This agrees with Secin et al.'s (1999) observations that due to the vertebrae having smaller vertebral bodies, they would be less stable than vertebrae at lower levels that have larger vertebral bodies.

The articular facets in the cervical spine are also more obliquely angled when compared to the more stable vertical facet joints of the thoracic and lumbar spine (Secin et al., 1999). The weaker muscle protection in the cervical region also offers less dynamic stability than for instance the larger trunk muscles (for the lumbar spine) that add to the stability lower down the spine. Lastly the relative mobility of the unsupported head on the cervical spine, makes this region essentially a highly mobile column with a large weight on the end of it, thus predisposing the region to a higher risk than lower levels (Shelly et al., 2006; Secin et al., 1999).

Anatomically as one moves down the cervical spine, namely from C_4-C_7 the diameter of the spinal cord gradually increases however the diameter of the spinal canal reduces. At these lower levels the spinal cord occupies normally about 75% of the spinal canal (Parke, 1988). Thus there is an increased risk of spinal cord damage at these levels due to stenosis when someone suffers a traumatic spinal cord injury. Considering the anatomy, it is then no surprise that research has confirmed that the most common levels of SCI in rugby are between C_4 and C_6 (Dennison et al., 2012; Kuster et al., 2012; Ning et al., 2011; Hermanus et al., 2010; Zahir & Ludwig, 2010; Kaplan et al., 2008; Shelly et al., 2006).

When considering that the levels C_4-C_6 are the most common injured levels in a traumatic SCI in rugby, the implications of such an injury are catastrophic. Depending on the severity of the injury the outcomes can vary, the individual could die due the SCI or suffer severe permanent or temporary disability (Dennison et al., 2012; Kuster et al., 2012; Dunn & van der Spuy, 2010; Hermanus et al., 2010; Shelly et al., 2006; Quarrie et al., 2002). If the individual survives, the SCI could cause loss of motor control, sensation, bladder and bowel control and often is associated with pain experienced by the patient (Dennison et al., 2012). In the long term SCIs have also been associated with unemployment, depression, divorce, substance abuse and even suicide (Dennison et al., 2012; Krause and Anson, 1996). If one suffers a complete SCI at these levels they would be only left with head, neck and little to no movement in the upper limbs, thus leaving them unable to care for themselves and thus being dependant on a carer to aid them with their activities of daily living (ADLs).

2.3 Incidence of SCI in rugby

When one considers the large number of individuals playing rugby worldwide, catastrophic SCIs are relatively infrequent however the effects of each individual injury are catastrophic (Zahir and Ludwig, 2010; Berry et al., 2006).

To quantify risk associated with a specific activity, the Health and Safety Executive (HSE) of the United Kingdom (UK) defined norms for participation in such activities (Kuster et al., 2012). Under this framework, they defined certain levels of risk in different ranges as per number of events per 100 000. Using this framework, the average incidence of SCI in rugby worldwide would fall under a tolerable risk of 2-100/100 000 (Kuster et al., 2012). Literature shows that incidence rates for catastrophic SCI in rugby worldwide range from 0.8-13/100 000 (Dennison et al., 2012).

Fuller et al. (2008) looked at the average incidence of SCIs in various countries from the available literature, he identified the following average: Australia 4.4/100 000 (1976-2002), New Zealand 4.2 / 100 000 (1976-2005), Ireland 0.89 /100 000 (1995-2004), England 0.8/100 000, Argentina 1.9 /100 000 (1977-1997) and Fiji 13/100 000 (1997, limited records for Fiji). Across all countries in their study the average was 4.6 /100 000. This figure is however the average over many decades and recently the number has decreased.

More recently Quarrie et al. (2007) highlighted that, in New Zealand rugby, the incidence of SCIs from scrums and other phases of play improved from the years 1996-2000 where the figures were 1.4 and 1.3/100 000 respectively to 0.2 and 1.1 /100 000 in 2001-2005. In total an average incidence in New Zealand since 2001, was 0.7/ 100 000 per annum (Quarrie et al., 2007).

In South Africa, Brown at al. (2013), indicated that between the years of 2008-2011, the incidence of SCIs in South African rugby was 1.04/ 100 000. Hermanus et al. (2010) indicated that South Africa had an incidence of about 0.6/100 000 between the years of 2001-2005 and 0,9 /100 000 between 1991-2000. These low figures however are most likely not an accurate value as there was no formal register for SCIs consistently throughout these years mentioned. The value is slightly higher when using Brown et al. (2013)’s figure of 1.04/100 000 which is most likely the most

accurate number. South Africa falls under the ‘acceptable’ level of risk according to the HSE UK’s framework. Considering that there is an estimated 651146 (Brown et al., 2013) rugby players at junior and senior level in South Africa and using the incidence of 1.04/100 000, it means that there is a bout six SCIs per annum in South African rugby. This is a relatively low figure when compared to the number of players in SA. However for those affected by these injuries, these statistics mean nothing.

Carmody et al. (2005) showed the average incidence of SCIs in rugby in Australia between the years of 1997-2002 to be 3.2/100 000. Berry et al. (2006) looked specifically at the number of SCIs in New South Wales. They highlighted that the figure for just this district was for the years 1986-1991, 9.2/100 000 and between the years 1995-2003, it was 6.8/ 100 000. These figures indicate a relatively high incidence of SCI in this specific state in Australia, when compared to the entire country’s statistics as per Carmody et al. (2005).

Carll et al. (2010) indicated that SCIs in French rugby diminished between the years 1996-2006 from 2.1/ 100 000 to 1.4/100 000 while Secin et al. (1999) identified the average incidence between 1977-1997 in Argentinean rugby to be only 0.9/ 100 000, which is less than one per year.

So worldwide it can be seen that all major rugby playing nations fall under the tolerable (2-100 /100 000) or acceptable (0.1-2 /100 000) levels of risk associated with catastrophic SCI in rugby. These injuries are thus rare. However this takes nothing away from the catastrophic effects they have for the individual, their families and their communities.

In rugby, these catastrophic SCIs occur on average to individuals in their early to mid-twenties (Patel et al., 2013; Kuster et al., 2012; Carll et al., 2010; Dunn & van der Spuy, 2010; Hermanus et al., 2010; Shelly et al., 2006; Banerjee et al., 2004; Quarrie et al., 2002). This means the individual has to live the majority of their lives as a disabled person. This can have serious implications not only on the individual but also the families and their communities. The effects of such an injury are not just physical; they are psychological, emotional and can incur enormous economic costs on the individual and community (Dennison et al., 2012; Kuster et al., 2012; Ning et al., 2011; Berry et al., 2006; Jackson et al., 2004; Quarrie et al., 2002).

2.4 Factors that influence spinal cord injuries in rugby

2.4.1 Playing position

With regards to the position, the hooker has been shown in literature to be at the greatest risk of sustaining a SCI (Carll et al., 2010; Hermanus et al., 2010; Kaplan et al., 2008; Quarrie et al., 2002; Secin et al., 1999). As earlier stated in the clinical anatomy portion of this paper, the cervical spine is at its most stable position in a lordotic position. When flexed the cervical spine loses this stability and is more susceptible to injury. In the case of a scrum, the front row can experience forces up to 1.5 tons when it engages their opponents (Kaplan et al., 2008). That means that the flexed cervical spine can experience forces that well exceed those required to cause damage to the vertebral body (4500N) or ligaments (2000N) of the cervical spine (Kaplan et al., 2008). It is thus no surprise that during the 1970s and 80s when the highest incidences of SCIs were noted worldwide, that the scrum was the phase of play responsible for the most SCI in rugby (Dennison et al., 2012; Quarrie et al., 2002). Due to recent law changes with regards to the scrum a shift has occurred where less SCI occur in this phase of play and now the majority occur during a tackle situation (Dennison et al., 2012; Hermanus et al., 2010; Quarrie et al., 2002). Due to this shift in phase of play, a larger spectrum of player positions has been recorded as sustaining a SCI. Even with this shift, forwards are still at greater risk than back line players and the hooker position still has the greatest risk of sustaining such an injury (Dennison et al., 2012; Carll et al., 2010; Hermanus et al., 2010; Kaplan et al., 2008; Quarrie et al., 2002).

2.4.2 Phase of play

Up until recently, when rules were changed with regard to the scrummage, South Africa and Ireland seemed to differ compared to Argentina, Australia and New Zealand in terms of the phase of play where the most SCIs occurred.

Argentina, Australia and New Zealand seemed to follow the trend that scrumming accounted for a larger percentage of SCIs while South Africa and Ireland have identified that tackling was their leading cause of SCI in rugby even prior to the law changes (Hermanus et al., 2010; Quarrie et al., 2007; Shelly et al., 2006; Berry et al., 2006; Quarrie et al., 2002; Secin et al., 1999).

Kuster et al. (2012) highlighted through their research that prior to the year 2000, the majority of SCIs in rugby occurred through scrummage however post the year 2000, tackling and open play rugby had now become the more common phase of play where they occurred. South Africa and Ireland seemed to be the only two nations that differed from this.

In their study, Hermanus et al. (2010) looked at SCI in rugby in South Africa from 1980-2007. The study showed that tackling accounted for 45% of the SCIs identified in this period while scrumming accounted for 37%. In a study done in the Western Cape, Noakes et al. (1999) analysed SCI at school boy level in the Western Cape since 1990. The study identified that 67 cases of adult and school boy SCI occurred in this period. Adult injuries accounted for 80% of the SCI (n= 54). They identified that tackling accounted for 52% of all the adults and school boys injured, rucks and mauls 25% and scrumming accounted for 23%. Similarly Dunn and van der Spuy (2010) looked at SCIs in Western Cape over a 5 year period (2003-2008) and also identified that tackles accounted for 52%, scrumming for 37% and rucks and mauls 7%.

In Ireland, Shelly et al. (2006) did a 10 year review (1995-2004) that identified only 12 SCIs in Irish rugby. Of these twelve, 8 were due to tackles, 2 occurred in scrums and 2 in rucks and mauls. Therefore 66% was due to tackling and 17% from scrums, rucks and mauls.

In contrast Argentina seems to have more injuries due to scrumming. Secin et al. (1999) did a 20 year (1977-1997) review of SCI in Argentinean rugby. They identified 18 cases of SCI in the 20 years. Of these 18, 11 were due to scrumming, 5 from tackles and 2 from mauls. That's 61% from scrumming while only 28% from tackles and 11% due to mauls. No studies could be found on more recent statistics for Argentina.

In Australia, Berry et al. (2006) highlighted that there was a higher incidence of SCI due to scrumming (35%) than in tackles (29%) for injuries that occurred between the years1986-2003. Unfortunately this study mainly looked at injuries in New South Wales. Carmody et al. (2005) confirmed that in Australia scrumming was the leading cause of SCIs in rugby union. The study identified through records that from rugby union and rugby league, 70 SCIs occurred in Australia from 1960-2003. From the

years 1960-1985, scrumming was responsible for 65% of the SCIs that occurred. From 1986-1996 it was responsible for 47% of the SCIs. However from 1996-2003, no SCIs due to scrummaging occurred in rugby league, they did account for 86% (six out of the seven) SCIs that occurred in rugby union. Studies could not be found that showed more recent values.

Finally in New Zealand, Quarrie et al. (2007) identified through records that in the period 1976-2005, there were 77 permanently disabling SCIs that occurred in New Zealand rugby. They showed that in the years 1976-2000, the scrum accounted for 48% (33/69), tackling 36% (25/69). Their study highlighted an interesting statistic from the International Rugby Board that the number of scrums per game from the 1980s until 2005 had dropped from an average of 31 to 19 per game thus decreasing the exposure to this phase of play. This decreased exposure to scrumming and the new law changes, has led to tackling becoming the leading phase of play where these injuries occur. From the year 2001 to 2005, tackling was responsible for 87.5% (7/8) of the SCIs while scrumming was only responsible for 12.5% (1/8).

It can be concluded that with law changes, prevention programs worldwide and decreased number of scrums per game there has been a decrease in SCIs due to scrumming. Unfortunately with the rise of SCIs occurring in other phases of play especially tackling, these catastrophic injuries are still occurring annually and the numbers remain relatively constant.

2.5 Mechanism of spinal cord injury in rugby

The mechanism of injury often depends on the phase of play that the injury occurred in. This literature review will look at the different phases and the mechanism of the injury for each phase.

a) Scrum related injuries

Prior to the year 2000, when scrumming was the leading cause of spinal cord injuries in rugby (Kuster et al., 2012; Quarrie et al., 2002), it was hypothesised that hyperflexion was the most common cause of SCI in rugby (Kuster et al., 2012; Kaplan et al., 2008; Quarrie et al., 2007; Shelly et al., 2006). When a player sustains

a SCI in a scrum, the mechanism of injury is either due to hyperflexion with or without rotation, as in the case of a scrum collapse or due to hyperextension on engagement of a scrum (Kuster et al., 2012;Kaplan et al., 2008; Quarrie et al., 2007; Shelly et al., 2006). There seems to be general agreement in literature that the most common cause in a scrum injury is due the hyperflexion thus supporting the hypothesis (Kuster et al., 2012; Carll et al., 2010; Kaplan et al., 2008; Shelly et al., 2006;Quarrie et al., 2002).

Shelly et al. (2006) performed a 10 year review of SCIs in Irish rugby. They found that hyperflexion injuries were the most common and that they also presented with a poorer neurological outcome when compared to those who sustained hyperextension injuries.

Hyperflexion can be defined as “an isolated flexion (single planar) force facilitating rapid forward movement of the head onto the torso thereby exceeding the normal anatomical range of 90º” (Kuster et al., 2012). This hyperflexion injury thus often leads to facet dislocation, namely bilateral facet dislocations (Dennison et al., 2012). Further analysis of these hyperflexion injuries is provided by Dennison et al. (2012). They identified through ex vivo spine investigations that the trauma to the spine “results in the facet joint contact and ramping of the superior facet up the inferior facet which results in distraction and flexion of the intervertebral joint and ultimately, facet joint dislocation”.

The above still holds true today for players that are injured during a scrum situation. However, due to the shift in phase of play where the SCIs are occurring, there is little consensus in the literature what the leading mechanism of injury is when a player sustains an injury when tackled or in open play (Carll et al., 2010; Quarrie et al., 2007).

b) Tackling injuries

In a systematic review performed to identify the leading mechanism of injury in modern rugby Kuster et al. (2012) identified that previously, prior to 2000, the hypeflexion hypothesis was a generally accepted notion as the most prevalent mechanism of injury. Since 2000 though, the game of rugby and its laws has changed and thus the phase of play that accounts for the most SCIs has also

changed. Tackling is now the leading cause of said injuries. Kuster et al. (2012) believe, from their findings, that buckling of the cervical spine, due to axial forces experienced in a tackling situation, is now the leading mechanism of injury in SCI in rugby. "Buckling is characterised by superior to inferior motion of the head while the neck assumes a c-shape (axial/ first order buckling) or a serpentine profile (second order buckling)" (Dennison et al., 2012).

Banerjee et al. (2004) described how the cervical spine, when slightly flexed responds to an axial load by buckling. This is due the force being transferred directly though the vertebrae as opposed to the surrounding muscles and ligaments as it would in a neutral lordotic position. This was confirmed through cadaveric studies that showed that cervical spine when in the straightened position and is in line with the applied load, responds by buckling (Banerjee et al., 2004).

Buckling has been shown to be a possible mechanism of injury in the tackling phase (either in a spear tackle situation or through a conventional tackle; that results in axial forces being experienced through the head and neck). Dennison et al. (2012) however highlighted that there is no in vivo studies that can prove that buckling occurs in the same manner in vivo as it does ex vivo. Studies have shown the effects of axial loading on the ex vivo spine, however, none have been identified to prove what is occurring in vivo (Dennison et al., 2012). Thus due to the inadequate research backing Kuster et al. (2012) that buckling is the leading cause of SCI in rugby today, one cannot write-off the hypothesis that hyperflexion is still the leading mechanism of injury.

