

**Life after the game: consequences of acute spinal cord injuries
in South African rugby union players**

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PhD Candidate

Marelise Badenhorst (BDNMAR010)

Supervisors

Prof Mike Lambert (University of Cape Town)

Prof Willem van Mechelen (VU University Medical Center)

Prof Evert Verhagen (VU University Medical Center)

Dr James Brown (University of Cape Town / Stellenbosch University)

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Declaration

I, Marelise Badenhorst, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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These publications have been edited to a similar format wherever possible, however, some aspects, such as the abstracts, remain according to journal guidelines.

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high mountains, thank you for these distractions. As always, I look forward to our future adventures.

List of Abbreviations

AFO	Ankle-foot Orthoses
ARU	Australian Rugby Union
CBPJPF	Chris Burger / Petro Jackson players' Fund
CBR	Community-based Rehabilitation
CHART	Craig Handicap Assessment and Reporting Technique
CPI	Community Participation Indicators
DAG	Directed Acyclic Graphs
HSE	United Kingdom Health and Safety executive
ICIDH	International Classification of Impairment, Disability and Handicap
ICF	World Health Organisation's International Classification of Functioning, Disability and Health
ICF-CR	World Health Organisation's International Classification of Functioning, Disability and Health – Conceptual Revision
NHI	National Health Insurance
NRP	South Africa's National Rehabilitation Policy
SARB	South African Rugby Board
SARU	South African Rugby Union
SCI	Spinal Cord Injury
SCIM	Spinal Cord Independence Measure
SICM	Serious Injury Case Manager
SES	Socio-economic status
TBI	Traumatic Brain Injury
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organisation
WHOQOL	World Health Organisation's Quality of Life Questionnaire
WHOQOL-BREF	Abbreviated version of the World Health Organisation's Quality of Life
QASA	Quad/Para association of South Africa
QoL	Quality of Life

Chapter 1

Background

Introduction

There is a well described association between participation in exercise and sport and the positive effects of physical, social and psychological health.^{1,2} Rugby union is a popular team sport across many countries.³ As a team sport, rugby shares these positive benefits. However, the physical demands of the game means that it is also associated with a risk of serious injuries, such as spinal cord injuries (SCIs).⁴⁻⁶ SCIs have profound long-term effects on every aspect of a person's life, including their overall quality of life (QoL).⁷⁻¹⁰ As such, a nationwide injury prevention programme called 'BokSmart' was launched in South Africa in 2009, with the aim to reduce and ultimately prevent these injuries.^{11,12} However, implementing an injury prevention programme in a country with vast socio-economic disparities, such as South Africa, is a difficult task.¹³ Additionally, optimal acute care after the injury, rehabilitation services and ongoing health maintenance are essential in the management of SCIs and may play a determining role in enhancing and maintaining health and functioning, and therefore QoL.¹⁴⁻¹⁶ In South Africa, socio-economic disparities also have a profound effect on healthcare access and the subsequent health of the population.¹⁴ Thus, the additional burden of an injury with permanent consequences may be substantial and is an important issue to investigate. This introductory chapter summarises the literature on the incidence and risk factors for rugby-related SCIs, and the immediate management of these injuries. It also summarises the long-term healthcare issues and overall QoL of players who sustain these injuries and identifies how these problems present both globally and in South Africa. This chapter also provides the overall structure of this PhD-thesis.

1. Rugby union and the risk of injury

Rugby is believed to have originated from football in the 19th century in England.⁶ In 1895, the game was split into rugby league (played with 13 players) and rugby union (played with 15 players).⁶ According to World Rugby, the sport is played in over 100 countries worldwide and has and grown from 2.8 million players in 2016 to 3.2 million players in 2016.¹⁷ In South Africa, the earliest recorded rugby match took place in 1862 between the military and civilians at Green Point Common in Cape Town.¹⁸ Today, rugby union (henceforth "rugby") is a popular team sport in South Africa, with 300 000 registered players at both junior and senior levels and a total number of approximately 470 000 players.^{17,19}

Rugby is a fast-paced, field-based team sport characterised by substantial physical demands, high-impact collisions with the players wearing minimal protective gear.⁶ A rugby team consists of eight forwards and seven backline players. Forward players are generally heavier players, with the emphasis on their strength and power. Backline players are often smaller in stature and require speed and agility.⁶ The objective of the game is to score as many points as possible by gaining territory and advancing the ball towards the opposition's try-line.²⁰ The attacking team is prevented from gaining territory and scoring points by tackling the player with the ball and regaining possession.²⁰ The scrum is another important facet of play, used to re-start the game after an infringement.²¹ The scrum consists of a set formation of eight players from each opposing team that physically engage and interlock with each other, using their heads, necks, shoulders and arms, to compete for possession of the ball.²¹

The high physical demands and exposure to contact situations and collisions results in an inherent risk of injury whilst playing the game.²² As such, rugby has one of the highest reported injury rates (81.0 injuries per 1000 player hours; 95% Confidence Interval [CI]: 63.0-105.0) amongst all professional team sports. This rate is comparable with other collision sports such as ice-hockey and rugby league.²² The incidence rate of injury in senior (adult) amateur rugby union players (46.8 injuries per 1000 player hours 95% CI 34.4-59.2) is lower than in professional players, but higher than the rate of injury of adolescent and youth rugby players.²³ In youth rugby specifically, injury incidences have been reported as 35.0 injuries per 1000 match hours (95% CI: 29.0-41.0) in English youth competitions²⁴ and 20.4 injuries per 1000 player hours (95% CI: 18.6-22.2) in South African youth tournaments.²⁵ Although these injuries contribute to a small proportion of all injuries, rugby is also associated with serious or 'catastrophic' injuries that may result in permanent disability.^{4,26}

2. Catastrophic injuries and injury prevention in rugby

A catastrophic injury is defined by BokSmart as: "*Any head, neck, spine, or brain injury that is life threatening, or has the potential to be permanently debilitating and that results in the emergency admission of a rugby player to a hospital or medical care centre*". These injuries can be further classified as Traumatic Brain Injuries (TBI), SCIs and acute cardiovascular events. In 2008, Fuller et al.⁴ Compared the risk of sustaining a catastrophic injury in rugby to the United Kingdom Health and Safety executive (HSE) risk standards. Risk of

catastrophic injury in Ireland, England and Argentina were classified as “Acceptable” (0.1-2.0 per 100 000 per year) and “Tolerable” (2.0-100 per 100 000 per year) in New Zealand, Australia and Fiji. A comparative analysis concluded that the risk of sustaining a catastrophic injury while playing rugby was no greater than the risk that the greater population encountered in many daily activities.⁴ In South Africa, the incidence of catastrophic injuries (excluding cardiac events) has previously been reported as 2.0 per 100 000 players (95% CI: 0.9-3.1)⁵, which is comparable with other rugby-playing nations such as New Zealand, Ireland, Australia, and the United Kingdom.^{4,27}

It is the responsibility of a sport’s governing body to ensure that injury risk factors have been identified and that preventive measures have been set in place as far as possible.²⁸ Accordingly, South Africa’s national rugby safety program, BokSmart, was launched in 2009 by the South African Rugby Union (SARU) in conjunction with the Chris Burger Petro Jackson Players’ Fund (CBPJPF).¹² The Chris Burger Players’ fund was established after the Western Province fullback player, Chris Burger, sustained a fatal cervical spine injury following a tackle in a Currie Cup match in Bloemfontein in 1980.²⁹ The fund was founded by the captain of the Western Province team at the time, Morné du Plessis and his teammates. The fund joined forces with a similar fund which was established in honour of Petro Jackson, a young player from Stellenbosch, who was also fatally injured following a neck injury during a match in 1987. The two funds amalgamated and became known as the CBPJPF following the unification of the South African Rugby Union and the former SA Rugby Board (SARB) in 1992.²⁹ As a non-profit organisation that provides psychological, physical and emotional support for players who have been seriously injured, the CBPJPF has a vested interest in rugby safety and played an important role motivating for the development of a nationwide catastrophic injury prevention program.¹²