There is no consensus to the exact mechanism of injury during this phase of play however there is a large amount of research highlighting that tackling is now the most common phase of play where SCIs occur (Dunn and van der Spuy, 2010; Hermanus et al., 2010; Kaplan et al., 2008; Quarrie et al., 2007; Shelly et al., 2006; Carmody et al., 2005; Quarrie et al., 2002).

c) Rucks and mauls

Very little research has been done on the exact mechanism of injury in these two phases of play; however, Scher (1983) identified the three possible ways a player could sustain a SCI in these phases of play. They were: "forced flexion of the ball

carrier's neck, forced flexion of the neck of the player at the bottom of the ruck and head and neck injury caused by charging into a mass of struggling players."

As can be seen above, the exact mechanism of injury depends on the phase of play that the injury is sustained in. Even though there is no consensus on the most common mechanism of injury, the majority of the literature shows that hyperflexion is still the leading cause of SCI in rugby.

2.6 Implications of Spinal Cord Injuries among Rugby Players

2.6.1 Financial implications

It is estimated that estimated that lifetime costs of a quadriplegic injured in their twenties could add up to $A 5 million (Australian dollars), which is about R45 million (Berry et al., 2006). These figures agree with Kuster et al. (2012)'s estimates when they said the lifetime costs of a twenty year old who became a quadriplegic in the late 1990s were around $2-3 million (±R20-30 million). In general agreement with the high costs post SCI in rugby players, Dennison et al. (2012) estimated the lifetime costs to be approximately $2,9 million (±R29 million). As can be seen the costs associated with such an injury are enormous and this in itself could add a huge strain on the individual and their families.

2.6.2 Quality of life following a SCI

Quality of life (QOL) is said to be the ultimate goal and one of the most important measures when determining the success of the rehabilitation process for disabled individuals (Chang et al., 2012; Sakakibara et al., 2012; Hammell, 2004). The World Health Organisation (WHO) defines this concept as "an individual's perceptions of their position in life in the context of their culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (Chang et al., 2012). From this definition, it is clear that QOL is a difficult concept to measure as every person will have a different perception of what QOL is to them. QOL is a subjective concept and thus is very difficult to define in an exact manner. Despite the guidelines provided by the WHO on its definition, to each person the idea of QOL could be seen very differently and it is for this very reason that it is a difficult aspect to study (Ravenek et al., 2012).

What we know from research is that people with SCI do report having a poorer QOL when compared to people without SCI (Sakakibara et al., 2012; Barker et al., 2009; Leduc and Lepage, 2002; Dijkers, 1999; Post et al., 1998). Research by Barker et al. (2009) identified normative values (using the WHOQOL-BREF) for SCI sufferers (n=270) and non SCI sufferers (n=1376) in Australia and compared the results for analysis. The normative values, the mean and (standard deviation), for each domain of the chronic SCI sufferers in Australia were: physical 63(19), psychological 66(18), social relationships 62(22), environmental 70(15) and a total across all domains of 261/400. This was compared to the normative data for non SCI sufferers in Australia which were: physical 80(17), psychological 73(14), social relationships 72 (19), environmental 75(14) and a total across all domains of 300/400. As can be seen in Barker et al. (2009)'s study not only did it identify normative data for the SCI population in Australia but it also identified that SCI sufferers in Australia experience a poorer QOL than non SCI sufferers.

As South Africa is considered a developing country and Australia being a first world country, it is important to also identify normative data of another developing country and see if the results differ. Cruz et al. (2011) identified the normative values, using the WHOQOL-BREF, for the general public of Brazil (non SCI sufferers, n=751). The results identified the following normative values: physical 58.9 (10.5), psychological 65.9 (10.8), social relationships 76.2 (18.8), environmental 59.9 (15.9) and total across all domains 261. As can be seen when comparing the general public of a first world country to a general public of a developing country, the difference in QOL is very significant. Thus the economic strength of the country does also play a factor for the QOL experienced by its population (Sekaran et al., 2010).

Considering that even though QOL has been reported to be poorer for SCI sufferers compared to those without, the scores were not much lower (Dijkers, 1999). Dijkers (1999)'s study identified that the longer a person lived with a SCI the better they rated their QOL. This was attributed to either that their expectations/standards that they judge QOL over time lower or that they have improvements in functional abilities/capabilities (Dijkers, 1999).

2.6.2.1 Factors that influence QOL post SCI

There are various factors that are outlined in research that affect the QOL of individuals post SCI and these include: level of injury/impairment, social support, marital status, self-perceived health, secondary complications experienced, employment, independence, mobility, sexual dysfunction, income and community integration/participation (Geyh et al., 2013; Chang et al., 2012; Pershouse et al., 2012; Sakakibara et al., 2012; van Leeuwen et al., 2010; Carpenter et al., 2007; Hammell, 2004; Whiteneck et al., 2004; McColl et al., 2003; Dijkers,1999).

a) Level of injury and impairment

Interestingly across all the research that was found, all showed little to no statistical association between the level of SCI or impairment and QOL (Chang et al., 2012; Carpenter et al., 2007; Charlifue et al., 2004;Hammell, 2004; McColl et al., 2003; Dijkers, 1999). There is so much disagreement in literature that one study even established that individuals with higher lesions and more severe neurological injuries reported high QOL (Charlifue et al., 2004). Part of this discrepancy could be due to the fact that subjective QOL is more strongly associated/related to participation rather than to impairment or disability (Whiteneck et al., 2004).

Impairment post SCI was shown to have little to no significant impact on overall QOL or even any individual domain other than physical health (Chang et al., 2012). This was further confirmed by McColl et al. (2003) who performed a longitudinal study that looked at aging and SCI. Their study also confirmed the minimal effect of impairment on QOL. Their research showed that those with higher level injuries experienced a feeling that they were aging more quickly than others and thus indirectly affected their outlook on perceived QOL. Interestingly though they showed that the longer one lived with a SCI, regardless of level lesion, a higher life satisfaction score (perceived QOL) was reported. The study also showed that those with a higher level of injury didn't report more health problems as one would expect from a person that has more disability due to a higher lesion.

It has been shown through research that impairment impacts mainly on participation and activities, and that it is mainly through these aspects that it has any indirect effect on QOL (Post & Noreau, 2005; McColl et al., 2003; Dijkers, 1999). This was

further strengthened by Djikers (1999) who in a meta-analysis showed that impairment and QOL had no significant direct relationship.

It can therefore be concluded that impairment/ level of injury does not seem to have a direct effect on QOL post SCI.

b) Social Support

Social support appears to have a significant effect on the QOL of an individual following a SCI (Kawanishi & Greguol, 2013; Sakakibara et al., 2012; Mortenson et al., 2010; Hammell, 2004). In a study that looked at the relationship and predictors of QOL following SCI at 3-15 months post discharge, Mortenson et al. (2010) showed that initially for the first 3 months following a SCI, mood played a major role with regards to QOL. However, as time passed, life experience and acceptance of the injury occurred and mood became less significant and social/family support became one of the major determinants of QOL along with environment. This was supported by Chang et al. (2012)'s finding that social support became a greater determinant at later points following a SCI. In a literature review, Hammell (2004) identified that in both qualitative and quantitative studies, social relationships and social support had positive correlations with QOL.

Social support has to be defined into different types, namely everyday emotional support, esteem support and problem solving support (van Leeuwen et al., 2010). These different forms of support influence life satisfaction in two ways. Firstly the direct effect, that is a more generalised effect on life satisfaction and is irrespective of level of stress the individual experiences (van Leeuwen et al., 2010).The second is the indirect effect or buffer effect, that protects individuals from potentially negative effects of stressful situations. Essentially this buffer effect indicates a greater association between social support and life satisfaction in more stressful situations (van Leeuwen et al., 2010). To simplify this, the greater the amount of stress, the greater the association between these two concepts. The associations that they identified in their study were that emotional everyday social support showed positive effects on life satisfaction and interestingly problem solving support had a negative effect on the individual's life satisfaction. They attributed this negative effect to either unwanted advice or that the support just highlighted to the SCI sufferer how dependent they are on others. They also identified in their study that a more

functionally dependent SCI sufferer will require more social support than a more independent SCI sufferer.

So as can be seen, social support is vital to a SCI sufferer however the right support and at the right time is important to ensure positive effects on the individual's QOL.

c) Marital Status

In a study done to establish the factors that influenced QOL in individuals with SCI, Chang et al. (2012) found marital status to be strong predictor of QOL. This was however contradicted by Mortenson et al. (2010) who found that marital status had no significant effect on QOL. Their study sought to establish factors that influenced QOL following SCI from 3-15 months post discharge. One possible reason for this is because they looked at such a limited time frame and as they stated in their study, social support plays a more vital role in the long term rather than initially. Marital status could perhaps play such a role in the long term.

In a study that focussed on pain following a SCI and the effects on QOL, it was established that marital status was the only characteristic that was identified to be associated with a higher QOL (Wollaars et al., 2007). This was supported by an earlier study by Charlifue and Holicky (1999). Their study looked at 225 long term SCI survivors and found that those that were married suffered from less depression, had greater life satisfaction and psychological well-being as well as a better QOL.

There is more literature where the consensus seems to be that marital status plays a significant role with regards to QOL and life satisfaction (Chang et al., 2012; van Leeuwen et al., 2010; Charlifue et al., 2004; McColl et al., 2003; Charlifue and Holicky, 1999). The only exception was the study by Mortenson et al. (2010) which found no correlation between marriage and QOL.

d) Employment

Being employed has been associated with improved QOL (Sakakibara et al., 2012; Franceschini et al., 2012; Hammell, 2007; Leduc & Lepage, 2002). For a disabled individual, employment is said to be one of the best predictors of independence, life satisfaction and QOL (Franceschini et al., 2012). Reintegration back to paid work is

also said to be one of the most important factors in an individual's reintegration back into society and has been shown to help improve self-worth and functional independence (Schönherr et al., 2004). It is thus an important goal of rehabilitation to assist the individual to return to work.

The majority of individuals who sustain SCI while paying rugby are in their mid-twenties. This therefore means that return to work is not just vital for the individual but also on a larger scale, the economy as a whole (Schönherr et al., 2004).

In a study by Leduc and Lepage (2002) that looked at over 940 people with SCI, they identified that the percentage of those employed is still well below that of the general population. They said it was most likely due to environmental limitations, medical complications, a lack of adequate training and a lack of integration measures.

It was shown in a meta-analysis, that following a SCI, as time passes and one gets older, SCI sufferers report an increased satisfaction with employment and this often compensates for a decreased satisfaction in other aspects of their life as they age, such as social interaction and sex (Sakakibara et al., 2012). Therefore one can deduce that the importance of employment almost increases as one gets older. Considering how young most traumatic spinal cord injuries sufferers in rugby are, this is an important factor to remember.

It was stated that employment enhances QOL for an individual in various ways such as financially, self-esteem, self-worth, improved health and community re-integration (Geyh et al., 2013).

For all health professionals that are involved in the rehabilitation process, it is vital that special efforts are made during the rehabilitation process that help the SCI sufferer to be as employable as possible (Krause & Anson, 1996). This is done by enhancing their skills and abilities and thus improving the employability of the individual.

To conclude, it is clear that being employed is associated with better QOL due to the various impacts it has on the different aspects of SCI sufferers' lives.

2.7 Community Reintegration and Participation post SCI

Dijkers (1998) describes community reintegration as “acquiring/resuming age/gender/culture appropriate roles/statuses including independence/ interdependence in decision making and productive behaviours carried out as a part of multi-varied relationships with family, friends and others in natural community settings”. In agreement, Steins et al. (2002) stated that “community reintegration extends beyond the person, it promotes his/her fullest inclusion and participation within the physical and psychosocial environment.”

There are various slight deviations but one common theme when defining community reintegration. Boschen et al. (2003) stated for “community reintegration to be considered to have occurred, the individuals concerned would be involved in community activities and social roles to the extent that they desire to be.”

Carpenter et al. (2007) further describes it as “the process of becoming part of the mainstream of family and community life, participating in normal roles and responsibilities, and being an active and contributing member of one’s social groups and society as a whole.”

As can be seen from above, that even though the definition may differ slightly, it essentially comes down to reintegrating the individual back into their social society (family and community) to a point that optimises their independence and QOL. It is essentially a similar concept to the construct of participation as defined by the ICF(Carpenter et al., 2007).

Participation in the community/family has been shown to be a strong predictor of perceived QOL (Chang et al., 2012; Post & Noreau, 2005). In the study by Chang et al. (2012) they found that participation was the strongest predictor of perceived QOL. Their unique study looked at factors associated with QOL using the ICF model. Of the different aspects of the ICF, impairment, activities and participation, participation was shown to be the most powerful determinant of QOL.

Data showing the QOL for individuals with SCI is very scarce. A study that was done by May and Warren (2002) that looked at 98 Canadian SCI sufferers and established their level of community reintegration and QOL. The study established that the individuals had a mean score of 23.05 (±13.54), illustrating a poor level of community

reintegration for the sample studied. This study did however look at SCI sufferers of varying ages (21-81 years old) and therefore this could explain the low scores identified in the study.

Following a SCI a person must undergo some major adjustments in their life, especially when it comes to their involvement in the community. Certain factors have been identified that either facilitate or make this process far more difficult for some individuals than others. These barriers are environment (home and community), general health/co-morbidities, depression, transport, access to health facilities, mobility, pain and social support/lack thereof (Ravenek et al., 2012; Silver et al., 2012; Sekaran et al., 2010; Martin et al., 2010; Carpenter et al. 2007; Schönherr et al., 2004; Whiteneck et al., 2004; Sandford et al., 1999).

In this current study, there are some rugby players that sustained a SCI while still at school. A study done by Sandford et al. (1999) that looked at return to school following a SCI, showed that even though architectural and transportation barriers were problematic, they didn't prevent the students returning to school. An important finding that they identified was that if the school was involved early on in the rehabilitation process, it made the transition back to school far easier for the students. This early involvement helped address certain psychosocial and physical barriers that the individuals were facing.

The environment in which the individual goes back to affects the level of community reintegration. A study by Sekaran et al. (2010) sought to establish the level of community reintegration for those with SCI in rural India. They found that, that those with a more severe neurological injury and older in age, demonstrated a decreased community reintegration. Interestingly environmental factors also played quite a significant role in reintegration in this study. They stated, with reference to Whiteneck et al. (2004) that this is very different when compared to research in western countries/ first world countries that show the environment had a much less significant effect on reintegration. Whiteneck et al. (2004) stated that the environment played more of a role with life satisfaction rather than societal reintegration. Various other studies however show that even in western countries, the environment plays a role with regard to community reintegration; namely accessibility and transport (Silver et al., 2012; Carpenter et al., 2007; Schönherr et al., 2004). There therefore appears to

be no consensus whether the environment plays a significant role on community reintegration post SCI, however, more of the literature identified in this review has supported that it actually does play a significant role when it comes to societal reintegration.

In a mixed method study Boschen et al. (2003) used quantitative and qualitative data to identify factors associated with reintegration back into the community following a SCI. They identified that the main factors in their sample of individuals were: social support (support groups, peer mentoring, family support), pain and health management, personalised rehabilitation and post rehabilitation services. These factors were identified to be the areas that the subjects reported to be the most important factors that aided or hindered them in the process of community reintegration. The weakness of this study however was that the participants were self-selected and this could lead to participation bias as they were probably higher functioning SCI sufferers or better adapted to life with a SCI and thus happier at the time of the study.

The role of community reintegration was further supported by Post and Noreau (2005)'s study. They stated in their paper that community reintegration/participation is a major determinant of QOL. They stated that if a physiotherapist focused on optimising the SCI patient's mobility and facilitated the needs required for reintegration back into the community, that they could optimise that individual's QOL.

An Australian study was performed to identify the relationship between disability and QOL across a lifespan of an individual with a SCI. They looked at 270 people that sustained a SCI over the last 60 years. Their results showed that community participation was the second most important predictor for perceived QOL. The most important predictor was the presence of secondary complications (Barker et al., 2009).

It is clear from these studies that community participation and reintegration are major predictors of QOL for individuals with SCI. It is a vital concept that we need to focus on during the rehabilitation of an individual that has sustained a SCI. As has already been highlighted in this literature review, impairment/level of lesion has no significant effect on QOL and hence we can conclude that regardless of the where the injury is or how severe, everyone has the potential for a good QOL.