The BokSmart program focusses on injury prevention, injury management and player performance, with specific attention to serious and catastrophic head, neck and spine injuries.¹¹ BokSmart was modelled on New Zealand’s rugby safety program, RugbySmart, which was developed to reduce both the number and severity of injuries in community rugby by educating coaches and referees about evidence-based strategies for injury prevention.³⁰ RugbySmart has been associated with a significant reduction in scrum-related spinal injuries.³¹

BokSmart consists of five key elements¹¹:

1. BokSmart Rugby safety workshops – a compulsory, biennial, DVD facilitated course, aimed at all coaches and referees.
2. BokSmart Rugby Medic programme – a rugby-specific First aid short course, aimed at underprivileged communities.
3. BokSmart SpineLine - a toll free number in conjunction with ER24, a private emergency response ambulance services, aiding in management and transportation of players who have sustained a serious head/neck or spine injury.
4. Free online education (accessible via <http://www.boksmart.com>) – practical advice on rugby safety and performance, as well as current research articles.
5. Communication and Social media platform.

The main aim of BokSmart is to prevent catastrophic injuries.¹¹ The program tries to achieve this and also reduce the rate of injury in general, through the education of players, coaches, referees, and support personnel.¹¹ Monitoring annual catastrophic injury incidences is necessary for BokSmart to achieve this goal.⁵ Accurate information and statistics on the incidence of catastrophic injuries in South-African rugby players was hampered by inadequate data collection procedures.³² As a consequence, data reporting and collection procedures were standardised in 2008. The data are analysed by the BokSmart programme to contribute to their annual reports. These analyses showed that rugby-related catastrophic injury rates in South Africa reduced in junior, but not in senior players, after the implementation of BokSmart.³³ The authors hypothesised that the absence of effect in seniors may be a result of either differences in effectiveness of BokSmart in this group or due to fewer player numbers.³³ Additionally, South Africa poses several challenges for the implementation of such an intervention strategy due to the many rural, under-resourced, low socio-economic communities that are present in the country.^{13,32,34} Therefore, it remains important for BokSmart to identify groups or geographical areas that are at higher risk of catastrophic injury and that may require additional interventions. Specifically, SCIs constitute the largest proportion of all rugby-related catastrophic injuries⁵ and as such, requires special investigation.

3. Acute spinal cord injury in rugby

There were eighty (n = 80) catastrophic injuries in South Africa between 2008 and 2014. This number excluded cardiovascular events. Most of these injuries were SCIs (n=69), of which thirty-seven (54%) had permanent neurological deficit outcomes.³⁵ At a national level, the overall annual incidence rate for permanent outcome SCI between 2008 and 2011 were reported as 1.0 per 100 000 players (95% CI: 0.3 - 1.8).⁵ For means of comparison, the only other study that could be found comprising a similar time period and methodology was conducted in the French rugby union.³⁶ In this study, the average annual incidence reported as 1.6 per 100 000 players, was comparable to South Africa's incidence rate. According to the United Kingdom HSE risk standards⁴, these overall annual incidence rates are within the 'acceptable risk' (0.1-2.0 per 100 000 per year) level. Most sports and sporting activities include a certain amount of injury risk to the participant.³⁷ However, the concept of 'acceptable risk' is a contentious issue. In rugby, perceptions regarding the acceptability of risk are different across stakeholder groups and are strongly influenced by pre-existing beliefs.^{28,38} Even if the risk of injury corresponds with that of other activities, specific attention should be given to injuries that have the potential to result in long-term or permanent disability or death.³⁸ Due to the severe consequences of these injuries, even one such injury per year remains a serious concern for the rugby union and community and should be prevented at all cost.¹² To this extent, BokSmart has adopted 'Vision Zero', which calls for every effort to be made to eliminate catastrophic injuries in rugby.¹²

In rugby, cervical spine injuries occur most commonly at lower cervical spinal levels, particularly the C4/C5 and C5/C6 motion segments and are primarily produced by buckling motion of the cervical spine due to force vectors with significant compressive components.³⁹ Additionally, facet dislocations, specifically bi-facet dislocations, have been identified as the most common type of injury.³⁹ Cervical injuries mainly occur in either the tackle (open phase of play) or in the scrum.²¹ The forceful impact upon engagement, as well as the possibility of the scrum collapsing, contribute to the risk of sustaining a catastrophic SCI.²¹ Based on the high proportion of scrum-related catastrophic injuries reported by BokSmart during 2008–2011, SARU approved a new set of scrum laws for amateur rugby in 2012. The aim of the laws was to minimise the opportunity for injuries sustained by impact and scrum collapse. These law changes were implemented at the start of the 2013 rugby season²¹ and included techniques of binding in the scrum before engagement. The laws progressed from

passive engagement at the younger age-groups, to active engagement with reduced impact, from a closer distance, to the sequence of engagement currently practised worldwide.²¹ Scrum-law changes have been associated with a reduction in scrum-related cervical spine injuries, and as such tackle components of rugby now carry a higher proportion of cervical spine injuries.^{21,40} However, when scrum related injuries do occur, they have a higher propensity to cause permanently debilitating SCIs.²¹

In the unfortunate event of a suspected SCI, a fast and efficient immediate medical management protocol should take priority, with the main aim of protecting and preserving cord function.⁴¹ The nature of the immediate medical management process may influence the eventual functional outcome of the player.^{41,42} An optimal immediate medical management approach, based on current guidelines, consists of the immobilisation of the player with a rigid cervical collar, on a backboard with supportive blocks and straps, by qualified personnel.⁴¹⁻⁴³ Lastly, optimal immediate management of these injuries will rely on a swift and organised transfer of the injured player to a medical facility equipped to deal with SCIs.^{41,44} In the period before the introduction of the BokSmart programme, the immediate medical management of rugby-related SCI was reported to have been delayed for longer than six hours for 49% of injured players, while 34% of players received no on-field management and only 5% of players received optimal care.³² In comparison, more recent unpublished data from the BokSmart serious injury report (2014) report that acute management was delayed by longer than 4 hours in only 7% of players, while 11% received no on-field management and 62% received optimal care.³⁵ The management of serious injuries requires an ongoing commitment by healthcare organisations, medical personnel, coaches and managers to ensure that the best possible management is offered. The barriers or facilitators that influence these management processes need to be identified.

In contrast to the clinical and biomechanical investigations of the nature of these injuries, and the specific immediate management guidelines, a paucity of research exists regarding the player's experience of a catastrophic injury. A different perspective and understanding may be gained by viewing the injury from the player's perspective, since the player is in a position to provide contextual information around the injury incident. This is important to consider, as contextual information may be imperative in optimising interventions^{45,46}, including injury prevention and on-field management.