Post SCI, it is obviously not enough to just focus on the individual. A SCI has a broad effect on the community, the economy and very importantly the carer of the individual (Middleton et al., 2014; Ebrahimzadeh et al., 2013; Chang et al., 2012; Schulz et al., 2009; Manigandan et al., 2000). It wouldn't be proper to complete the literature review without exploring the impact SCI has on the carers.

The carer plays a vital role in the individual's life, assisting them with activities of daily living (ADLs), general health and well-being.

2.8 Caregiver Strain and QOL post SCI

"Caregiver burden/strain is defined as a perception that the individual has in relation to his/her physical health, social life, emotion and status, as a result of caring for a family member/patient, resulting in the concept of burden as the product of a specific, subjective and interpretive process of chronic disease" (Nogueira et al., 2013).

Post SCI, the individual, especially those with tetraplegia/quadriplegia, will require assistance from either a relative or a paid caregiver (Graça et al., 2013). These caregivers will play a vital role in the day to day lives of the SCI sufferer. They will be required to assist with a wide range of services that will include activities of daily living (ADLs), general health and hygiene, ambulation, services that promote independence and emotional support (Graça et al., 2013).

The role of the carer is said to be so important that one could say they are the SCI sufferer's main 'life support' (Ebrahimzadeh et al., 2013). This often leaves a considerable amount of burden/ strain on the carer (Middleton et al., 2014; Peters et al., 2013; Rodakowski et al., 2013; Schulz et al., 2009; Boschen et al., 2005; Unalan et al., 2001; Chan, 2000). Research has shown not only do carers experience a burden/strain, they actually experience a poorer QOL than the general public (Middleton et al., 2014; Ebrahimzadeh et al., 2014; Ebrahimzadeh et al., 2013; Peters et al., 2013; Graça et al., 2013; Rodakowski et al., 2013; Schulz et al., 2009; Dreer et al., 2007; Manigandan et al., 2000).

If the burden that the carer experiences is excessive it can have detrimental effects on their health and well-being, in severe cases it could lead to an emotional breakdown, depression and burnout syndrome (Rodakowski et al., 2013; Schulz et

al., 2009; Boschen et al., 2005; Unalan et al., 2001; Chan, 2000; Manigandan et al., 2000).

This is supported by Manigandan et al. (2000)'s study. Their study looked at the psychological wellbeing of the caregiver of a SCI sufferer. It was shown that 79% of the carers showed signs of psychological distress and that 18,4% of the sample had signs of severe depression, while 47,4% showed signs of borderline depression (Manigandan et al., 2000). They identified that poor level of education was one of the leading causes for their findings. The weakness of this study was that it had a relatively small sample size, they only had 38 caregivers in the study and thus these results might not be representative of the larger population of caregivers.

Interestingly unlike the SCI sufferer whose QOL is not affected by the level of the lesion/severity of the injury, the caregiver's QOL is affected by it. Dreer et al. (2007) showed in their study a link between caregivers caring for individuals with greater disability or higher level of lesion and probable depression status. This finding was also supported by Middleton et al. (2014)'s findings. They identified a link between level of impairment and strain on the carer. They performed a prospective longitudinal cohort study that measured various outcome measures at four different time points, six weeks prior to discharge, six weeks, one year and two years post discharge. Two of the outcome measures they looked at specifically were health related QOL (HRQOL) (using the Short form 36, SF-36) and burden on the carer (using the Caregiver Strain Index, CSI). They identified a link between injury severity and burden on the carer only at the two year post discharge mark.

Similar findings were established by Boschen et al. (2005). They found that severity of injury had an effect on caregivers QOL and integration in society. Both studies by Middleton et al. (2014) and Boschen et al. (2005) stated that it may not have been the direct effect of the severity of the injury that affected the caregivers QOL and strain but rather the implications of the said injury, i.e. the individual with a SCI may have a poor integration into society and this could lead to the carer having a poor integration as well. The more severe impairment could also require more assistance or more time by the caregiver in caring for the individual and thus creating a greater burden on the carer. Post et al. (2005) established that individuals with higher lesions, that were more disabled, required more time for assistance with the ADLs.

This increased support for ADLs was shown to have a strong relationship with the strain/burden on the caregiver. Their study showed that in their group of 265 couples (one member had SCI and the other was the primary caregiver) 24.8 % of the carers reported a high level of burden / strain with the leading factor associated with this burden being the amount of support required for ADLs.

In a study done by Unalan et al. (2001) on the QOL of the primary caregiver of an individual with a SCI, it was established that the caregivers had a significant lower score than the control group. The studied included 50 primary caregivers, these caregivers were then compared to 40 healthy age matched controls. The caregivers scored lower than the control group when reporting their level QOL (according to the SF-36).This illustrates that being a primary caregiver of an individual with SCI interferes significantly with the QOL that they experience. Interestingly, even though the study showed that being a caregiver had negative effects on QOL, their study, unlike other studies, showed there was no relationship with other parameters and QOL of the carer such as severity of injury and secondary complications.

The negative effect caregiving has on QOL was further established in studies by Lucke et al. (2004) and Graca et al. (2013). Lucke et al. (2004) focused on the initial six months following a SCI and Graca et al. (2014) looked at carers who had been caring for their recipients for many years. Their studies showed that feelings of isolation, disappointment, strain, emotional involvement and pain were the leading causes of poor QOL among the caregivers. The main limitation of both studies is that they used small sample sizes and thus the results may not be representative of the caregiver population and care must be taken when generalising these results.

More often than not, the spouse is the primary caregiver. Chan (2000) looked at the effects of a SCI on the spouses of those injured. The study found that the level of stress experienced by the spouse is comparable to that of the injured individual. He showed that this stress can lead to depression and significant strain/ burden on the spouse. He highlighted the different types of coping strategies of the spouse and how this can alter the strain they experience. It is thus important to assist the spouse or carer during the rehabilitation phase with education on how to cope with their new altered life/role. Increased stress, anger, resentment, fatigue, burnout and

depression have all been shown to be experienced by spouses who are the primary caregiver of the disabled individual (Post et al., 2005; Weitzenkamp et al., 1997).

The notion that caregivers are affected in a similar way to the individual with a SCI is also supported by Boschen et al. (2005). Their study showed that 'support providers' of an individual with a SCI present with a low level of community reintegration as a result of the assistance they give the individual. Individuals with a higher level lesion can be more dependent on the support provider and hence the carer may experience a negative effect on their community reintegration. This study identified that burden/ strain is experienced by the support provider and that the QOL of the carer is affected by this. They did however note that support providers seemed to take the greatest strain initially following the discharge of the individual they care for. As time passed, the support providers adapted and developed coping mechanisms and strategies to cope with their role as a support provider. They attributed this to the support provider being unprepared and not educated sufficiently for their role as primary caregiver/ support provider initially. Their study highlighted the importance of support providers/caregivers to be heavily involved in the rehabilitation process, especially from the early days while the individual may still be in a facility. By being more prepared and educated for their roles and assistance with advice for coping strategies, their burden could be lessened and their QOL preserved or even improved.

This is supported by Boschen et al. (2005) as previously stated. Caregivers seem to cope better as time goes by due to developing and learning strategies to cope. Middleton et al. (2014) also agree with this assertion. Their study established that rather than a 'wear and tear hypothesis', the carer actually adapts to their role and that instead of deterioration in health related QOL and psychological distress there is actually improvement. Their study showed that the health related QOL actually improved and psychological distress lowered from the time of discharge to the end of two years. This was most likely due to the caregiver adapting and assimilating to their role as a caregiver. Interestingly though this was not consistent with caregiver strain over the two years. The strain seemed to be relatively consistent and this highlighted the continual challenges faced by the caregiver (Middleton et al., 2014).

Peters et al. (2013) looked at strain and QOL on carers on three neurological disorders, Parkinson's disease, motor neuron disease and multiple sclerosis. Even though this study didn't look at carers of SCI, it highlighted two important observations. The first being, that caregivers reported a lower QOL than the general public/control group and that they experience significant strain due to their roles as carers. Secondly it showed that carers that complained more of problems with health issues and social services were those with a lower QOL and greater strain. This was an interesting finding as it was identified that there was no clear trend for any one disease and that carers were less driven by the disease than by the problems reported by the patient. Schulz et al. (2009) highlighted that it is recognised that caregivers of all chronic illnesses and disability suffer psychiatric and physical morbidity however they believe that a caregiver of an individual with a SCI is at a far greater risk of negative outcomes due to the spectrum of unique challenges they face.

Studies have been done to find ways of improving QOL of the caregivers of SCI individuals. One such study is by Schulz et al. (2009). They performed a randomised control trial to establish ways of improving the QOL of the caregivers of SCI individuals. Their study consisted of 173 carer and recipients dyads. They divided these dyads into three groups randomly. The first would be a caregiver only treatment group in which they received a multicomponent intervention according to their risk profile. The second group, a dual target group, where the carer and the recipient would both receive an intervention that would help manage their risk factors. Finally a third group (control group) for the caregiver only where they would receive a standard print out with information about caregiving for a SCI patient. Over a 12 month period, the dual treatment approach showed significant improvement in QOL, fewer health symptoms and improved social integration not only for the carer but for the dyad as a whole. Interestingly the caregiver only approach showed no significant improvement in QOL or burden. This highlights the fact that in rehabilitation following a SCI, one cannot just treat the SCI sufferer and the caregiver as separate entities but rather as a dyad (a team) with interventions focused on improving QOL and strain for both parties involved.

The concept of looking at the caregiver and the individual with a SCI as a dyad or a single unit rather than individuals is vital in improving the QOL for both involved.

Dreer et al. (2007) identified in their study that the number of caregivers that presented with depression and/or symptoms of depression, paralleled that of the number of individuals with SCI they cared for. This highlights the intricate link between the carer and their recipient.

Social support is an important part of caregiving post SCI. Rodakowski et al. (2013) looked at the effects of social support on the caregiver of an ageing adult with SCI. They noted that as a carer of an ageing individual with a SCI, the caregiver is at a high risk of developing depression or other psychiatric and physical morbidities. If the caregiver develops depression, which not only has serious implications for the carer but it also could directly affect the individual they care for. The depression of the caregiver could potentially affect the participation in daily activities, the general health and the QOL of the one they care for. They showed that it is important to identify factors associated with caregiver depression and to assist the carer in managing and coping with the strains of their job. Along with perceived health status, the two most significant factors associated with caregiver depression, were identified to be negative social interactions and social integration of the carers. They found that carers of ageing SCI sufferers were at risk of suffering the adverse effects of social isolation and lack of support. They also identified various predictors that were associated with depressive symptoms. These predictors were perceived health, negative social interactions, social integration, dyad co-residential status and employment status.

It has been shown that primary caregivers of an individual with SCI present with a lower HRQOL than the average person (Blanes et al., 2007). Carers can spend as much as 11.3 hours of each day caring for the individual with SCI. This can result in chronic illness (Blanes et al., 2007). The physical complaints seem to be more psychosomatic in origin rather than an actual physical illness (Unalan et al., 2001). This is supported by Belasco and Sesso (2002) who observed that caregivers present more with psychopathology rather than actual physical illness. They also added that caregivers report worse health than the general public and make more visits to a physician. The study by Blanes et al. (2007) showed that the carers in their study presented with low HRQOL scores and the two areas of the SF-36 where they scored lowest were bodily pain and vitality being. In this study it can quite clearly be seen that there is a considerable amount of strain on the caregiver and this strain

can manifest in psychopathological symptoms and even physical illness thus lowering the individuals HRQOL. Another study that supports this is Nogueira et al. (2013), where they identified that one of the factors that had a significant correlation with caregiver burden was self-reported disease.

Along with self-reported disease being a significant factor associated with caregiver burden, Nogueira et al. (2013) highlighted three specific areas that were associated with this strain. These were disappointment, general strain and environment, of which environment was the strongest. The environment encompasses accessibility of health care services and the facilitators or barriers in the environment that were related to caring for the patient and those that affected social integration. There is a close link between health, psychological and risk factors and these not only affect the patient but the carer as well. They are a dyad and both parts of the dyad require attention in the rehabilitation phase. Both the patient and the carer's QOL and health must be considered when planning management post discharge from a hospital or rehabilitation clinic post SCI.

2.9 Conclusion

A spinal cord injury is a catastrophic event that affects not just the individual but also their caregivers, their families and their communities. The lives of the caregiver and the individual with SCI are very closely linked and the rehabilitation process must recognise this and focus on both parties and thus treat them as a dyad and not as individuals.

QOL is the ultimate goal of rehabilitation and it is essential to ensure that we focus on QOL for all involved and affected by the SCI. The review showed the close link between community reintegration and QOL for the individual and also their caregiver. It also highlighted the strain/burden experienced by the caregiver and how if guided and helped in their role as a carer that this strain can be managed and by doing so improve their QOL.

CHAPTER 3

3. METHODOLOGY

3.1 Introduction

In this chapter the procedure which was followed to obtain the data and how the data were analysed will be explained. The process used for the validation of the questionnaire as well as the content of the questionnaire will be outlined in detail. The pilot study and how its outcome influenced the method in which the main study was done will be narrated.

3.2 Study design

This research used a quantitative cross sectional design to answer the objectives.

3.3 Study Participants

3.3.1 Source of subjects

This research focussed on patients with traumatic SCI due to injuries sustained while playing rugby and their carers. Participants were sourced from the Chris Burger/Petro Jackson (CBPJ) Foundation. This foundation was founded for players who have sustained SCI while playing rugby. All the beneficiaries of the Chris Burger/Petro Jackson (CBPJ) Foundation and their caregivers were considered for inclusion in the study.

3.3.2 Sample Selection and Size

A sample of convenience was used for this study. All the beneficiaries of the Chris Burger/Petro Jackson (CBPJ) Foundation and their caregivers were considered for inclusion in the study. To date, more than 100 rugby players with SCI are recipients of the CBPJ Foundation and these recipients and their caregivers were considered for recruitment as participants for the study. Those recipients of the CBPJ foundation that fitted the inclusion criteria were used in this study.

3.3.2.1 Inclusion Criteria

Participants were included in the study if they:

- were rugby players who sustained a SCI while playing rugby - either during practice or during a match.
- were recipients of the CBPJ Foundation.
- gave consent to the foundation that they could be used in the study.
- had a primary caregiver who also consented to participating in the study
- were 18 years or older at the time of the study.

3.3.2.2 Exclusion Criteria:

Participants were excluded from the study if:

- they had recently sustained the SCI within the past year (to reduce the risk of psychological strain).
- they were illiterate and hence could not read the questionnaires

3.4 Outcome Measures

i) For Individuals with SCI

To gather data needed to answer the objectives of the study, for the participants that had sustained SCI, the following outcome measures were used:

a) The Modified Reintegration to Normal Living Index

To evaluate the level of community reintegration of the individual who sustained the SCI, the Modified Reintegration to Normal Living Index (mRNLI) was used. (See Appendix A)

Purpose of tool

This tool assesses the degree to which disabled individuals achieve normal reintegration back into their communities (Miller et al., 2011).

Description

The mRNLI is a self-report questionnaire with 11 declarative statements, the questionnaire covers seven domains that include: indoor, community and distance mobility, self-care, daily activities (work and school), recreational and social

activities, family role(s), personal relationships, presentation of self to others and general coping skills (Miller et al., 2011). The first eight items represent 'daily functioning' and the remaining 3 items represent 'perception of self'. Each domain is accompanied by a four point likert scale. The four options in the likert scale are "does not describe me or my situation", “sometimes describes me or my situation”, mostly describes me or my situation” and "fully describes me or my situation". Each domain is scored out of 10. Item scores are summed to provide a total score of 110 points; this score is then transformed to create a score based on 100 points (Miller et al., 2011).

Reliability of the mRNL

Miller et al. (2011) and Daneski et al. (2003) identified that the mRNL is a reliable and valid tool to use when identifying the level of reintegration into the community. The RNLI was developed through a rigorous research procedure. This was done through literature reviews, incorporation of experiences of investigators, and open- and closed-ended questionnaires given to patients with myocardial infarction, cancer, SCIs and other chronic diseases, health professionals, significant others and lay people (Wood-Dauphinee et al., 1988). Limitations however were identified in the original RNLI and thus a modified version called the mRNL was created to improve the readability and to simplify the rating scale (Miller et al., 2011). Alterations modified the way the subject rated their responses, from a visual analogue scale (VAS) one -10cm to a closed ended likert scale. Looking at this research by Wood-Dauphine et al. (1988) and the procedures the researchers underwent, one can assume the content validity of the questionnaire (Miller et al., 2011). Due to the content validity of this index, it is appropriate for the use in this current study.

Research from both Miller et al. (2011) and Daneski et al. (2003) have shown that the mRNL and the RNLI have acceptable and good test retest reliability. It has been shown that the RNLI had an excellent internal consistency, with patients α=0.9 and significant others α= 0.92 (Wood-Dauphinee et al., 1988). Miller et al. (2011) identified that the modifications in phrasing and scoring done to create the mRNL improved the validity and reliability of the index over the original RNLI. Thus making the mRNL an appropriate and valid tool for this current study. This is important to this

study as it indicates the data that will be collected will consistently and accurately represent the degree of community reintegration for the sample being studied.

Choice of tool

This outcome measure is free and easy to use, it requires no training and can be completed in under 10mins. It has been shown to be a valid and a reliable tool, with a higher score indicating a better reintegration into the community. It has also been used in similar studies when looking at QOL of SCI patients.

b) World Health Organisation Quality Of Life- BREF (WHOQOL- BREF)

To assess the QOL of the SCI rugby players, the WHOQOL-BREF was used. (see Appendix B)

Purpose of tool

The WHOQOL- BREF assesses QOL, focusing on the domains that correlate with the definition of QOL as per the WHO. (Introduction, administration, scoring and generic version of the assessment, 1996)

Description

The WHOQOL-BREF is a questionnaire that can be used for any culture and in any country to measure the reported quality of life for an individual. It investigates QOL across six different contexts. QOL is defined “as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” It was developed collaboratively and field-tested across a number of cultural contexts. (Cruz et al., 2011)

Reliability and Validity of the WHOQOL- BREF

It has excellent construct validity and discriminate validity, using a t test $p<0.001$ for all domains except environment $p= 0.022$ (Jang et al., 2004).

The concept of QOL was explored and discussed by 15 culturally diverse field centres and they identified specific areas that should be considered when assessing QOL (Harper, 1996). Through this process the WHOQOL-100 was developed. Due

to the length of this questionnaire, the WHOQOL-group developed a shorter questionnaire based on this original WHOQOL-100. This abridged version was then called WHOQOL-BREF (Cruz et al., 2011).

When compared to the SF-36, the WHOQOL- BREF showed very good internal consistency. Its α value across the domains were as follows: overall QOL and general health 0.79, physical capacity 0.87, physiological well-being 0.83, social relationships 0.85 and environment 0.86 (Lin et al., 2007).

The WHOQOL- BREF also has very good intra-interviewer (ICC= 0.84-0.98) reliability and fair inter-interviewer reliability (ICC= 0.56-0.95) (Lin et al., 2007).

Choice of tool

The WHOQOL- BREF is free to use and requires no training. It has low ceiling and floor values and thus is efficient in identifying differences across the population. When scoring, the higher the score the better the QOL. It has also been tested on SCI patients and has been shown to be an effective outcome measure tool (Lin et al., 2007; Jang et al., 2004).

c) Demographics Questionnaire

A self-designed demographic questionnaire was developed for data collection. This was created mainly to gather demographic data about the individual that had SCI. (see Appendix C)

Description:

The questionnaire was created using information obtained from literature. Common factors that were identified from similar research by Hermanus et al., 2010; Fuller et al., 2008; Kaplan et al., 2008; Shelly et al., 2006 and Quarrie et al., 2002.

The questionnaire sought to collect information on the following:

- Year the injury was sustained
- The level of spinal cord injury

- Their age at the time of the injury
- The level of competition that they were playing in when they sustained the injury
- The positon they were playing in
- Did they receive rehabilitation following the injury
- If they received rehabilitation in a specific facility, the length of time they were there
- Were they currently receiving any form of therapy ie physiotherapy, occupational therapy, psychologist, psychiatrist. If so, how often.
- Were they satisfied with the rehabilitation they received
- Were they employed
- Were they married or living with their partner

To ensure objective and measurable results the questionnaire contained only closed ended questions and allowed for no subjectivity. It contained either yes/no answers, multiple choice or asked for a specific age/date.

To ensure content validity, the questionnaire was given to physiotherapists that have been working with SCI patients for five years or more. They looked at the information in the questionnaire against the intended objectives. Minor changes were done from this process which centred on making the questions less ambiguous.

ii) For caregivers of individuals with SCI

The following outcome instruments were administered on the caregivers:

a) Modified Caregiver strain index

To assess caregiver strain, the Modified Caregiver strain index was used. (see Appendix D)

Purpose of tool:

The purpose of this tool is to determine the level of strain on a caregiver (Sullivan, 2007).

Description:

The Caregiver Strain Index (CSI) is a tool that can be used to measure the strain experienced by carers and family members. It is a 13-question tool that measures the degree of strain that a carer experiences (Sullivan, 2007). There is at least one item for each of the following major domains: Employment, Financial, Physical, Social and Time. A positive response to the questions identifies a greater strain. This tool can be used on any adult/individual that provides care for another adult. The Modified Caregiver Strain Index is, as its name implies, is a modified version of the CSI. This tool was developed in 2003 and like the CSI, the greater the score the greater the strain experienced by the caregiver (Thornton and Travis, 2003; Robinson, 1983).

Validity and reliability:

The CSI has a good internal reliability coefficient (alpha=.90), this is higher than the coefficient originally reported for the CSI in 1983 (alpha=.86) (Thornton and Travis, 2003). Test-retest data collected by Thornton and Travis (2003) indicated a reliability coefficient of .88. This indicates an excellent test retest reliability for the CSI.

Choice of tool:

The Modified CSI has been shown to have a better internal reliability than the original CSI. It's easy and quick to administer and has been shown to be valid and reliable to identify strain on a caregiver.

b) The World Health Organisation Quality Of Life Assessment- BREF (WHOQOL- BREF)

To assess the QOL of the carers, the WHOQOL-BREF was used. This instrument has already been described above. (see Appendix B)

3.5 Procedure:

3.5.1 Pilot study:

A pilot study was done before the commencement of the main study. The objectives of the pilot study were to:

- establish the amount of time it would take to complete the questionnaires
- identify any unforeseen problems/difficulties in completing the questionnaires

3.5.1.1 Methodology of the Pilot Study

The questionnaires were translated into Afrikaans using forward and backward translation. A physiotherapist whose first language was Afrikaans translated the questionnaires into Afrikaans. Once translated, another individual in the health field translated back into English. This was then compared to the original to see if the translation was appropriate. The pilot study was done using two quadriplegic patients, one English and the other Afrikaans, and their carers. Each individual and their carer were asked to complete the questionnaires. Along with completing them they were asked to time how long it took and if they had any difficulty understanding or completing any of the questions.

From the results of this pilot study it was identified that it would take approximately 41 minutes for the SCI sufferer and approximately 17 and a half minutes for the carer to complete the relevant questionnaires. All questions were understood easily and all who undertook the pilot study were able to complete the questionnaires without any problems in comprehension of what was being asked. This showed that no adjustments were required to utilise these questionnaires in the main study.

3.5.2 Main study

Ethical clearance was applied for and granted by the University of the Witwatersrand Ethics Committee for Research on Human Subjects (Ethical clearance no. M121134, see Appendix E). Before commencing the study, written authorisation from the Foundation and the consent from the recipients was sought and received.

From the CBPJ Foundation the addresses, contact information and names of their recipients was sought. The appropriate participants were identified, according to the inclusion and exclusion criteria. These participants were then split into groups of participants that required English questionnaires and those that required Afrikaans questionnaires. They were then sub-divided into sub groups, those with email access and those that required the postal service for delivery of the questionnaires.

As approximately half the participants had access to the internet and email, a web based format for the questionnaires was created. This was done using Survey

Monkey. A web link for each questionnaire was then created and along with the information documents and introductory letter were all sent to their email addresses asking them to click on the link and complete the questionnaires.

For those that required the postal service for delivery of the questionnaires, a pack was sent to them via registered post .The pack contained the following: a letter showing consent from the CBPJ foundation granting permission for the study to use its participants and two envelopes, one for the individual that sustained SCI and the other for the carer. Each envelope contained a basic information document about the study, informed consent documents, a demographic sheet for the individual that sustained SCI and the relevant questionnaires for each person. A self-addressed envelope was also included and both parties placed their sealed envelopes into this one for posting and returned it to the researcher.

For those participants who were not able to complete the forms independently, a carer was required to do this. To ensure confidentiality and to prevent any bias, the carer who filled out these forms could not be the same carer who was being studied and completing the CSI and carer QOL questionnaire.

Correspondence with the participants occurred via email or postage. A blanket reminder to complete and return the questionnaires was sent to everyone after two weeks. Those who had completed the questionnaire were asked to ignore the reminder.

After all possible questionnaires had been returned, data were analysed.

3.6 Ethical considerations:

The study was commenced after receiving ethical clearance from the ethics committee. Participants were told in the information letter that completion of the questionnaire would be deemed as giving their consent to participating in the study. There was anonymity, as there were no identifiers on the questionnaires and there was confidentiality of all participants in the study. This was achieved by ensuring that all data collected was kept confidential and was used for the purpose of the research only.

3.7 Data analysis

Data analysis was done as summarised in the table below:

Table 3.1: Summary of data analysis done to answer study objectives

Study Objective	Type of data collected	Data Analysis
To determine the QOL of the individual post SCI in rugby.	Ordinal data. WHOQOL-BREF scores. Mean scores and standard deviations.	Descriptive statistics with data summarised as means and standard deviations and displayed in tables
To determine the level of community re-integration of the individual post SCI in rugby	Ordinal data. mRNL scores. Mean scores and standard deviations	Descriptive statistics with data summarised as frequencies and percentages and displayed in tables
To establish if a relationship exists between community re-integration and quality of life post SCI.	Ordinal data	A Pearson's correlation test was used to establish if there is relationship between community reintegration and QOL. The significance level was set at $p \leq 0,05$.
To determine the QOL of the caregiver post SCI in rugby.	Ordinal data. WHOQOL-BREF scores. Mean scores and standard deviations.	Descriptive statistics with data summarised as frequencies and percentages and displayed in tables
To determine the level of caregiver strain of the caregiver post SCI in rugby	Ordinal data. CSI scores. Mean scores and standard deviations.	Descriptive statistics with data summarised as frequencies and percentages and displayed in tables

Chapter 4

4. Results

4.1 Introduction

The following chapter will provide the results of the study. The results presentation will follow the objectives of the study.

4.2 Response Rate and Demographics of Study Sample

a) Response rate

Using the study inclusion criteria 70 participants were suitable for inclusion into the study. Of these 70 participants, 38 had access to the internet and the remaining 32 only had access to the postal service. Of these, three participants declined participation in the study. From the resultant sample size of n=67, a return rate of 46% (n=31) was achieved. Of these returned packs, only 33% of them were 100% complete, with all questionnaire of the pack completed and returned. The remaining 13% collected had various questionnaires incomplete/not returned.

b) Demographics of the study sample

The distribution of the demographics of the study sample are shown in Table 4.1 below.

Table 4.1: Distribution of the demographics of the study sample (n = 31)

Descriptor	**Category**	**n (%)**
Year of injury	1960-1970	1 (3)
	1980-1990	10(32)
	1991-2000	11(35)
	2001-2010	7 (23)
	2011-2014	1(3)
	Year not indicated	1 (3)
Level of injury	C_3-C_4	2(6)
	C_4–C_6	21 (68)
	C_6-C_8	8 (26)
Age at time of injury (years)	14 – 18	16 (52)
	19 – 22	8 (26)
	23 – 26	2 (6)
	27 – 29	2 (6)
	30 – 35	2 (6)
	Incomplete	1 (3)
	Mean age and (s.d.)	20.3 (5)
Level of competition	School	15 (48)
	University	4 (13)
	Club	11 (35)
	Provincial	1 (3)
	National team	0
Player position	Prop	10 (32)
	Hooker	9 (29)
	Lock	3 (10)
	Flanker	4 (13)
	8th Man	1 (3)
	1st Centre	2 (6)
	Wing	2 (6)
Length of rehabilitation stay (months)	2 – 5	18 (58)
	6 – 10	5 (16)
	11 – 15	2 (6)
	16 – 20	1 (1)
	Incomplete	5 (16)
	Mean length of rehabilitation (months)(s.d).	5,5 (3,7)
Satisfied with rehabilitation received	Yes	19 (61)
	No	10 (32)
	Didn't answer	2 (7)
Receiving ongoing therapy/rehab	Physiotherapy	10 (32)
	Occupational Therapist	1 (3)
	Chiropractor	1 (3)
	Psychologist/ Psychiatrist	0 (0)
Employment Status	Employed	17 (55)
	Unemployed	14 (45)
Marital Status	Married	8 (26)
	Single	23 (74)

For this sample the majority of SCIs occurred in the decades of the 1980s and 1990s (68%). The most commonly affected region of the spine was C_4-C_6 (68%). Most of the injuries occurred at either school boy (48%) or club level (35%) affecting individuals with the mean age (s.d.) of 20.3(5). The most common positions affected were the prop (32%) and the hooker (29%).

4.3 Quality of life post SCI (recipients and carers)

QOL was measured using the WHOQOL-BREF, it is scored using four domains, physical, psychological, social relationships and environment. It also has two questions that ask the individual about their perceived QOL and perceived health, they are added together to get a score out of 10. The WHOQOL-BREF scores have been converted to get a rating 0-100, the higher the value the greater the QOL. To convert the scores out of 100, a table was used from the WHOQOL-BREF administration guide.

The mean QOL scores for the individuals with SCI and their carers are shown in Table 4.2 below.

Table 4.2: The QOL scores for the individuals with SCI and their carers.

	Perceived QOL and health	Physical Domain	Psychological Domain	Social relationships Domain	Environmental Domain	Total of all four domains
Recipient (n=31) Mean (SD)	7,81 (1,22)	54,77 (10,74)	67,26 (12,41)	55,20 (24,63)	65,97 (17,96)	243,84 (48,10)
Carer (n=22) Mean (s.d.)	7,09 (1,44)	53,91 (9,61)	63,5 (8,75)	59,64(20,34)	61,23 (16,22)	238,27 (54,93)

The individuals with SCI scored higher than the carers in every domain other than the social relationships domain.

4.4 Community reintegration of individuals with SCI

Only 28 mRNL questionnaires were completed and returned. The higher the score the greater the degree of community reintegration. Table 4.3 below shows a summary of the scores.

Table 4.3: Summary of community reintegration scores for the individuals with SCI

mRNL Score	n (%)
30 – 50	2 (7)
51 – 60	1 (4)
61 – 70	8 (29)
71 – 80	7 (25)
81 – 90	4 (14)
91 – 100	6 (21)
Mean mRNL score (s.d.)	75.71 (± 16.04)

The individuals with SCI were fairly well integrated with a mean score of 75.71 (± 16.04) on the mRNL.

4.5 Caregiver strain

For the modified caregiver strain index, the higher the score the greater the strain on the carer. Table 4.4 below shows a summary of the mCSI scores that were collected.

Table 4.4: The mCSI scores of the caregivers

mCSI score	n (%)
1 – 5	5 (16)
6 – 10	15 (48)
11 – 15	8 (26)
16 – 26	3 (10)
≤ 12	25 (81)
≥ 13	6 (19)
Mean CSI score (s.d.)	9.06 (± 4.60)

From this sample, only 19% (n = 6) experienced moderate to extreme levels of caregiving strain. The mean caregiver strain was 9.06 (± 4.60).

4.6 Relationship between QOL and reintegration into the community:

A Pearson's correlation coefficient test was used to establish the type of relationship between QOL and reintegration into the community. Using the different domains highlighted in the WHOQOL-BREF, each domain score was used individually with the mRNL score to establish the type of relationship existed with any element of QOL. A further test was done to establish the relationship between QOL in general (all 4 domains added together) and reintegration into the community. Significance for the correlations was set at $p \leq 0.05$.