4. Consequences of spinal cord injury

SCIs have the potential to be fatal. When they are not, they are associated with various physical, emotional, social and economic consequences.^{16,40} Individuals who sustain a SCI are faced with multiple challenges in daily functioning.⁴⁷ The consequences of such an injury can be described by applying the World Health Organisation's International Classification of Functioning, Disability and Health (ICF). This is a classification of health and health-related domains.⁴⁸ The ICF contains three components of human functioning, namely *body functions and structures*, *activity* and *participation* (Figure 1). Disability, in this context, refers to the interaction of *impairments* of body functions and structure, limitation of various *activities* and restriction of *participation* in various life roles. The framework progresses beyond the medical model, which sees the physical injury as the main determinant of functional outcome.^{48,49} Instead, the ICF also considers other critical aspects that may affect disability such as personal factors and the individual's environment.^{48,49}

QoL is an important outcome of any medical treatment or rehabilitation processes, as it shifts the focus from the disease (or *impairment*) to a holistic view of the patient.^{50,51} Yet, QoL is not included within the ICF framework.⁵² Subsequently, the inclusion of QoL in the ICF has been identified as one of the future directions of development of the framework.^{48,52}

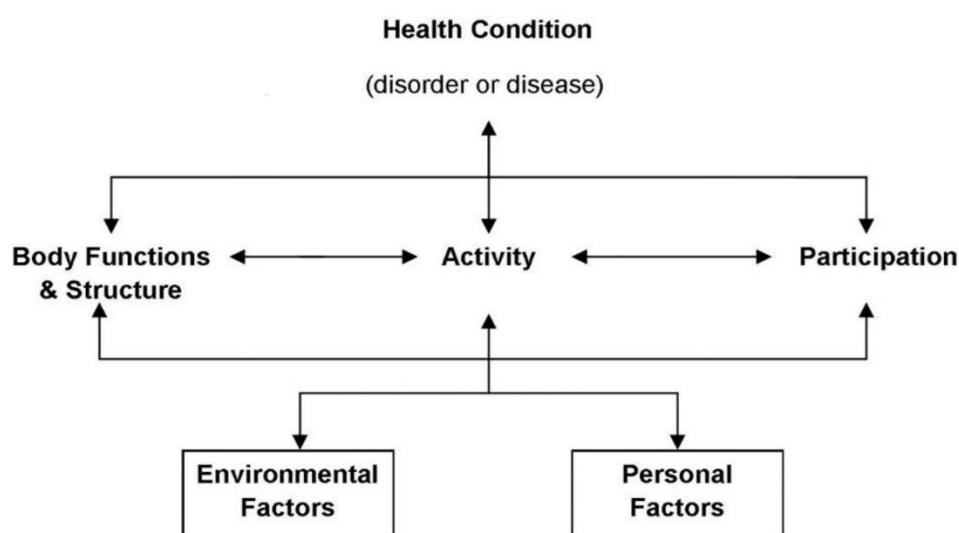


Figure 1. The International Classification of Functioning, Disability and Health (ICF), from WHO (2001).

In 2013, a conceptual revision of the ICF (ICF-CR) was proposed to enhance its biopsychosocial content by positioning QoL as a major component of human functioning with contribution of each of the other subsystems (Figure 2).⁵² The revision was suggested following certain criticisms raised in the literature, such as the omission of QoL in the original model, the lack of clarity between *activities* and *participation* components, and a thorough understanding of how contextual factors interact with other components of the framework.^{52,53} Specific criticism of the visual presentation of the ICF relates to the relationship between the different components. For example, with all the arrows pointing towards “*activities*” in the center of the current graphic (Figure 1), one may assume that *activities* are at the heart of the model, which is not the case or intention of the ICF.^{48,52}

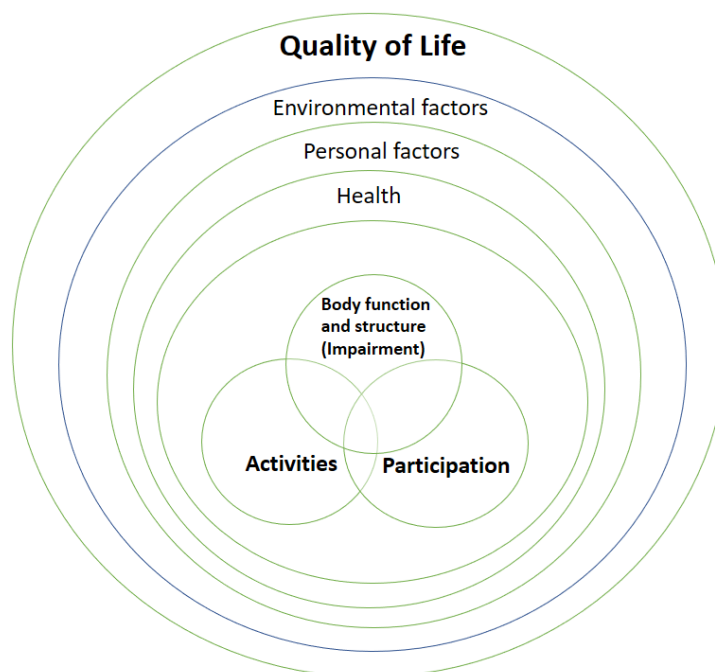


Figure 2. The ICF conceptual revision (ICF-CR), based on Ravenek et al (2013).

The term QoL is frequently used in research studies, but not always uniformly.^{54–56} The World Health Organisation (WHO) defines QoL as “an individual’s perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”. During the conceptualization of the ICF-CR, the positioning of QoL as the largest and most complex component in the framework was supported by the definition of QoL provided by the WHO.⁵² QoL may be

reduced following SCI⁵⁷ and as depicted in the ICF-CR, may potentially be influenced by various factors. For example, the ability of individuals with SCI to function independently, as far as possible, and to participate in meaningful roles in family and society may be associated with increased QoL.⁵⁶ However, this ability may be restricted or facilitated by environmental or personal factors relating to the individual.⁵⁶ The following section will describe the various components (and their interactions) within the ICF model, in relation to individuals with SCI.

Body function and structure

Depending on the extent of the SCI, the clinical presentation can include impairment of sensory and/or motor control below level of injury.⁵⁸ Additionally, SCIs affect autonomic functions such as breathing, heart rate, blood pressure, temperature control, bowel and bladder control, and sexual function. As the majority of rugby-related SCIs are sustained at cervical level^{32,39,59}, these injured players will generally present with sensory and motor loss both in the upper and lower limbs, a condition described as tetraplegia/quadruplegia.⁵⁸ Additionally, the physical and functional *impairments* associated SCI, may contribute to an increased risk for the development of secondary conditions such as pressure ulcers, deep vein thrombosis, heterotrophic ossification, neuropathic and musculoskeletal pain and spasticity, respiratory and cardiovascular diseases, diabetes, obesity and osteoporosis.⁶⁰⁻⁶³ These secondary conditions may reduce perceived QoL in persons with SCI, increase healthcare costs due to re-hospitalisations and reduce life-expectancy.^{63,64} Interestingly, some studies have reported associations between the actual lesion level (severity of SCI) and QoL⁶⁵, while other studies found no such associations.^{66,67} Variable definitions of QoL as well as measurement instruments, and the interactions of demographic and contextual factors may all play a role in these differences.

Activities

The severity of the *impairments* and subsequent functional limitations depends on the extent and location (lesion level) of the spinal cord injury.⁶⁸ For example, individuals with high level cervical spine lesions (C1-C4), are likely to need help with almost all their mobility and self-care needs, although they may be able to use a power wheelchair with chin controls.⁶⁹ In contrast, persons with C5 quadriplegia, will require a power wheelchair with hand controls for most of their mobility needs, although a manual wheelchair with grip

enhancements may be used for short-distance mobility on level surfaces.^{68,69} Individuals with a C6 injury may be able to perform independent transfers from a bed to a chair, although they usually require assistance with these, while individuals with C7 quadriplegia have the ability to extend their elbows, which greatly assists in their mobility and self-care skills. Individuals with C8 quadriplegia and below have functional finger flexion, which improves their independence in terms of hand activities.⁶⁹

These functional capabilities are described for persons living in ideal circumstances^{68,69} and most of these self-care activities and mobility tasks require specific skills training to reach higher levels of functioning.^{70,71} An improvement of these skills is, therefore, likely to have a substantial impact on the level of functioning.⁷² However, a South African study indicated that patients may be discharged from in-patient rehabilitation facilities in both private or government institutions, before they reach functional independence.⁷¹ When considering the contribution of other ICF components; lack of appropriate equipment such as wheelchairs and other services, limited knowledge about SCI, limited access to healthcare and rehabilitation services, loss of employment and lack of financial resources may all contribute to sub-optimal levels of functioning and independence.^{71,73,74} Furthermore, individuals with higher independence in *activity* have higher reported levels QoL.^{67,75,76}

Participation

Impairments in body function and subsequent restrictions in the ability to perform certain activities, may inevitably affect participation roles for the individual.⁵² Compared to *impairments* and *activity*, *participation* is perhaps a dominant concept as *participation* outcomes are significant in their own right, but also in their relationship to QoL in people with SCI.⁷⁷ *Participation* can mean taking part, being included, involved or engaged in certain roles or activities.^{48,78} It may also include a feeling of being accepted or having access to resources.⁷⁸ The ICF includes a number of domains that illustrate the complex and multifaceted nature of *participation*, often disrupted as a consequence of a health condition.^{48,79} It is clear that inclusion of *participation* in studies concerned with disability is important, but the subjective nature of *participation* can cause challenges with measurement.^{80,81} For example, the Craig Handicap Assessment and Reporting Technique (CHART) is a widely-used measure of *participation* in disability research⁷⁷ and demonstrates adequate reliability and validity in SCI samples.⁸² However, CHART is

classified as an objective measure of *participation* (from an outsider's perspective) and is based on the ICIDH framework (International Classification of Impairment, Disability and Handicap), which is an earlier version of the ICF.⁸¹ The ICF's focus on difficulty of *participation* reflects the outsider's view of what is important and has been criticised for failing to conceptualise subjective aspects of *participation*.⁸¹ Brown⁸³ argues that the value of *participation* emerges in life situations that are meaningful and important to the individual, as opposed to factors of *participation* that are considered important by the healthcare professional or researcher. Issues of choice and control, importance, belonging, and satisfaction have been included in recent definitions of *participation*.^{84,85} Similarly, community *participation* can be defined as the process of becoming part of family and community life, participating in normal roles and responsibilities, and being an active member of one's social groups and society as a whole.⁸⁶ Participation in these activities may occur with, or for others, to fulfil certain societal roles and may be determined by the interaction of environmental, personal and cultural factors.^{78,87,88} Involvement in social activities and support from family members and friends are important predictors of both life satisfaction and happiness for people with SCI, while isolation from family and lack of supportive relationships make it difficult to fully engage in community participation.^{78,89,90} As such, participation in home, social and leisure activities affect QoL positively in person with SCI.^{66,91}

Specifically, participation in productive work has been identified amongst the most important 'participation activities' for adults with disabilities and being employed is regarded as a key indicator to social integration.^{66,92,93} A study of the life-experiences of men with SCIs found they considered successful employment very important, not just from an economic perspective, but also because it represented their ability to participate in society similar to able-bodied men⁹⁴ The average global employment rate for people with spinal cord injury is 37%, with Europe having the highest rate of 51%.⁹⁵ Unfortunately, the South-African Census of 2011 showed low overall absorption rates of disabled people in the labour market.⁹⁶ Specific employment data for people with SCI in South Africa could not be found. However, Statistics South Africa reports that only 21% of males and 18% of females with severe walking difficulties are employed.⁹⁷ These percentages are lower for persons with severe self-care difficulties (13% for males and 12% for females).⁹⁷ Marginalisation of people with disabilities may result in loss of productivity and opportunities to generate

income, which again is linked to health and QoL.⁹⁸ Additionally, lack of skills and education are also important barriers to employment for people with disabilities in South-Africa.^{96,97} Health problems may also directly affect a person's ability to participate in the community or to be employed.^{16,91,99} Therefore, good health may be seen as the foundation that enables successful participation in everyday life and various life roles.¹⁶

As discussed earlier, *participation* may be especially important in roles and activities that have meaning for the individual.^{83,85} For individuals involved in sport before their injury, sport or exercise may be an important *participation* outcome and as such, may be part of an identity that they strive to maintain.^{100,101} Sport and recreation may mitigate feelings of stigmatisation and stereotyping for people with disabilities and create opportunities to build social networks, experience freedom and success, and serve to facilitate the identity negotiating process.¹⁰² Studies have shown that participation in sports and recreational activities may improve self-confidence, self-esteem, social participation, performance of activities of daily life and quality of life, in people with SCIs.¹⁰³⁻¹⁰⁵ Persons with SCI who engaged in organised sports have also been shown to have decreased depression and anxiety, increased life satisfaction and increased opportunity for gainful employment, compared with non-active persons with disabilities.¹⁰⁶ Furthermore, it has been shown that after sustaining a SCI, participation in a preferred sport was associated with better psychological adjustment, while participation in a team sport was associated with better psychological adjustment than individual sports.¹⁰⁷ From a health perspective, physical activity and exercise is a well-described intervention for chronic disease prevention and health maintenance for people with disabilities.¹⁰⁸⁻¹¹⁰ Facilitators of physical activity participation include the perception of social contact and fun, intrinsic motivation and self-efficacy and selection of an appropriate activity or sport.¹¹¹ Despite the reported benefits of physical activity for people with disabilities, participation levels remain low.¹¹¹⁻¹¹³ Patients often participate in various activities during their rehabilitation period, but these activities are often not sustained post-rehabilitation.¹¹⁴ Various barriers to participation in sports and physical activities need to be considered in the long-term. Examples of these barriers are cost, level of disability and health, lack of facilities or knowledge, difficulties with transport and accessibility, fatigue, energy, motivation, pain, psychological and psychosocial issues.^{111,115} A South African study has shown a relationship between physical fitness, specifically with regards to pushing a wheelchair, and community participation in people with SCI.¹¹⁶ However, little is known

about the experiences of individuals with disabilities in South Africa, and in low and middle-income countries in general, regarding their experiences and perceptions of the barriers or facilitators of participation in physical activity.¹¹⁷

Personal factors

Personal factors may interact with, and influence the other components of functioning within the ICF model.^{48,52,118} The ICF defines personal factors as the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states.⁴⁸ These factors may include race, age, gender, lifestyle, habits, social background and socio-economic status, education, profession, individual psychological assets and coping styles, all of which may influence disability in some respect.⁴⁸ In South Africa, as is often the case in other low and middle-income countries, socio-economic status (SES) is associated with a variety of factors, such as health, educational performance and physical activity participation^{119–122} SES is understood in terms of its proxies, such as income, education or occupation.¹²⁰ It is access to such resources that enables individuals and/or groups to thrive in the social world.¹²³ In South Africa, access to wealth was formed on the basis of race through decades of inequality and socio-economic division.¹²⁰ This was achieved by placing restrictions on where non-white people could live and the type of education and occupation they had access to, creating a society of inequality in which conventional ways of economic growth was cut short for these marginalised groups.^{120,124} It is well described that in general, individuals with disabilities, especially those from low socio-economic communities, have poorer health outcomes, lower education levels, less economic participation and higher rates of poverty than people without disabilities.^{117,125} Apart from the physical and emotional consequences, the economic consequences of these injuries include the direct costs of care as well as indirect costs resulting from loss of future productivity.¹²⁶ Employment of either the injured individual or others within the household is crucial when considering the life-time cost of SCI, which has been estimated to be higher than for conditions such as dementia, multiple sclerosis and cerebral palsy.⁵⁸ The estimated lifetime economic burden per individual with SCI has been reported as US\$ 1.5 million for incomplete paraplegia to US\$ 3.0 million for complete quadriplegia¹²⁷, while the lifetime net healthcare cost was recently reported as US\$ 336 000, rising to US\$ 479 600 if associated with a pressure ulcer during initial hospitalisation.¹²⁸