A summary of the various correlations is shown in Table 4.5 below.

Table 4.5: Summary of the correlations between mRNL scores and the various QOL domains.

QOL Domains	**r-value**	**p-value**
Physical Domain	0.54	0.003
Psychological Domain	0.38	0.05
Social Relationships Domain	0.55	0.002
Environmental Domain	0.60	0.001
Total score across domains	0.65	<0.001

Most of the domains had a moderate positive correlation score with community reintegration except for the psychological domain which had a weak positive correlation score. The strongest correlation was the total score of the WHOQOL-BREF and the mRNL score ($r = 0.65$: $p<0.001$).

4.7 Conclusion

From these results it was identified that the QOL of the SCI sufferers in this study was poorer than that of the general public (when comparing to other studies). However when comparing the scores to their carers, the SCI sufferer reported a greater QOL.

The findings have also shown that on average the SCI sufferers in this study reported a good reintegration back into the community with a mean score (s.d.) of 75.71 (± 16.04). The study also showed that their reintegration back into the community has a significant and positive correlation with the QOL that they experience ($r=0.65$, $p<0.001$). The study established that on average the carers in this study experience a moderate to low level of strain.

Chapter 5

5. Discussion

5.1 Introduction

The main aim of this study was to identify the QOL of South African rugby players and their carers post SCI. The results to this aim will now be discussed in this chapter under the following headings:

5.2 Demographics and size of the study sample

5.3 QOL of the individual post spinal cord injury in rugby

5.4 Level of community re-integration for the individual who sustained a spinal cord in rugby

5.5 The relationship between community re-integration and QOL post SCI

5.6 Quality of life and the strain on the caregiver caring for an individual post SCI

5.7 Limitations of the study

5.2 Demographics and size of the study sample

a) Sample size and rate of return of questionnaires

Of the 70 participants that were identified to be viable for the study, three participants declined participation and thus the sample size was now n=67. Of these 67 participants, 35 had access to the internet and the remaining 32 only had access to the postal service. An overall return rate of 46% (n=31) was achieved. Of those returned packs only 33% were 100% complete.

The poor return was due to a three month postal strike that occurred over the data collection period. This was highlighted when reviewing the return rates of both modes of data collection, the internet survey was 69% and the postal return rate was just 16%. The return rate was low however it is still significant enough to allow for a viable study and for notable deductions to be made from the data collected.

b) Year of injury

Despite the small sample size in this study, the years in which most injuries occurred agree with findings elsewhere. As seen in the study by Hermanus et al. (2010) the highest number of SCIs in rugby in South Africa was noted in the 1980's and 1990's, the results from this current study support these previous findings. According to the data collected from the demographics questionnaire, 68% (21/31) of the participants in this current study were injured in the 1980's and 1990's.

During the 1980's there was a notable rise in the frequency of reported SCIs in rugby, of these injuries, the majority were caused in the scrummage phase of play (Quarrie et al. 2007; Shelly et al., 2006; Haylen 2004). According to Quarrie et al. (2007) one of the reasons for the high number of SCI's occurring in this time was due the number of scrums per game. Quarrie et al. (2007) highlighted that the average number of scrums per game from the 1980's compared to the 21st century has gone from 31 to 19 per game. Due to the high numbers of scrummaging per game, the risk would thus be greater for a SCI to occur. Haylen (2004) also suggested the theory that the increase of SCIs in the 1980's was because the game was being played more aggressively than previous years. Proposed law changes were then implemented. In the 1990's a shift was seen, the number of scrums per game started to decrease and due to law changes the incidence of SCIs during scrumming decreased however the number of SCIs occurring during the tackling phase began to increase (Quarrie et al., 2007; Haylen, 2004; Quarrie et al., 2002). Even with the decreased incidence of SCIs in scrumming in the 1990's, the increase in other phases such as tackling, negated the decrease in the reported SCIs in the 1990's. This was noted by Haylen (2004) and this current research is consistent with this finding.

c) Level of injury

The majority (68%) of the injuries in this current sample occurred in the C_4-C_6 region. This agrees with previous research studies (Dennison et al., 2012; Kuster et al., 2012; Ning et al., 2011; Hermanus et al., 2010; Zahir & Ludwig, 2010; Kaplan et al., 2008; Shelly et al., 2006).

Studies have shown that certain anatomical features of the cervical spine predispose this area to be at the greatest risk for SCIs in rugby (Dennison et al., 2012; Kuster et al., 2012; Ning et al., 2011; Hermanus et al., 2010; Zahir & Ludwig, 2010; Kaplan et al., 2008; Shelly et al., 2006). Due to smaller vertebral bodies, more obliquely angled facets joint and less supporting musculature than the rest of the spine, the cervical region was shown to be at the greatest risk of SCI in rugby (Shelly et al., 2006; Banerjee et al., 2004; Secin et al., 1999). Furthermore, Parke (1988) identified that the lower region of the cervical spine (C_4-C_7) to be at a greater risk of spinal cord damage due to spinal stenosis than the upper region. This is because anatomically as one moves down the cervical spine, the diameter of the spinal cord gradually increases however the diameter of the spinal canal reduces (Parke, 1988).

Due to these anatomical predisposing factors and the mechanism of injury (hyperflexion or hyperextension) studies have shown the levels C_4-C_6 to be the most common region affected in the cervical spine (Dennison et al., 2012; Kuster et al., 2012; Ning et al., 2011; Hermanus et al., 2010; Zahir & Ludwig, 2010; Kaplan et al., 2008; Shelly et al., 2006). The findings of this current study are consistent with these previous studies.

d) Age at time of SCI

The mean age (s.d.) at the time of the SCI for the individuals in this sample was 20.3 (5). The youngest in this study was 14 years old when sustaining the SCI and the oldest was 35. This data is consistent with other studies (Patel et al., 2013; Kuster et al., 2012; Carll et al., 2010; Dunn & van der Spuy, 2010; Hermanus et al., 2010; Shelly et al., 2006; Banerjee et al., 2004; Quarrie et al., 2002).

Worldwide the most common age group to be affected by a SCI in rugby are those in their early to mid-twenties (Patel et al., 2013; Kuster et al., 2012; Carll et al., 2010; Dunn & van der Spuy, 2010; Hermanus et al., 2010; Shelly et al., 2006; Banerjee et al., 2004; Quarrie et al., 2002). The data collected in this study showed that the majority in this sample was actually below the age of 20 years. According to the results, 61% of the sample was either 20 years or younger at the time of injury. These results indicate that the sample population represents the lower bracket of the most common worldwide age group affected. Possible causes for this young population being at such high risk have been suggested in previous research (Bottini

et al., 2000; Milburn, 1993). Bottini et al. (2000) suggested that the susceptibility of schoolboys to experience a SCI, especially in the scrum, was due to the lack of development of the ligamentous and muscular structures in the cervical spine. The immature ligamentous and muscular structures lead to a greater risk of fractures and/ or dislocations to occur. Secin et al. (1999) suggested that the aggressive nature of schoolboy rugby could also add to the population being at greater risk.

Another possible reason for this young population to be at a greater risk could also be due to players playing out of position, for instance filling in for an injured or absent player in a key position such as a hooker or prop in a scrum. The inexperience and possible lack of strength specific for these key positions would not only increase the risk for that individual sustaining an injury but also others in the scrum as they could cause the scrum to collapse. Following strict law changes with regards to scrumming and tackling, it has been noted that there has been a decrease in the number of SCIs affecting this younger population in South Africa (Brown et al., 2013; Noakes et al., 1999) .

Considering the young age group identified in this study it is understandable that the most common levels of competition that the injuries occurred in were at school boy level (48%, n=15/31) and club level (35 %, n=11/31). This is also consistent with other research stating the high incidence of SCIs occurring at club level and schoolboy level rather than at a professional level (Dunn & van der Spuy 2010; Hermanus et al., 2010; Berry et al., 2006; Shelly et al., 2006; Quarrie et al., 2002). The relatively low incidence rate at a professional level can be attributed to various factors such as conditioning and the experience of the modern day professional rugby player. The most important factor could be due to the law changes and the enforcing of these laws by higher quality referees at a professional level. Prevention programmes that aim to improve the quality of refereeing and law enforcement at lower levels of play, have been shown to coincide with a reduction in SCI in countries such as New Zealand thus highlighting the importance of this factor (Quarrie et al., 2007).

Regardless of the possible causes for this age group being at risk, the current study’s data does support previous research with regard to the average age and the level of play for the population that sustain a SCI in rugby.

e) Player position

For the sample in this study it was identified that the two most common positions that sustained a SCI were the prop (32%) and the hooker (29%). These findings are consistent with other research that identifies these two positions to be at a high risk of a SCI, with hooker being at the greatest risk (Carll et al., 2010; Hermanus et al., 2010; Kaplan et al., 2008; Quarrie et al., 2002; Secin et al., 1999).

Of all the injured rugby players only four were backline players, this highlights that even with law changes and changes in phase of play that account for the SCIs, the forward players are still at greater risk than the back line players. This is also consistent with other research that highlights this statement (Dennison et al., 2012; Carll et al., 2010; Hermanus et al., 2010; Kaplan et al., 2008; Quarrie et al., 2002).

Prior to the year 2000 scrummaging was the leading cause of SCI in rugby (Kuster et al., 2012; Quarrie et al., 2002). It has also been noted that props and hookers are at greatest risk of sustaining a SCI than other positions, with hooker at greatest risk of all (Brown et al., 2013; Hermanus et al., 2010; Kaplan et al., 2008; Shelly et al., 2006; Quarrie et al., 2002; Secin et al., 1999) . Noting these two observations from previous research, and that the majority of the individuals in this sample were injured prior to the year 2000, it is understandable that the prop and hooker positions were the accountable for the most SCIs in this sample.

f) Rehabilitation

In this current sample population, all the individuals went to a rehabilitation facility following the SCI. The length of stay varied from two to 18 months. Half of the individuals were there for 3-4 months with only one individual staying as long as 18 months. In this current study the researcher is measuring the degree of community reintegration, as community reintegration and optimising the QOL for the individual post SCI are the ultimate goals of rehabilitation it was important to identify if the individuals did actually receive adequate rehabilitation. Looking at the duration of time spent at the rehabilitation facilities one could argue that yes adequate time was spent in these facilities. However time spent in a facility doesn't unfortunately mean adequate rehabilitation was given or that appropriate rehabilitation was given to facilitate these goals.

When asked if the individuals were satisfied with the rehabilitation they received, 61% answered ‘yes’ however 32% answered ‘no’. Of those that answered ‘no’, one was the individual that was in the rehabilitation facility for 18 months. This is an alarmingly high percentage of individuals that were dissatisfied with the rehabilitation they received. When one considers the cost of being at a rehabilitation facility and the importance of this vital stage in the SCI sufferer’s life, the health practitioner must ensure the adequate care and rehab is given to all patients. The knowledge that not only the SCI sufferer but also their families and caregivers could gain from time in a rehabilitation facility is invaluable. This knowledge could ease the transition for all involved following a SCI and thus more focus and expertise is required at this vital time so that all receive the best care they deserve and need.

g) Employment status

Of the 31 participants in the study 18(58%) are currently employed. When comparing to other research that studied employment rates following a SCI, this current sample’s rate would be considered a relatively high. Previous studies looking at employment rates following a SCI report a large spectrum of rates ranging from 14-31% (Leduc & Lepage 2002; Krause & Anson 1996). Therefore the current sample group is over 20% higher than the ‘high’ end of the spectrum from previous research.

Of the questionnaires that were returned the majority were via the internet and thus one could assume that most of these individuals live in a metropolitan area that has all the amenities required to have an internet connection. For those in rural areas that don’t have access to the internet or due to the postal strike, it meant their data couldn’t be collected. As metropolitan areas have better access and availability of employment options, those living in these areas have a greater chance of being employed. Therefore a possible reason for this high employment rate could be due to the small sample size in this study, there could be an over representation of employed individuals for the population when compared to SCI population as a whole.

Another reason for the high employment rate when compared to other countries could be due to the fact that companies in South Africa are required to hire disabled individuals to work for them, as they score a greater BEE (black economic empowerment) rating. A greater BEE rating for a company means an edge when it

comes to applying for tenders and possibly improve business opportunities. This is thus a possible factor that could improve the rate of employment following a SCI in South Africa (BBBEE Explained, n.d.).

An important statistic to remember when looking at this sample is that the majority of the individuals in this study have been living with a SCI for more than 10 years and have thus adapted to life with a SCI. When looking at the mean score for community reintegration for the sample (75.71 (± 16.04)), it shows that on average the sample is well reintegrated back into the community and therefore it is understandable that there is such a high employment rate. A study by Krause and Coker (2006) reported high employment rates such as this current study, the research showed that the longer the duration was following a SCI, the greater the employment rates became. The study looked at a population over a 30 year period 1973-2002. The rate of employment was identified over the 30 year period and ranged from 44% (1973) to 61% (2002). The study showed that within the first 15 years following the SCI the increase in employment rate was at its greatest (44-63%) then after the next 15 years there was a slight decline (61%). For the majority in this current sample they would fall under either one of these brackets thus supporting the research done by Krause and Coker (2006) and accounting for the high employment rate.

For a disabled individual, employment can be the one the best predictors of independence, life satisfaction and QOL (Franceschini et al., 2012). However the importance of the employment status is not only for the QOL and independence for the individual but when one considers the age that these participants got injured, they will spend the majority of their lives disabled. Looking at the more recent studies that estimate lifetime costs of an individual with a SCI, they indicate that they could be close to R30 million (Dennison et al., 2012). Other studies estimate even higher costs (Berry et al., 2006; Kuster et al, 2012). One has to consider the financial impact this has on them, their family and the economy. Thus having an income will help them dramatically in the management of their condition and ease the financial strain on them and the economy.

h) Marital Status

In this sample of the 31 participants, only eight (26%) reported to be either married or living with a partner. This percentage is low when comparing it to other research

that has identified statistics for SCI subjects and marital status (Chang et al., 2012; Mortenson et al., 2010; van Leeuwen et al., 2010; Barker et al., 2009; Lidal et al., 2008; Charlifue et al., 2004). When looking at percentages of participants married in other research the rates ranged from 31% (Charlifue et al., 2004) to 60,7% (Chang et al., 2012), with the majority of the other researcher's results in the 50's %.

The low rates for this study could be due the age at the time of injury for these participants. The majority of this study's participants were injured below the age of 20, when one considers the disability they experience and the implications on having a relationship (physical, sexual and emotional) one could understand the difficulty in finding a partner to share their lives with. For any SCI sufferer, especially quadriplegics, there is an insecurity associated with the disability and having a relationship especially one of a sexual nature. When considering that the partner or spouse of the SCI sufferer may have to be the carer as well as their partner, one can understand the difficulty in finding such a relationship. For the individual with the SCI, it presents with many physical, emotional and psychological barriers when allowing themselves to be open to a relationship, especially one of marriage. For a population that was injured so young, they may not have had a long term partner at the time of injury and therefore had to meet someone after the injury. Along with the SCI sufferer's barriers, the potential spouse/partner also has barriers when entering a relationship with a SCI sufferer. Research has shown that the spouse of a SCI sufferer experiences substantial burden of support (Post et al., 2005). This potential strain, along with the many other physical and emotional aspects can make the situation very difficult/complicated and thus could account for this population's low rates.

Another possible reason for the low rates when compared to other research is the difference in demographics for the participants. All of the research looked at a population of SCI sufferers as a collective. The research was not specifically looking at just tetraplegics/ quadriplecs but rather a mixed sample of both paraplegics and quadriplegics, this could skew the figures to present with higher rates.

5.3 QOL of the individual post spinal cord injury in rugby

The difficulty when measuring QOL is that it is very subjective. However, this study by using the WHOQOL-BREF, was able to look at the various aspects of a person's

life and try to make this concept as objective and measurable as possible. The WHOQOL-BREF is divided into four domains, the physical, psychological, social relationships and the environmental domain. The findings showed that the domains that the SCI sufferers scored highest in were the psychological and environmental domains. The mean scores and were 67.26 (±12.41) and 65.97 (±17.96) respectively. The domain that the subjects scored the lowest in was the physical domain, with a mean score of 54.77 (±10.74). The social relationships domain scored slightly higher than the physical domain with a mean score of 55.20 (±24.63).

a) Physical domain

The physical domain of the WHOQOL-BREF looks at how the individual feels they cope with the following: ability of the individual to cope with their everyday lives with the level pain they experience, their energy levels, amount of sleep they have, mobility and ease of getting around, their satisfaction with their capacity to work and if they are satisfied with how they perform their ADLs. It has been shown that SCI sufferers can experience many secondary complications due to the SCI and that quadriplegics are at greater risk than paraplegics (Mckinley et al., 1999). Secondary complications associated with SCI sufferers are pressure sores, pain, urinary tract infections, autonomic dysreflxia, pneumonia, bladder and bowel dysfunction, deep vein thrombosis and emboli and fractures due to osteoporosis (Jenson et al., 2005; Teasell et al., 2000; Mckinley et al., 1999). Looking at these complications that SCI sufferers could experience and that quadiplegics are at greater risk and present more frequently than other SCI sufferers. It is clear that these complications if experienced would affect the scores for this domain and thus could contribute to the lower mean scores identified in this study if the subjects were experiencing them.

When comparing this population's score for this domain to the normative data for SCI sufferers in Australia, this sample scored significantly lower than mean score 63 (±19) (Barker et al., 2009). A possible reason for this discrepancy between the two SCI groups could be due to lifestyle the SCI sufferer's experience. In Australia a SCI sufferer will receive an allowance for not only their carer($A121 paid fortnightly) but also an allowance for mobility ($A91-128) and for sickness ($A465-518 paid fortnightly), therefore if one is over the age of 22 and under the pension age the individual would receive a substantial support from the Australian Government (Disability payments and allowances, n.d.). Essentially individuals would receive

around R12865 per month to assist in their day to day lives managing their disability. Comparing this value to South Africa's disability grant of R1350 per month (You and your rights: Disability grants, n.d.), one can understand the difference the money could make to the everyday lives of these individuals. The money could be used to improve accessibility in the homes and the comfort in which they live thus impacting on their physical domain.

Another possible reason for the large discrepancy could be due to the fact that of the 207 SCI sufferers that made up Barker et al. (2009)'s, only 107 were complete quadriplegics, the rest were either complete paraplegics or ambulant incomplete SCI sufferers, therefore these would increase the mean score for the population. As already mentioned quadriplegics present more frequently and are at greater risk of secondary complications associated with the SCI therefore as this population was purely looking at quadriplegics it is understandable that the mean would be lower than more functional lower level lesion sufferers.

As this domain also looks at their satisfaction with their capacity to work, considering that in Barker et al. (2009)'s study 41% of the individuals were employed when compared to the 55% of this study it is surprising that this group didn't score better in this domain. As the sample of this current study had a greater percentage that were currently employed one would expect that they would score higher in this domain, especially with regards to the satisfaction with their capacity to work. One could argue that employment status and therefore capacity for work plays such a small part in the domain when comparing to the many other questions in the domain, thus plays a minor role in the total score.

b) Psychological domain

This domain looks at aspects of the individual's life such as: to what extent they enjoy life or if they find their lives meaningful, do they accept their bodily appearance, how satisfied they are with themselves and how often they experience depression, anxiety and despair. The population in this study scored minimally higher when compared to SCI sample from Barker et al. (2009)'s study. The difference in this domain however was not substantial with a mean difference of only 1.26. This illustrates that regardless of level on injury all SCI sufferers do experience the same obstacles when it comes to the psychological aspect of living with a SCI.

The possible reason for this sample experiencing slightly higher scores could be due to length of time the majority of the participants have lived with a SCI. Research by Dijkers (1999) identified that the longer one suffered from a SCI and the older one got, the greater the scores of their reported QOL became. Dijkers (1999) illustrated that the longer one lives with a SCI the better the individual is able to cope with the injury. From a psychological aspect the individual becomes aware of realistic expectations of what they can expect from life and how to cope with the difficulties they face on a day to day basis.

c) Social relationships domain

This domain looks at how satisfied the individual is with their personal relationships, their sex life and with the support they get from friends. The individuals in this current study scored a substantially lower score than the normative value for SCI sufferers in Australia (Barker et al., 2009). When looking at the marital status for both populations one can understand the difference in scores. In this current study only 26% were married or living with their spouse compared to the 51% for the Australian population. The marital status/ living with a spouse could account for the difference in scores especially when it comes to the sex life satisfaction and personal relationships questions. Previous research has also supported this, by highlighting the positive relationship of marital status, social support and QOL (Chang et al., 2012; van Leeuwen et al., 2010; Mortenson et al., 2010; Charlifue et al., 2004; McColl et al., 2003; Charlifue and Holicky, 1999). Research has shown that marital status for a SCI sufferer correlates with a greater QOL (Chang et al., 2012; van Leeuwen et al., 2010; Charlifue et al., 2004; McColl et al., 2003; Charlifue and Holicky, 1999). It can therefore be understood that the Australian population scored higher in this domain.

Quadriplegics/tetraplegics will suffer from sexual dysfunction as a complication of the SCI (Anderson et al., 2007; Middleton et al., 2007). This complication is associated with the autonomic dysfunction due to the SCI. A dangerous but common problem associated with sexual intercourse for a quadriplegic is the risk of experiencing autonomic dysreflexia while having sexual intercourse. Other issues associated with bladder and bowel dysfunfunction/incontinence while having sexual intercourse has also been shown to be a deterrent for individuals with a SCI to have sex (Anderson

et al., 2007). Considering these issues associated with sex and a SCI sufferer, it can explain why the participants scored poorly with regard to this particular question and scored lowest for this domain. Thus the scores support the literature that state that sexual function plays an important role in QOL (Anderson et al. 2007).

d) Environmental domain

This domain looks at how safe the individual feels in their daily environment, how healthy their home environment is, it also looks at the accessibility to information, health services and leisure activities. The domain also has questions pertaining to the satisfaction with their current living space, the health services they receive and their transport. When compared to Barker et al. (2009)'s sample of SCI sufferers, this current group scored substantially lower. The environment has been shown to act either as facilitator or barrier for the QOL experienced by SCI sufferers (Franceschini et al., 2012; Mortenson et al., 2010; Sekaran et al., 2010). As already discussed the money the SCI sufferers receive from both governments differs hugely. When considering that money received could improve the accessibility in their home environment and improve accessibility to transport and thus ease of mobility for the individual it is expected to see a difference in this domain.

Another important factor is that Australia is a first world country and South Africa is a developing county. When considering that a first world country should have better access to health care services, transport systems and everyday amenities, it is understandable to see the difference in scores in this domain. This is supported by research by Sekaran et al. (2010) that showed that environment and socio economic factors played a far greater role with relation to QOL in developing countries than in first world countries. The study identified that the environment could act as a major barrier when in relation to QOL, this was more so in developing countries than first world countries, as first world country's environment accessibility is so much more advanced thus it plays a minor role as barrier in QOL but rather is more a facilitator (Sekaran et al., 2010; Whiteneck et al., 2004). Therefore this highlights the importance the country's economy and infrastructure can play in the QOL of SCI sufferers living there.

When comparing QOL scores with the non SCI sufferers/general public in Barker et al. (2009)'s study, the difference across all domains was far greater than scores for

the SCI sufferers from this study. A less significant difference in QOL scores was noted however when comparing the scores to the general public/ non SCI sufferers in Brazil (Cruz et al., 2011). Previous research confirms this finding that SCI sufferers experience a poorer QOL than the general public (Sakakibara et al., 2012; Barker et al., 2009; Lepuc and Lepage, 2002; Dijkers, 1997; Post et al., 1998). A possible reason for the less significant difference in scores when comparing to the Brazilian general public to that of Australia is that, like South Africa, Brazil is a developing country whilst Australia is considered to be a first world country. As already discussed this could play a role in the QOL experienced by the individuals living in these countries. Djikers (1999) stated that even though SCI sufferers do experience a poorer QOL than that of the general public however the scores are not much lower. This is supported by this study when it is compared to the general public of another developing country (Brazil).

5.4 Level of community re-integration for the individual who sustained a spinal cord in rugby

The community re-integration mean score for the SCI participants was 75.71 (±16.04) indicating a relatively well reintegrated sample population. To measure community reintegration for this population the mRNL was used, this questionnaire looks at various aspects of the individual's daily lives. More specifically it looks at the ease at which the individual moves around their homes, their communities, it looks at level of comfort with regard to ADLs, how their time is spent (work/recreational activities), their roles in their families and the level of socialising with their families and friends and if they are comfortable in the company of other or on their own. For the current sample the employment rate was 55%, one would assume if the individual is working and interacting with other people in the community that they would score relatively well on many of these aspects of the questionnaire. Therefore as over half of the individuals in this sample were employed, this statistic could account the high mean score.

The ultimate goal of rehabilitation is to optimise the QOL, independence and the level of community reintegration the individual will experience. Considering that 61% of the individuals were happy with the rehabilitation received, one could assume that they received adequate rehab to help facilitate their ease back into the community.

Once again this high percentage could also be a factor that lead to the high mRNL mean score identified.

Research has shown that environment can play a major role in community reintegration especially with regard to transport and accessibility (Ravenek et al., 2012; Silver et al., 2012; Sekaran et al., 2010; Martin et al., 2010; Carpenter et al. 2007; Schönherr et al., 2004; Whiteneck et al., 2004; Sandford et al., 1999). Research by Sekaran et al. (2010) suggested that environment plays a far greater role as a barrier to community reintegration in developing and poorer countries than in first world countries. This is because their environment/infrastructure is far more advanced and therefore no longer acts as a barrier in first world countries. If one goes by the research that environment does affect community reintegration especially in developing countries (Sekaran et al., 2010), then this could account for the relatively high score for this population. Of the returned mRNL questionnaires, the majority were via the internet survey (68 %). To have taken part in this study using the internet, it indicates that these individuals lived in a metropolitan area/ environment that had access to resources and amenities such as electricity, a phone line and a computer. Therefore if in a metropolitan area, the accessibility to health care and transport is far better than in rural areas, with these facilities available to the individuals the environment facilitates community reintegration and therefore could account for the relatively high score.

Such amenities that may facilitate community reintegration may not be available to those individuals living in rural areas in South Africa. Unfortunately due to exclusion criteria and/or the postal strike that occurred during the research process, the data from the participants in rural areas in South Africa could not be collected. Without this data, one cannot deduce if those in rural areas with poorer access to much needed facilities would score as highly in the mRNL as did the recipients that did partake in the study.

This result showed that participants in this study were generally better reintegrated than those in May and Warren (2002)'s study. As time passes following a SCI and the individual gets older, aspects of the ageing SCI sufferer such as community reintegration and health related QOL decline (Krause & Coker, 2006). Therefore this large difference in scores could be due the age distribution (21-81 years old) for the

sample studied in May and Warren (2002)'s study being far larger and on average older than this current study. The research by Krause and Coker (2006) therefore supports the possibility that the large difference in mean scores could be accounted for by the age distribution for the two study populations.

Findings from this current study supports the research by Whiteneck et al. (2004) that shows that level of impairment plays a minor role in community reintegration. As the population in this study are all quadriplegics/tetraplegics and considering that the mean score was relatively high shows that the impairment played a minor role in limiting the degree of community reintegration for this sample.

5.5 The relationship between community re-integration and QOL post SCI

Using Pearson's correlation, a positive, significant relationship was identified between community reintegration and QOL (total score of all domains). The correlation coefficient for the relationship was r= 0.65 and p= <0.001.

Community reintegration/ participation following a SCI has been shown to be a strong predictor of QOL (Chang et al., 2012; Post & Noreau, 2005). In this study however the findings show only a moderately strong correlation. The findings do however have a higher correlation value than previous research looking at the link between community reintegration and QOL (Chang et al., 2012; Kumar et al., 2012). The discrepancy could be due to outcome measures used as each study used a different outcome measure to measure community reintegration. As different measures look at different aspects and some are more in depth than others, scores could vary.

By using the WHOQOL-BREF, it allowed for further investigation into this relationship. This researcher was able to identify which component of QOL had the greatest relationship with reintegration back into the community. When looking at the relationship between the mRNL scores and each specific domain of the WHOQOL-BREF (see table 4.5), the specific domain that had the strongest relationship and correlation and that was most significant, was the environmental domain. This domain has questions pertaining to the individual's environment that they experience on a daily basis and if they are satisfied with the environment and access to facilities that they use. It is thus no surprise that reintegration back into the community has

such a high correlation with this domain, as the environment can play such an important role in community reintegration. Environment has been shown to play a vital role in community reintegration/participation as it can be either a barrier or a facilitator (Ravenek et al., 2012; Silver et al., 2012; Sekaran et al., 2010; Martin et al., 2010; Carpenter et al. 2007; Schönherr et al., 2004; Whiteneck et al., 2004; Sandford et al., 1999).

The next strongest correlation was the social relationships domain. This domain looks at the personal relationships and the social support the individual experiences. This correlation supports the research by Whiteneck et al. (2004) that states that family support plays a major role in community reintegration. Their study suggested that family support, emotional adjustment and coping strategy played a more vital role in community reintegration than environment. In this current study however these findings were reversed as environment was found to play a more important role in community reintegration. As this research was done in the United States of America, which is a first world country and this current study in South Africa, a developing country, these findings supports the research of Sekaran et al. (2010) that states the environment plays a lesser role in first world countries than developing ones in relation to community reintegration.

The domain with the weakest correlation to reintegration into the community was the psychological domain. This domain focuses on how the person feels about themselves, from a physical and intellectual aspect and the degree/frequency they suffer from anxiety, mood, depression and despair. Aspects of psychological status such as depression, post-traumatic stress syndrome, anxiety and mood imbalance have been associated with SCI sufferers (North, 1999). These psychological disorders would negatively affect community integration as they would often cause the individual to be withdrawn/ isolated and therefore want to stay away from mixing with other people. Another psychological factor that could be a barrier to community reintegration is self-image as one would not feel comfortable mixing with others in the in community. Looking at the findings from this study though, the correlation between the psychological domain and community reintegration was weak. This could be due to the duration of time the majority of individuals have lived with a SCI thus no longer experiencing such negative effects psychologically from the injury. As stated by Middleton et al. (2014) that as the duration of time increases post SCI, the

psychological distress decreases. This therefore this could account for the relatively good psychological domain scores. The scores are possibly not high enough to facilitate community reintegration and nor are they low enough to be a barrier to it and thus present with a lower correlation score/ relationship to community reintegration. They therefore are playing a minor role to community reintegration in this study.

Overall even though environment had the strongest correlation of all the domains to reintegration into the community, no score was as significant or as strong as the total score for the WHOQOL-BREF and mRNL, indicating that holistically QOL is related to the degree of community reintegration more so than any specific aspect of QOL. As optimising QOL is the ultimate goal of rehabilitation and that the community reintegration plays such a vital role in QOL, rehabilitation should focus on optimising a patient's reintegration into society and thus look at the patient holistically across all domains.

5.6 Quality of life and the strain on the caregiver caring for an individual post SCI

To measure the QOL for the carers, the WHOQOL-BREF was used and the following results were identified for this sample. The findings showed that carers QOL was poorer than not only the general public but also the SCI sufferers they cared for. The domain mean scores were: physical 53,91 (±9,61), psychological 63,5 (±8,75), social relationships 59,64 (±20,34), environmental domain 61,23 (±16,22) and the overall total of all domains 238,27 (±54,93).

With regard to the strain the carers experienced the modified CSI was used. Of those packs returned, 31 mCSI's were completed. The findings showed that mean score was 9.06 (±4.60) (see table 4.4). From these results it shows that the carers in this sample, on average, presented with a moderate level of strain. Literature has shown that caring for a SCI sufferer does exert a strain on the carer and this current study illustrates this (Nogueira et al. 2013; Schulz et al., 2009;Post et al. 2005).