Complete spinal cord lesions have also been shown to result in substantially higher costs than incomplete lesions.¹²⁹

No studies relating to these costs could be found for a South African population. However, there is growing evidence of households falling into poverty or forced into deeper poverty when faced with substantial medical expenses due to injury or ill-health, especially when these factors are associated with loss of household income.^{130,131} The costs of caring for a person with a disability is further complicated should the ‘breadwinner’ (household’s biggest earner) be rendered unable to work.⁹⁸ And when employment is secured, having a disability will likely affect the level of income and this disparity is further inflated by race. For example, the average annual income of a black South African with severe walking difficulty is ZAR 14 851¹, compared to ZAR 20 839 for a black person without a disability. In contrast, within the same disability category, a white person will earn ZAR 83 786, compared to ZAR 170 986 for a white person without a disability.⁹⁴ Again, income levels are even less for people with severe difficulties with self-care.⁹⁷ In South Africa, people with disabilities have access to a disability grant (social grant). However, the maximum amount that can be claimed is ZAR 1 700 per month, which is considerably less than the average minimum wage of ZAR 3 500 per month for 40 hour work week.¹³² Furthermore, this small amount often has to support a whole family.⁹⁸ The international disability rights movement emphasises that disability is a human rights issue that needs to be addressed via social change to services, policies and legislation.¹³³ The movement also considers the relationship between poverty and disability and calls for economic development to enhance the quality of life of people with disabilities.¹³⁴

Besides the implicit physical insult, SCI have a debilitating psychological effect with a substantial proportion of patients suffering from depression and anxiety, which may also affect QoL.^{135–139} Individual psychological assets may therefore play an important role within the ICF model.¹³⁷ Evidence shows that coping strategies and psychological resources, as well as pre-injury factors such as personality, relate to adjustment and mental health after SCI.^{140,141} Self-esteem, self-efficacy and social skills are prominent factors which might serve to buffer negative consequences of, and to enhance adjustment to, SCI.^{137,142,143} High

¹ ZAR: *South African Rand*. 1 € = ZAR 15.28; 1 US\$ = ZAR 13.40 (Exchange rate on 6 February 2019)

self-efficacy or self-esteem has been linked to improved mental health and less secondary physical conditions in persons with SCI.^{136,144,145} Specifically, with regards to rugby-related spinal cord injuries, the literature has focused on the combined loss of masculine and athletic identities, the process of identity reconstruction and the immense psycho-social and emotional impact of SCI.^{7,8,146–149} Individuals with a strong athletic identity before sustaining a SCI may have substantial adaptation difficulties after their injury.⁸ However, athletic identity has also been reported as a factor that may promote recovery and enhance long-term adjustment in disability.¹⁵⁰

With regards to age- and time-related factors, time since injury has been reported as a cross-cultural predictor of QoL.⁶⁶ Geyh et al.⁶⁶ reported that individuals, who were older and sustained their spinal cord injury more recently, experienced more depressed moods, lower life satisfaction, lower purpose in life, lower social skills and lower self-efficacy, although in general the sample seemed to be well adjusted to SCI.¹⁵¹ In contrast, other studies with smaller samples have found no association between time since injury and QoL, life satisfaction or depression in people with SCI.^{91,152} It appears that the relationship between age-related and time-dependent processes and factors such as psychological well-being and QoL are not yet well understood in persons with SCI and warrants further research.

Environmental factors

Environmental factors may influence a person with SCI's *functioning* and include for example, social support and attitudes, systems and policies, the built environment and architectural characteristics, transportation, legal and social structures, assistive technology, information technology and access, as well as the natural environment, climate and terrain.^{48,153} In people with SCI, QoL may be affected by economic and environmental factors, such as accessibility to healthcare, quality of education or adequacy of housing.⁵⁶ The social model of disability describes disability as a condition that is completely socially-imposed and includes a degree of social oppression.⁹⁸ The social model calls on society to change its attitude and importantly, the environment, as a person will only be as 'disabled' as his / her environment and society forces them to be.⁹⁸ The quality of the environment in terms of accessibility, employment and social support appear to significantly influence a person with a SCI to maintain their lifestyle.^{154,155} Environmental factors can therefore act as barriers or facilitators of *participation*, but are also substantial contributors to life

satisfaction.¹⁵⁶ Importantly, the impact of the environment on *participation* plays a role at the immediate/individual, community, and societal levels and should be assessed and addressed as such.¹⁵³

Health systems are considered as environmental factors and may interact with personal factors, such as race, income and insurance, to influence healthcare access.¹⁵⁷ Disability adds another dimension to the issue of accessibility of healthcare.¹¹⁷ People with disabilities have been shown to have unequal access to healthcare services, and experience poorer levels of health and have more unmet health needs compared to people without disabilities.^{117,158,159} Data from the World Health Organisation's 2010 World Health Survey of low-income countries indicate that the costs related to accessing healthcare is the most common barrier experienced for people with disabilities.¹¹⁷ The treatment of SCIs, like most health issues in developing countries, is affected by poverty.¹⁶⁰ Compared to high income countries, studies from low income countries confirm that individuals with SCI are experiencing a higher occurrence of urinary tract infections and pressure sores, which are worsened by the degree of poverty.⁷³ These complications lead to unnecessary suffering, often causing premature death.⁷³ In contrast, in high-income countries, the main causes of death for people with SCI are less easily preventable respiratory problems such as pneumonia and influenza.¹⁶¹ A household survey of individuals with disabilities living in Africa found the following to be barriers to healthcare: lack of transport, unavailability of services, costs associated with the visit to the health facility, insufficient medication or equipment and negative experiences or inadequate skills of healthcare providers.¹⁶² Similarly, data from the South African General Household Survey (2014) indicate that persons with disabilities were more likely to have poorer physical accessibility to healthcare in terms of having no medical aid, using public healthcare facilities, walking to the health facility and taking longer travelling time compared to persons without disabilities.¹⁵⁸

South Africa has both a private and a public health system. A minority of the population (approximately 16%) of the population makes use of the private health system, and these costs are mostly covered by private voluntary health insurance.¹⁶³ The remaining majority of the population relies on the national, tax-funded, public health system.¹⁴ South Africa's pre-democracy healthcare system was racially segregated and even though Apartheid ended in 1994, the public health system is still faced with considerable challenges, including the

unequal distribution of human resources in healthcare, creating unremitting barriers and shortfalls in the public system.^{163,164} These challenges are partly due to the persistence of economic inequalities between races, resulting in inequitable health access for poor, uninsured, black South Africans and rural groups.¹⁶⁰ In underprivileged, rural communities the medical management and rehabilitation of catastrophic injuries (SCIs) are difficult, due to factors such as distance, difficult terrain and limited resources.³² A South African study of rugby-related catastrophic injuries noted (with race as a proxy of SES), that 56% of white players recovered fully, compared to only 34% of coloured players and 10% of black players.³² This disparity among SES groups emphasises the need for adequate treatment and care in previously disadvantaged communities.