When compared to the norms for the general populations (non SCI sufferers) in Australia (Barker et al., 2009) and Brazil (Cruz et al., 2011), the carers in this sample scored significantly lower than both populations. Not only did the caregivers report a

lower QOL score than the general public, they scored lower than the SCI subjects that they were caring for. This result shows that carers experience an impaired QOL and present with a poorer QOL than the general public, this result supports previous literature that highlighted this finding (Middleton et al., 2014; Peters et al., 2013; Dreer et al., 2007; Unalan et al., 2001; Manigandan et al., 2000). When comparing the carer's results to that of the SCI sufferer, the only domain that the carer scored higher than the SCI subjects was in social relationships domain.

This domain focuses on the relationships the individual has with their friends, family and sexual partner/s. As the carer has possibly no physical impairment or limitation, they would experience less difficulties and obstacles in these aspects of their lives and thus score higher in this social relationships domain. The one main limiting factor could be the time available to them to experience these relationships and therefore when compared to the general public they do score lower. This finding was supported by the analysis of the mCSI, when asked if caregiving was confining 23% said 'yes on a regular basis' while 45% 'yes sometimes'. In total 68% of the carers felt caregiving was confining for any period of time. For such a large percentage finding it confining it could be a contributing factor for the low social domain scores.

A question in the mCSI asked if personal plans had to be changed due to caregiving and 48% said yes (32% on a regular basis and 16% sometimes). With almost half of the carers saying at some point personal plans had to be changed due to caregiving it could be a contributing factor for the low social relationships scores. This lack of time available to the carer was highlighted in a study by Blanes et al. (2007) who identified that the carers in their sample, on average cared for the patient at least 11.3 hours of each day. These long hours coupled with the psychological and physical strain that could lead to exhaustion and burnout (Post et al., 2005), therefore causing them to possibly having no energy/time to have a relationship. Therefore these factors could all account for the low scores when compared to the general public.

The domain in which the carer scored the highest was the psychological domain. Even with this domain being the highest score for the carers it was still lower than the SCI sufferer. Literature by Dreer et al. (2007) and Post et al. (2005) identified the percentage of carers suffering from depressive symptoms and psychological strain

can parallel that observed in SCI sufferers and can even present worse than the SCI sufferer. The results from this study can support this finding, thus leading to the carers and SCI sufferers reporting lower scores for this domain than the general public. A possible reason for the carers scoring worse than the SCI sufferers for this domain could be that the SCI have adapted over time to life with a SCI. As SCI sufferers can have multiple carers over time, they may not be the same individual who cared for the individual from the discharge from the rehabilitation centre thus have not had the same amount of time to adapt to strain and psychological toll of caring for a SCI. They therefore may not have developed coping strategies to cope with this lifestyle and thus score lower for this domain.

A study by Middleton et al. (2014) found that carers over time learn to adapt to the challenge of caring for an individual with a SCI and therefore report a higher QOL as time passes, for this reason the researcher believes that the carers may not be the same carer the recipient has had all along the process. Numerous studies have identified that caregivers and spouses of SCI sufferers experience significant psychological strain and this can take its toll and cause various psychological problems (Middleton et al. 2014; Dreer et al. 2007; Boschen et al. 2005; Sheija & Manigandan 2005; Post et al. 2005). These psychological problems would then negatively affect the QOL of the carer. From the mCSI analysis, findings could also help explain the low scores for the psychological domain. Firstly when asked if caregiving lead to emotional adjustment, for the 13% said ‘yes on a regular basis’ while 48% said ‘yes sometimes’. Therefore 61% found that found for any period of time that caregiving lead to an emotional strain. This emotional strain could contribute to lower scores in the psychological domain. Another question asked if the carer felt overwhelmed, 23% said ‘yes on a regular basis’ and 35% said ‘ yes sometimes’. This finding means that 58% felt overwhelmed due to the strains of caregiving for any period of time. This is an alarming high figure and will be a major contributor to the lower psychological domain scores.

Of the two remaining domains, the carers, like the SCI sufferers scored the lowest for the physical domain. As the quadriplegic is so dependent on the carer for the physical demands of their everyday lives, the relationship between the two individual’s physical domains would be linked. Previous research showed that even though level of impairment didn’t directly affect QOL for the SCI sufferer it did have

an effect on the QOL of the carer (Dreer et al., 2007). The greater the impairment the more assistance is required by the carer and therefore would affect the areas highlighted in the physical domain of the WHOQOL-BREF. There is a strong correlation between amount of assistance required along with hours worked and depression for the carer of a SCI sufferer (Graça et al., 2013). The greater the physical and emotional stress, fatigue, exhaustion and depression leads to impaired QOL experienced by the carer (Graça et al., 2013).

Specifically when looking at the current sample other reasons for the low physical domain scores could be identified when analysing the mCSI questionnaires. A question in the mCSI asks if caregiving is a physical strain, for this only 32% answered 'yes on a regular basis' while 61% answered 'yes sometimes'. With such a large percentage (93%) saying yes it is a strain for any time period, it could account for the lower scores for the physical domain for the carers. Another element in the physical domain is satisfaction with sleep experienced. In the mCSI's the carer is asked if sleep is disturbed, the percentage of individuals that said 'yes on a regular basis' was only 6% however those that said 'yes sometimes' was 32%. Therefore 38% of all the carers experienced some sleep disturbance which is another component for the physical domain and thus this finding could also lead to lower scores for this domain.

The last domain covered in the WHOQOL-BREF is the environmental domain. For this domain the carer scored lower than the SCI sufferer which is interesting as for the most part the carer shares the same environment as the SCI sufferer. From analysis of the mCSI questionnaires certain contributing factors could be identified namely that 71% found caregiving to financially straining. This is something that falls under the environmental domain questions in the WHOQOL-BREF and therefore could contribute to the lower scores for this domain. As already mentioned 68% of the carers felt that caregiving was confining, this together with 65% found that there were other demands on their time (other family members of the one they cared for) could be contributing to the lower scores. These two aspects would affect numerous questions in the environmental domain and therefore lead to lower scores.

As the SCI sufferer relies so heavily on their carers, the carer's QOL is something that needs attention, excessive strain and poor coping mechanisms could mean they

could be at risk of burnout or other psychological or physical morbidities (Blanes et al., 2007; Boschen et al., 2005; Post & Noreau, 2005; Manigandan et al., 2000). Not only is this detrimental to the carer but research has shown that if the carer themselves suffers from depression, the one they care for could be directly affected (Rodakowski et al., 2013).

The longer the duration of time is following the SCI, the carers' QOL improves along with that of the SCI individual that they care for (Boschen et al., 2005; Dijkers, 1999). A study by Boschen et al. (2005) identified along with Dijkers (1999) that like an individual suffering with a SCI, whose QOL improves as they get older, the carer's QOL also presents in the same way. Interestingly Boschen et al. (2005) did identify that even though the carers QOL improved in time, the strain they experienced stayed relatively constant. The improved QOL was attributed to the carer probably assimilating to their role as carer however the relatively constant CSI scores indicate the constant and continual challenges that carers face.

When analysing the results of the strain of the carers in this sample, the mean score showed that on average, the carers reported a moderate strain intensity level. However 19% presented with a moderate to extreme level of strain. This is important to note as strain can have adverse effects on the carers health (Nogueira et al., 2013; Rodakowski et al., 2013; Blanes et al., 2007).

Peters et al. (2013) identified that carers of any chronic neurological patient experience poorer QOL and a significant strain regardless of the type disease. However due to the degree of disability experienced by a quadriplegic, their lives are so inextricably linked to and dependent on the carer. It has been stated in previous research by Schulz et al. (2009) that a carer of a chronic SCI sufferer is at greatest risk of all in experiencing negative outcomes due to the spectrum of problems that they face.

This constant strain experienced by carers can lead to health related issues either physical or psychosomatic in origin. Research by Nogueira et al. (2013) identified that there was a significant correlation between caregiver strain and self-reported disease. Their study concluded that there is a close link between health (physical and psychological) and the strain the carer experiences. With this in mind one

cannot just ignore the strain the carer undergoes, this will not only have a detrimental effect on the carer but on the one they care for as well.

The research by Schulz et al. (2009) described the relationship between a carer and the one whom they care for, as being a dyad, this is the perfect description of the relationship. In this current study it identifies that both the SCI sufferer and their carer experience a poorer QOL than that of the general public. Both the carer and the SCI sufferer are thus impacted significantly by the SCI. This study thus highlights this inextricable link between the two individuals. Neither can be considered individually but rather always together when looking at life after a SCI. Rehabilitation should involve both subjects from the start and this would help both parties to be better prepared for the road ahead. It will give them coping mechanisms for the obstacles and challenges they will face together and thus empower them both in managing this catastrophic injury.

5.7 Limitations of the study

Due to this study being questionnaire based and the fact that not all the subjects had internet, it relied on the postal service to deliver the questionnaires. Unfortunately due to a three month postal strike, many of the questionnaires were never returned. Due to the poor return rate, the sample size of this study was small (n=31) making it difficult to generalise the findings from this study to all individuals in South Africa who sustained SCI while playing rugby.

Chapter 6

6. Conclusion and Recommendations

6.1 Conclusion

The demographics of this population studied were similar to those found in previous studies that looked at SCI and rugby players. The decades that had the most SCI occurring for this sample was in the 1980's and 1990's. The most common level of injury was the C_4-C_6 spinal levels. Most of the injuries occurred at either school boy or club level affecting individuals with the mean age (s.d.) of 20.3(5). The most common positions affected were the prop and the hooker. This population presented with a high percentage of employed individuals.

The population of SCI sufferers in this study presented with an impaired QOL. The domain that the individuals presented with highest QOL was in the psychological domain and this could be attributed to the long duration of time that individuals have been living with a SCI. The domain with poorest QOL was the physical domain and this could be attributed to the many complications associated with the level of injury impact that level of injury plays with regards to everyday life.

The individuals with SCI sustained while playing rugby have a relatively high level of community reintegration. This could be attributed to quality of rehabilitation the population received and that the majority in this sample lived in metropolitan areas that had amenities that facilitated community reintegration.

A positive relationship was identified between QOL and community reintegration. As both of these aspects are said to be the ultimate goals of rehabilitation it is understandable that they are linked.

The QOL of the carers of SCI sufferers were shown to be impaired due to their role as a caregiver. The mean strain experienced by the sample studied was of a moderate level of intensity, with only a small percentage reporting significantly high levels.

6.2 Recommendations

6.2.1 Study design

If future research is done on a nationwide scale such as in this study, it is suggested that researchers bypass the postal system and do telephonic interviews and thus ensure a larger sample and data collection. Another approach could be to include some qualitative research questions, as QOL is such a difficult concept to measure it could help get more of an in depth idea how is life after the SCI for both individuals in the dyad. With more knowledge, we as health professionals could assist in helping to improve the rehabilitation process of these individuals that would ensure that the most beneficial care is given to all involved.

6.2.2 Possible interventions

From the data collected it highlights a major concern and that is the strain and the QOL experienced by the carers. Much is being done to aid the sufferers of the SCI but from this paper it highlights the need of intervention for the carers to be implemented. A possible intervention going forward is to look at starting up support groups in the different areas for the carers to meet and discuss the issues they are dealing with and how they could cope with them. Another important consideration is from a rehabilitation point of view and that is to get carers involved from day one in the rehabilitation process. We must consider the SCI sufferer and the carer as a unit or a dyad. The focus must be from a holistic point of view and for both parties involved. Rehabilitation should not only involve physical rehabilitation but must also include a psychological aspect as well for both parties.

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8. Appendices

8.1 Appendix A: Modified Reintegration to Normal Living (mRNL)

Modified Reintegration to Normal Living Index (mRNL Index)

For each of the following statements, please indicate how well each statement describes you and/or your situation by placing a mark in a box. Please mark only one box per question.

	Does not describe me or my situation	Sometimes describes me or my situation	Mostly describes me or my situation	Fully describes me or my situation
1. I move around my house as I need to.				
2. I move around my community as I need to.				
3. I am able to make longer trips as I need to.				
4. I am comfortable with how my self-care needs are met (dressing, feeding toileting bathing).				
5. I spend most of my days occupied in work activity that is necessary or important to me (such as paid or voluntary work, housework, or studying etc.).				
6. I am able to participate in recreational activities as I want to (hobbies, crafts, sports, reading, television, games, computers etc.).				
7. I socialise with friends, family and/or business acquaintances as I want to or is necessary.				
8. I have a role in my family which meets my needs and those of my family members. (Family means people with whom you live and/or relatives with whom you don't live but see on a regular basis.)				
9. In general, I am comfortable with my personal relationships.				
10. In general, I am comfortable with myself when I am in the company of others.				
11. I feel that I can deal with life events as they happen.				

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Wood-Dauphinee S, Opzoomer A, Williams I, Marchand B, Spitzer W. Assessment of global function: The Reintegration to Normal Living Index. Arch Phys Med Rehabil 1988;69:583-90

Modified Reintegration to Normal Living Index

Vir elkeen van die volgende stellings, dui asseblief aan hoe goed elke stelling jou en/of jou situasie beskryf deur ‘n merkie in ‘n blokkie te maak. Merk asseblief slegs een blokkie per vraag.

	Beskryf nie my of my situasie nie	Beskryf my of my situasie partykeer	Beskryf my of my situasie meeste van die tyd	Beskryf my of my situasie ten volle
1. Ek beweeg in en om huis soos nodig.				
2. Ek beweeg in my gemeenskap rond soos nodig.				
3. Ek is in staat om op langer uitstappies te gaan soos nodig.				
4. Ek is gemaklik met die mate waartoe my selfsorg behoeftes bevredig word (aantrek, eet, toilet toe gaan, bad).				
5. Ek spandeer die meeste van my tyd aan werksaktiwiteite wat nodig of belangrik is vir my. (soos betaalde of vrywillige werk, huiswerk, of studier ens.)				
6. Ek is in staat om deel te neem aan ontspannings- aktiwiteite soos ek wil. (stokperdjies, handewerk, sport, lees, televisie kyk, speletjies, rekenaars ens.)				
7. Ek sosialiseer met vriende, familie en/of besigheidskennisse soos wat ek wil of soos nodig.				
8. Ek speel ‘n rol in my familie wat my behoeftes bevredig asook die van my familielede. (Familie beteken mense wat saam met jou bly en/of familielede wat nie saammet jou bly nie, maar wat jy op ‘n gereelde basis sien.)				
9. Ek is oor die algemeen gemaklik met my persoonlike verhoudings.				
10. Ek is oor die algemeen gemaklik met myself wanneer ek in ander se geselskap is.				
11. Ek voel dat ek lewensgebeurtenisse kan hanteer soos hulle gebeur.				

8.2 Appendix B: World health Organisation Quality of Life BREF (WHOQOL-BREF)

THE WORLD HEALTH ORGANIZATION QUALITY OF LIFE (WHOQOL) -BREF

The World Health Organization Quality of Life (WHOQOL)-BREF

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WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5

20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

Do you have any comments about the assessment?

_____

_____

[The following table should be completed after the interview is finished]

		Equations for computing domain scores	Raw score	Transformed scores*	
				4-20	0-100
27.	**Domain 1**	(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18 ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐	a. =	b:	c:
28.	**Domain 2**	Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26) ☐ + ☐ + ☐ + ☐ + ☐ + ☐	a. =	b:	c:
29.	**Domain 3**	Q20 + Q21 + Q22 ☐ + ☐ + ☐	a. =	b:	c:
30.	**Domain 4**	Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25 ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐	a. =	b:	c:

* See Procedures Manual, pages 13-15

World Health Organisation Quality Of Life- BREF

WHOQOL-BREF

Die volgende vrae word gevra om uit te vind hoe jy oor jou kwaliteit van lewe, gensondheid en ander areas van jou lewe voel.

Kies asseblief die antwoord wat die meeste van toepassing is. As jy onseker is oor ‘n antwoord is jou eerst reaksie op ‘n vraag gewoonlik die beste.

Hou asseblief jou standaarde, verwagtinge, die dinge wat vir jou plesier verskaf en jou bekommerusse in gedagte. Ons vra dat jy oor jou lewe gedurende **die afgelope vier weke** na dink.