Rehabilitation services are also an essential component of primary healthcare.¹⁶⁵ The goal of South Africa's National Rehabilitation Policy (NRP), published in 2000, is to improve accessibility to all rehabilitation services. This is in accordance with every person's constitutional right to have access to necessary healthcare services.¹⁶⁶ However, access to rehabilitation for people with disabilities remains problematic in South Africa, as indicated by a high percentage of unmet rehabilitation needs for people with disabilities. This can be attributed to mainly inadequate finances and transport problems.^{165,167} However, it can be concluded that there are many unanswered questions about rehabilitation for people with disabilities in South Africa as there is a paucity of literature pertaining to healthcare and rehabilitation barriers and facilitators in a South-African SCI population.

Summary

This review of the literature provides the background to the specific areas of focus presented in this PhD thesis. Even though the risk of rugby-related SCIs is low (about 1 injury per 100 000 players in South Africa), the permanent nature of such an injury results in a traumatic, life-altering event for the player and the player's family and therefore remains a serious concern for all involved. These consequences are worsened by the socio-economic disparities in South Africa, that affects many factors including the accessibility to adequate healthcare. Socio-economic disparities are also reflected in the rugby-playing society, where differences between playing facilities, level of coaching and medical assistance pose additional challenges for players from disadvantaged backgrounds.

Sporting bodies have a responsibility to maintain the health and welfare of the athletes participating in their sport.¹⁶⁸ In rugby specifically, various injury prevention programmes exist,^{27,30} demonstrating the importance of preventing serious spinal injury. Given the consequences of these injuries, the reduction in the incidence of rugby-related SCI should be a continued priority. However, this responsibility should not only include prevention and promotion efforts but should extend to the player whose life has been permanently affected by injury. There is a paucity of research investigating the immediate management, consequences and QoL for players who sustain SCIs whilst playing rugby.

As discussed in this review, QoL of individuals who have sustained a SCI may be influenced by various barriers and facilitators as presented in the ICF. Identification of these barriers and facilitators is an essential first step in designing strategies and interventions to address current issues. An understanding of the challenges that these players face from the moment of injury, to re-integration into their communities are needed if we are to ascribe to the notions of long-term player welfare and adhere to a continued duty of care.

Thesis outline

The thesis was grounded in a pragmatist paradigm and adopted multiple methodological approaches (Table 1). A pragmatic approach directs the research focus to the problem to be researched and the consequences of the research, as the most important determinants of the research design.¹⁶⁹ In this approach, various different methods are often used to gather information that is meaningful and applicable to specific populations.¹⁷⁰ Pragmatism as a paradigmatic stance permits the integration of principles from critical, interpretive, and scientific/positivist paradigms and thus, the integration of both quantitative and qualitative lines of inquiry.¹⁷¹

The overall aim of this thesis is to investigate the risk, immediate management and current QoL of acute spinal cord injury within the South African rugby playing population. To answer this overall research question, five objectives are investigated in five chapters:

Chapter two compares the catastrophic injury rates between the 14 different rugby regions of South Africa between 2008 and 2014.

A qualitative approach is used in **Chapter three** to describe the injury experience from the players' perspective, including the injury mechanism and other contextual factors related to the injury.

Chapter four also uses a qualitative approach to understand the players' perception of factors related to the optimal immediate management of a SCI within the South African context.

Chapter five investigates the current QoL and associated factors among individuals with rugby-related SCI, using the ICF framework.

In **Chapter six**, barriers and facilitators to healthcare, as an important component of QoL, are described in both the public and private healthcare sectors.

Chapter seven includes a summary and overall discussion of the studies conducted in chapters two to six, the implication of these findings, as well as recommendation for future research.

Table 1. Methods, population and time-frame of data collection

Chapters	Methods	Population and time-frame
Chapter 2	Quantitative (Injury rates)	Analysis for this chapter was conducted first (in 2015) and used prospective, population-based data from the BokSmart / CBPJPF database that was collected between 2008-2014. The population included males and females.
Chapter 3 - 6	Qualitative (Semi-structured interviews) Quantitative (Questionnaires)	Data for these chapters was collected in 2016. Qualitative and quantitative data were collected simultaneously from study participants recruited from the BokSmart / CBPJPF database. The participants were all male.

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Chapter 2

A comparison of catastrophic injury incidence rates by provincial rugby union in South Africa

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Abstract

Objectives

To compare catastrophic injury rates between the 14 South African provincial rugby unions.

Design

A prospective, population-based study conducted among all South African unions between 2008-2014.

Methods

Player numbers in each union were obtained from South African rugby's 2013 census. Catastrophic injuries were analysed from BokSmart's serious injury database. Incidence rates with 95% confidence intervals were calculated. Catastrophic injuries (acute spinal cord injuries and traumatic brain injuries) within unions were compared statistically, using a Poisson regression with incidence rate ratios (IRR) and a 95% confidence level ($P < 0.05$).

Results

Catastrophic injury incidence rates per union ranged from 1.8 per 100 000 players (95%CI: 0.0 to 6.5) to 7.9 (95%CI: 0.0 to 28.5) per 100 000 players per year. The highest incidence rate of permanent outcome acute spinal cord injuries was reported at 7.1 per 100 000 players (95%CI 0.0 to 17.6). Compared to this union, five ($n = 5/14$, 36%) of the unions had significantly lower incidence rates of acute spinal cord injuries. Proportionately, three unions had more acute spinal cord injuries and three other unions had more traumatic brain injuries.

Conclusion

There were significant differences in the catastrophic injury incidence rates amongst the provincial unions in South Africa. Future studies should investigate the underlying reasons contributing to these provincial differences.

Introduction

Safety in sports is an important requirement for continued participation.¹ Prevention, reduction and control of sports injuries are therefore important points of concern for clinicians, researchers and inevitably society as a whole.¹ Rugby union (henceforth “rugby”) is one of the most popular team sports and has one of the highest reported match-related injury incidence rates amongst professional team sports.^{2,3} It is a fast-paced game, characterised by high physical demands and frequent exposure to physical contact and high impact collisions.⁴

Though catastrophic injuries are rare, the results are emotionally and financially devastating, for the player and their family, and also negatively affects the image of the sport.⁴ These injuries are also of public concern, although the magnitude of concern may be dominated by perception of risk rather than actual risk.⁵ In South Africa, the incidence of catastrophic injuries (excluding cardiac events) has previously been reported as 2.0 per 100 000 players (95%CI: 0.9 to 3.1)⁶, while the incidence of permanently disabling acute spinal cord injuries (SCIs) was reported as 1.0 per 100 000 players (95%CI: 0.3 to 1.8).⁶ These rates are comparable with other rugby-playing nations such as New Zealand, Ireland, Australia, and the United Kingdom.^{5,7}

To reduce this risk, the South African rugby union (SA RUGBY) requires that all coaches and referees undergo biennial training as a core component of South Africa’s national rugby safety program, BokSmart. As with any intervention, the effectiveness of an injury prevention program could be assessed by comparing injury rates before and after implementation.⁸ Subsequently, BokSmart was found to be associated with a significant improvement in serious injury rates in junior, but not in senior players.⁷ The authors postulated that the absence of effect in senior players may be a result of either differences in effectiveness of BokSmart, or due to fewer player numbers in this age group.^{6,7} These and previous catastrophic injury rates for South Africa were calculated with estimated player numbers, obtained from World Rugby (formerly IRB), as no other accurate player numbers were available.^{6,7} Subsequently, SA RUGBY commissioned a census of all affiliated rugby playing schools and clubs in South Africa, to determine accurate player numbers (SA RUGBY development survey 2013). Accurate player numbers are essential for catastrophic

injury incidence calculation.⁹ It is the responsibility of governing bodies, teams, and individuals involved to monitor and reduce the risk of injury where possible.¹⁰ South Africa has distinct socio-economic disparity among both players, coaches and referees.¹¹ This poses specific challenges for any nationwide intervention, including BokSmart. Previous studies investigated the nationwide incidence of catastrophic injuries⁶, but the incidence within individual provincial rugby unions has not yet been investigated. Provincial rugby unions with high catastrophic injury rates may benefit from further investigation into possible contributing factors. Thus, the aim of this study was to compare the catastrophic injury rate between the 14 South African provincial rugby unions between 2008 and 2014.¹²

Methods

A prospective, population-based study was conducted among all provincial rugby unions in South Africa. SA RUGBY is the governing body for rugby in South Africa, consisting of 14 provincial rugby unions dispersed across the country. In 2012, SA RUGBY commissioned a census of all affiliated rugby playing schools and clubs in South Africa, to determine accurate player numbers. A telephonic survey was conducted nationwide to collect the data. In addition to the telephonic survey, a verification process was also conducted. The aim of the verification process was to assess the accuracy of these data by physically visiting at random a limited number of the schools and clubs that had been telephonically interviewed. The overall data collection process lasted for one year, from March 2012 until March 2013.¹³ For the purpose of the current data analysis, player numbers were assumed to be stable over the seven years of investigation.

Permission to analyse the data was obtained, with SA RUGBY and CBPJPF's permission, by the University of Cape Town (UCT) Human Research Ethics Committee. The following definitions were adopted for this article:

A catastrophic injury is defined by BokSmart and the Chris Burger/Petro Jackson Players' Fund (CBPJPF) as: *'Any head, neck, spine or brain injury that is life threatening, or has the potential to be permanently debilitating and results in the emergency admission of a rugby player to a hospital or medical care center'*.

Acute spinal cord injuries (SCIs) and traumatic brain injuries (TBIs) of all outcomes (full recovery/neurological deficit/quadruplegic and fatal) in both junior and senior levels, which

fit the above definition, were included in the analysis. Cardiac events were not included in this study. The term SCI with permanent outcome describes a SCI with resultant neurological deficit, quadriplegia or death. Cases with full recovery outcomes are therefore excluded from this category. SCI with 'near miss' outcome refers to cases of SCI fitting the above catastrophic injury definition, that had a full recovery outcome/no resultant neurological deficit remaining.

Catastrophic injury data for this study were analysed from the serious injury database which is managed jointly by the BokSmart programme, and the CBPJPF. The CBPJPF is a non-profit organisation that provides assistance for players who have sustained a permanently disabling injury while playing rugby in South Africa. Catastrophic injury data for this study were collected prospectively from 2008-2014. Incidence rates were presented as an annual average (over the seven-year period) per 100 000 participating players. The numerator was calculated from the number of injuries collected prospectively from 2008-2014 and the denominator was the population at risk (i.e. the total number of rugby players per provincial rugby union as verified by the 2013 census). These player numbers included males and females and under-seven to adult (amateur and professional). Incidence rates with 95% confidence intervals (95% CI) were calculated using the standard formulae suggested for rugby union injury studies.¹⁴ Any negative lower bound 95% confidence limits were presented as '0'. Catastrophic injuries, SCIs with permanent outcome, SCIs with 'near miss' outcomes and TBIs within provincial rugby unions were compared statistically using a Poisson regression with incidence rate ratios (IRR) and a 95% level of confidence ($P < 0.05$).

Results

The total number of verified players in South Africa was reported at 291 940¹³, which is less than the previously documented 651 146 players, as estimated by the IRB / World Rugby and that was used to calculate incidence rates in earlier studies.⁶ In the period between 2008 and 2014 there were eighty ($n=80$) catastrophic injuries, excluding cardiovascular events (Table 1). The overall average incidence rate of catastrophic injury was 3.9 per 100 000 players (95%CI: 1.7 to 6.2) per year. Incidence rates amongst provincial rugby unions ranged from 1.8 per 100 000 players (95%CI: 0.0 to 6.5) in the Kings to 7.6 per 100 000 players (95%CI: 0.0 to 18.6) in Boland and 7.9 per 100 000 players (95%CI: 0.0 to 28.5) in Griquas

(Figure 1). The risk of sustaining a catastrophic injury was 76% less likely in the Kings ($p=0.01$), compared to Boland ($IRR=0.24$). Of the sixty-nine ($n=69$) SCIs sustained, thirty-seven ($n=37$; 54%) had permanent outcomes (Table 1). The outcome of two of the SCIs ($n=2/69$; 3%) was not provided. The overall annual incidence rate for permanent outcome SCI was 1.8 per 100 000 players (95%CI: 0.3 to 3.4). Amongst the provincial rugby unions, Boland had the highest incidence rate of permanent outcome SCIs (7.1 per 100 000 players, 95%CI: 0.0 to 17.6) (Figure 1). Compared to Boland, the Lions were 92% less likely to sustain a SCI with permanent outcome ($p = 0.01$).

Table 1. Catastrophic injury numbers, permanent outcome and ‘near miss’ acute spinal cord injuries (SCIs) and traumatic brain injuries (TBI) per provincial rugby union.

Provincial rugby union	Player numbers	Catastrophic injuries	SCI Permanent outcome injuries	SCI ‘Near miss’ injuries	Catastrophic TBI
Boland	24 310	13	12	-	1
Bulldogs	35 772	8	6	1	1
Bulls	27 544	7	5	2	-
Cheetahs	17 050	3	-	2	1
Eagles	13 442	5	1	4	-
Griffons	7 656	2	1	1	-
Griquas	7 216	4	1	3	-
Kings	31 416	4	2	-	2
Leopards	11 638	2	1	1	-
Lions	26 752	7	1	2	4
Pumas	11 022	3	-	3	-
Sharks	20 108	4	1	3	-
Valke	15 202	3	1	1	-
WP	42 812	15	5	7	2
National (all provinces)	291 940	80	37	30	11

Furthermore, the Sharks ($p = 0.03$), Kings ($p = 0.01$), Western Province ($p = 0.01$) and Bulldogs ($p = 0.03$) were 90%, 87%, 76% and 66% less likely than Boland to sustain an SCI with permanent outcome (Figure 1). Of the thirteen ($n = 13$) catastrophic injuries reported in Boland, 92% ($n = 12/13$) had permanent outcomes (Figure 2). Additionally, Cheetahs and Pumas had no reported SCIs with permanent outcomes during this period.