		Baie swak	Swak	Nie swak of goed	Goed	Baie Goed
1.	Hoe sal jy jou kwaliteit van lewe beskryf?	1	2	3	4	5

		Baie ontevrede	Ontevrede	Nie tevrede of ontevrede nie	Tevrede	Baie tevrede
2.	Hoe tevrede is jy met jou gesondheid?	1	2	3	4	5

Die volgende vrae word gevra om uit te vind **hoe baie** jy sekere dinge ervaar het gedurende die afgelope vier weke.

		Glad nie	‘n Bietjie	N’ Matige hoeveelheid	Baie	Uitermatige hoeveelheid
3.	Tot watter mate voel jy dat fisiese pyn jou verhoed om die dinge te doen wat jy moet doen?	5	4	3	2	1
4.	Tot watter mate benodig jy mediese behandeling om te funksioneer in jou alledaagse lewe?	5	4	3	2	1
5.	Hoe baie geniet jy die lewe?	1	2	3	4	5
6.	Tot watter mate voel jy dat jou lewe betekenisvol is?	1	2	3	4	5

		Glad nie	‘n Bietjie	‘n Matige hoeveelheid	Baie	Uitermatige
7.	Hoe goed is jy in staat om te kan konsentreer?	1	2	3	4	5
8.	Hoe veilig voel jy in jou alledaagse lewe?	1	2	3	4	5
9.	Hoe gesond is jou fisiese omgewing?	1	2	3	4	5

Die volgende vrae word gevra om uit te vind hoe ten volle jy sekere dinge kan ervaar of sekere dinge kon doen gedurende die afgelope vier weke.

		Glad nie	‘n Bietjie	Matig	Meestal	Genoegsaam
10.	Het jy genoeg energie vir jou alledaagse lewe?	1	2	3	4	5
11.	Is jy in staat om jou liggaamlike voorkoms te aanvaar?	1	2	3	4	5
12.	Het jy genoeg geld om in jou behoeftes te voorsien?	1	2	3	4	5
13.	Hoe beskikbaar is die inligting wat jy nodig het vir jou dag-to-dag lewe?	1	2	3	4	5
14.	Tot watter mate het jy geleentheid vir ontspanningsaktiwiteite?	1	2	3	4	5

		Baie Swak	Swak	Nie swak of goed nie	Goed	Baie Goed
15.	Hoe goed kom jy van een plek na ‘n ander?	1	2	3	4	5

		Baie ontevrede	Ontevrede	Nie tevrede of ontevrede nie	Tevrede	Baie tevrede
16.	Hoe tevrede is jy met jou slaap?	1	2	3	4	5
17.	Hoe tevrede is jy met jou vermoë om jou alledaagse aktiwiteite te verrig?	1	2	3	4	5
18.	Hoe tevrede is jy vermoë om te kan werk?	1	2	3	4	5
19.	Hoe tevrede is jy met jouself?	1	2	3	4	5
20.	Hoe tevrede is jy met jou persoonlike verhoudings?	1	2	3	4	5
21.	Hoe tevrede is jy met jou sekslewe?	1	2	3	4	5
22.	Hoe tevrede is jy met die ondersteuning wat jy van jou vriende kry?	1	2	3	4	5
23.	Hoe tevrede is jy met die toestand van jou blyplek?	1	2	3	4	5
24.	Hoe tevrede is jy met jou toegang tot gesondheidsdienste?	1	2	3	4	5
25.	Hoe tevrede is jy met jou vervoer?	1	2	3	4	5

Die volgende vraag verwys na hoe gereeld jy sekere dinge gevoel of ervaar het gedurende die afgelope vier weke.

		Nooit	Selde	Gereeld	Baie Gereeld	Altyd
26.	Hoe gereeld ervaar jy negatiewe gevoelens soos om af te voel, wanhoop, angstigheid, depressie?	5	4	3	2	1

Het jy enige kommentaar aangaande die evaluering?

_____

_____

_____

_____

_____

_____

8.3 Appendix C: Demographics questionnaire

Demographic Questionnaire:

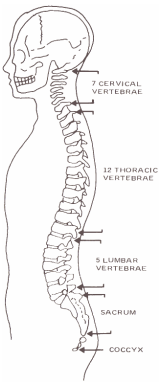
Title of Study: **Life after spinal cord injury in South African rugby: Carer and the injured individual perspective.**

Please tick the appropriate box and where applicable please specify the answers in the space provided.

Participant Information:

1. In which year were you injured? .....

2. At what level of the spinal cord is the injury



C1	☐	C6	☐	T3	☐
C2	☐	C7	☐	T4	☐
C3	☐	C8	☐	T5	☐
C4	☐	T1	☐	T6	☐
C5	☐	T2	☐	T7	☐

Other Level: ☐

3. Your age at the time of injury: ..

4. Level of competition that you were playing when you were injured:

School: ☐
Varsity: ☐
Club: ☐
Provincial: ☐
National team: ☐

5. Position that you were playing at the time of injury:

Prop	☐	Wing	☐
Hooker	☐	Fullback	☐
Lock	☐		
Flanker	☐		
8th Man	☐		
Scrum half	☐		
Fly Half	☐		
1st Centre	☐		
2nd centre	☐		

6. Did you receive any rehabilitation? Yes☐ No ☐

7. If so, how long were you at the rehabilitation facility?

   Days ☐ If possible please specify how many:……
   Weeks ☐ If possible please specify how many:……
   Months ☐ If possible please specify how many:……

8. Are you currently receiving any physiotherapy, occupational therapy etc.?:

   Physiotherapy ☐
   Occupational Therapy ☐
   Speech Therapy ☐
   Dietician ☐
   Psychologist/Psychiatrist ☐
   Other ☐ If ticked Other please specify:……..

9. If so how often do you receive this therapy?

   Once a month ☐
   Twice a month ☐
   Once a week ☐
   Twice a week ☐
   Other:.....

10. Are you satisfied with the rehabilitation and therapy you received/available to you after the injury: Yes ☐ No ☐

11. Are you currently employed: Yes ☐ No ☐

12. Are you married or live with your partner: Yes ☐ No ☐

    Thank you for your participation in this questionnaire.

Demografiese Vraelys:

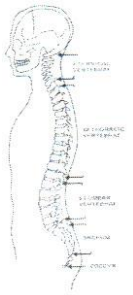
Titel van studie: Lewe na 'n rugmurg besering in Suid-Afrikaanse rugby: Versorger en die beseerde se individuele perspektief.

Merk asb. die toepaslike blokkie en waar van toepassing spesifiseer asb. die antwoorde in die spasie voorsien.

Deelnemer inligting:

1. In watter jaar is jy beseer? .....

2. Op watter vlak van die rugmurg is die besering?



C1	☐	C6	☐	T3	☐
C2	☐	C7	☐	T4	☐
C3	☐	C8	☐	T5	☐
C4	☐	T1	☐	T6	☐
C5	☐	T2	☐	T7	☐

Ander vlak: ☐

3. Jou ouderdom in die tyd van die besering: .....

4. Vlak van kompetisie waar jy gespeel het tydens jou besering:

Skool: ☐
Universiteit: ☐
Klub: ☐
Provinsiaal: ☐
Nasionale span: ☐

5. Posisie wat jy gespeel het tydens jou besering:

Stut	☐	Vleuel	☐
Haker	☐	Heelagter	☐
Slot	☐		
Flank	☐		
8ste Man	☐		
Skrumskakel	☐		
Losskakel	☐		
1ste Senter	☐		
2de Senter	☐		

6. Het jy engie rehabilitasie ontvang? Ja ☐ Nee ☐

7. Indien wel, vir hoe lank was jy by die rehabilitasie fasiliteit?

Dae	☐	Indien moontlik, spesifiseer hoeveel: .....
Weke	☐	Indien moontlik, spesifiseer hoeveel: .....
Maande	☐	Indien moontlik, spesifiseer hoeveel: .....

8. Ontvang jy huidiglik enige fisioterapie, arbeidsterapie ens.?:

Fisioterapie	☐	
Arbeidsterapie	☐	
Spraakterapie	☐	
Dieetkundige	☐	
Sielkundige/Psigiater	☐	
Ander	☐	Indien Ander, spesifiseer asb: .....

9. Indien wel, hoe gereeld ontvang jy die terapie?

1 x per maand	☐
2 x per maand	☐
1 x per week	☐
2 x per week	☐

Ander: .....

10. Is jy tevrede met die rehabilitasie en terapie wat jy ontvang het/beskikbaar was aan jou na die besering Ja ☐ Nee ☐

Dankie vir jou deelname aan hierdie vraelys.

8.4 Appendix D: Modified Caregiver Strain Index (mCSI)

try this:
general assessment series
Best Practices in Nursing Care to Older Adults
From The Hartford Institute for Geriatric Nursing, New York University, College of Nursing

Issue Number 14, Revised 2007

Series Editor: Marie Boltz, PhD, GNP-BC
Series Co-Editor: Sherry A. Greenberg, MSN, GNP-BC
New York University College of Nursing

The Modified Caregiver Strain Index (CSI)

By M. Terry Sullivan, RN, MSW, MSN, CMC, Connecticut Community Care, Inc.

WHY: Informal supporters provide the majority of long-term care to chronically disabled older adults. Caregiving has been recognized as an activity with perceived benefits and burdens. Caregivers may be prone to depression, grief, fatigue, and changes in social relationships. They may also experience physical health problems. Perceived caregiver burden has been associated with premature institutionalization and patient reports of unmet needs. Screening tools are useful to identify families who would benefit from a more comprehensive assessment of the caregiving experience.

BEST TOOL: The Modified Caregiver Strain Index (CSI) is a tool that can be used to quickly screen for caregiver strain with long-term family caregivers. It is a 13-question tool that measures strain related to care provision. There is at least one item for each of the following major domains: Employment, Financial, Physical, Social, and Time. This instrument can be used to assess individuals of any age who have assumed the role of caregiver for an older adult. The Modified Caregiver Strain Index is a version of the Caregiver Strain Index developed in 1983. The tool was modified and developed in 2003 with a sample of 158 family caregivers providing assistance to adults aged 53 and older living in a community-based setting (Travis, et al, 2002; Thornton & Travis, 2003). Scoring is 2 points for each 'yes', and 1 point for each 'sometimes' response. The higher the score, the higher the level of caregiver strain.

VALIDITY AND RELIABILITY: Internal reliability coefficient is slightly higher (=.90) than the coefficient originally reported for the CSI in 1983 (=.86). Two-week retest data for one-third of the caregiving sample (n=53) were available and resulted in a test-retest reliability coefficient of .88.

STRENGTHS AND LIMITATIONS: The Modified CSI is a brief, easily administered, self-administered instrument. Long-term family caregivers were not comfortable with the dichotomous choice on the CSI and the modified instrument provides the ability to choose a middle category response best suited to some situations. The Modified CSI clarifies and updates some of the items on the original instrument. The tool is limited by lack of a corresponding subjective rating of caregiving impact. There is no breakdown of score regarding low, moderate or high caregiver strain, so professional judgment is needed to evaluate by total score the level of caregiver strain. The tool effectively identifies families who may benefit from more in-depth assessment and follow-up.

FOLLOW-UP: The higher the score on the Modified CSI, the greater the need for more in-depth assessment to facilitate appropriate intervention. Additional items and further efforts to develop and test a set of subscales could enhance the applicability of the instrument for research and practice. The patient's cognitive status and problematic behaviors should be assessed, as well as the caregiver's perception of role overload or deprivation in key relationships, goals or activities. Family conflict, work role-caregiving conflict, and caregiver social support are also important variables in the overall caregiving experience. Additional work with highly strained long-term caregivers who are receiving little or no formal services is indicated.

MORE ON THE TOPIC:

Best practice information on care of older adults: www.ConsultGeriRN.org.
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Modified Caregiver Strain Index

Directions: Here is a list of things that other caregivers have found to be difficult. Please put a checkmark in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes, On a Regular Basis=2	Yes, Sometimes =1	No=0
My sleep is disturbed (For example: the person I care for is in and out of bed or wanders around at night)			
Caregiving is inconvenient (For example: helping takes so much time or it's a long drive over to help)			
Caregiving is a physical strain (For example: lifting in or out of a chair; effort or concentration is required)			
Caregiving is confining (For example: helping restricts free time or I cannot go visiting)			
There have been family adjustments (For example: helping has disrupted my routine; there is no privacy)			
There have been changes in personal plans (For example: I had to turn down a job; I could not go on vacation)			
There have been other demands on my time (For example: other family members need me)			
There have been emotional adjustments (For example: severe arguments about caregiving)			
Some behavior is upsetting (For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)			
It is upsetting to find the person I care for has changed so much from his/her former self (For example: he/she is a different person than he/she used to be)			
There have been work adjustments (For example: I have to take time off for caregiving duties)			
Caregiving is a financial strain			
I feel completely overwhelmed (For example: I worry about the person I care for; I have concerns about how I will manage)			

[Sum responses for "Yes, on a regular basis" (2 pts each) and "yes, sometimes" (1 pt each)]

Total Score =

Thornton, M., & Travis, S.S. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. *The Journal of Gerontology, Series B, Psychological Sciences and Social Sciences, 58*(2), p. S129. Copyright © The Gerontological Society of America. Reproduced by permission of the publisher.



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Modified Caregiver Strain index

Instruksies: Hier is ‘n lys van dinge wat vir ander versorgers moeilik was. Merk asseblief die kolom wat op jou van toepassing is. Ons het voorbeelde ingesluit van versorgers se mees algemene ervarings om jou te help nadink oor elke item. Jou situasie mag dalk effens verskil, maar die item kan nogsteeds van toepassing wees.

	Ja, op ‘n gereelde basis=2	Ja, partykeer=1	Nee= 0
My slaap word versteur (Byvoorbeeld: Die person wat ek versorg is in en uit die bed of dwaal rond gedeurende die nag)			
Versorging is ongerieflik (Byvoorbeeld: Hulp vat baie lank of dis ver om te ry om te gaan help)			
Versorging is fisies stremmend (Byvoorbeeld: in en uit die stoel tel, moeite of konsentrasie word benodig)			
Versorging is bindend (Byvoorbeeld: Om te help beperk vrye tyd of ek kan nie by iemand gaan kuier nie)			
Daar was aanpassings in die familie (Byvoorbeeld: Om te hulp versteur my roetine, daar is gaan privaatheid nie)			
Daar was veranderings van my persoonlike planne (Byvoorbeeld: Ek moes ‘n werk van die hand wys, ek kan nie met vakansie gaan nie.)			
Daar was ander dinge wat my tyd verg (Byvoorbeeld: Ander familielede het my nodig)			
Daar was emosionele aanpassings (Byvoorbeeld: Erge argumente oor versorging)			
Sekere gedrag is ontstellend (Byvoorbeeld: inkontinensie, die person wat versorg word sukkel om dinge te onthou, die persoon wat ek versorg beskuldig ander mense daarvan dat hulle dinge vat)			
Dit is onstellend dat die person wat ek versorg so verskil van hy/sy was (Byvoorbeeld: Hy/sy is ‘n ander mens as wat hy/sy was)			
Daar was werksaanpassings (Byvoorbeeld: Ek moet tyd afvat om my versorgings-verpligting na te kom)			
Versorgings is finansieel stremmend			
Ek voel totaal en al oorweldig (Byvoorbeeld: Ek bekommer my oor die person wat ek versorg, ek bekommer my oor hoe ek gaan regkom)			

8.5 Appendix E: Ethical Clearance certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Mr Joshua Sandler

CLEARANCE CERTIFICATE — M121134

PROJECT — Life After Spinal Cord Injury in South African Rugby: Carer and the Injured Individual Perspective (RE-SUBMISSION)

INVESTIGATORS — Mr Joshua Sandler.

DEPARTMENT — Department of Physiotherapy

DATE CONSIDERED — 30/11/2012

DECISION OF THE COMMITTEE* — Appoved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 18/03/2013 CHAIRPERSON ..... (Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Dr Witness Mudzi

DECLARATION OF INVESTIGATOR(S)
To be completed in duplicate and ONE COPY returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. I agree to a completion of a yearly progress report.
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

8.6 Appendix F: Turnitin certificate