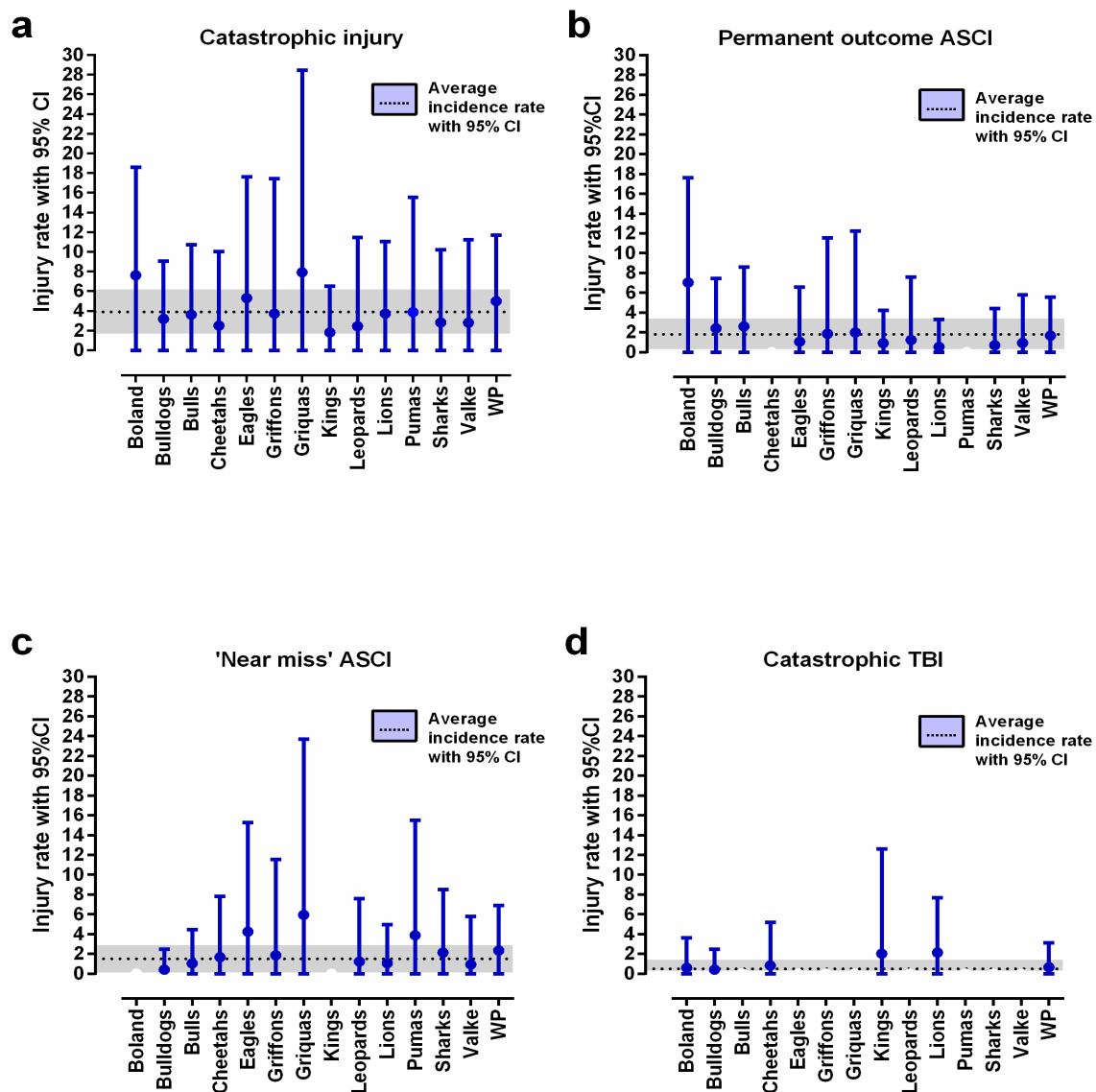


Figure 1. Incidence rates with 95% confidence intervals for catastrophic injury (1a), acute spinal cord injury (SCI) with permanent (1b) or 'near miss' outcomes (1c), and (1d) traumatic brain injury (TBI) per 100 000 players per provincial rugby union.

Forty-three percent ($n = 30/69$; 43%) of SCIs sustained between 2008 and 2014 were classified as ‘near miss’ injuries (Table 1). Incidence rates ranged from 0.0 per 100 000 players in Boland and Kings, to 5.9 per 100 000 players (95%CI: 0.0 to 23.7) in Griquas (Figure 1). Seventy-five percent (75%) of Griquas’ injuries were ‘near miss’ SCI (Figure 2). Although Griquas had three ($n = 3$) ‘near miss’ injuries, this provincial rugby union only had four ($n = 4$) catastrophic injuries in total. Traumatic brain injuries, meeting the operational definition used in this study, accounted for fourteen percent ($n = 11/87$; 14%) of catastrophic injuries between the period of 2008 and 2014 (Table 1). The average annual incidence of TBIs was 0.5 per 100 000 players (95%CI: 0.3 to 1.4). The Kings (2.0 per 100 000 players, 95%CI: 0.0 to 12.6) and Lions (2.1 per 100 000 players, 95%CI: 0.0 to 7.7) were the provincial rugby unions with the highest TBI incidence (Figure 1). All other provincial rugby unions had incidence rates ranging from 0.0 to 0.8 per 100 000 players.

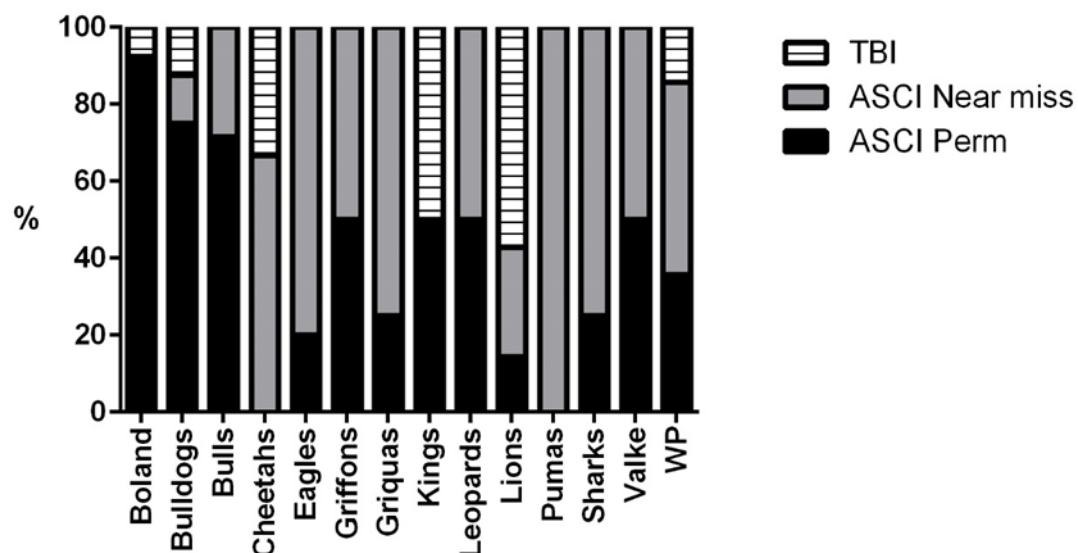


Figure 2. Proportional distribution of acute spinal cord injury (SCI) with permanent (Perm) or ‘near miss’ outcomes and traumatic brain injury (TBI), within each provincial rugby union.

Discussion

The highest catastrophic injury incidence rate among the provincial rugby unions occurred in Boland (7.6 per 100 000 players, 95%CI: 0.0 to 18.6) and Griquas (7.9 per 100 000 players, 95%CI 0.0 to 28.5). However, when delving deeper into the data, Boland still had the highest incidence of SCI with permanent outcomes (7.1 per 100 000 players, 95% CI: 0.0 to 17.6). In contrast, the incidence of SCI with permanent outcomes in Griquas was much lower, at 2.0 per 100 000 players (95%CI: 0.0 to 12.3). When looking at proportional distribution of permanent SCIs and TBIs within each provincial rugby union, Boland, Bulldogs, and Bulls had proportionately more permanent SCIs, and Lions, Kings and Cheetahs had proportionately more TBIs, in that order.

It is currently difficult to draw any pertinent conclusions on the reasons for the regional differences in these injury rates and proportions. However, the results of this study can be utilised by SA RUGBY and BokSmart to potentially direct further investigations around these injury patterns and within these provincial rugby unions. Similarly, lessons could be learned from provincial rugby unions with lower injury rates or proportions. Interestingly, some provincial rugby unions such as Griquas and Eagles show a high number of catastrophic injuries, but a large proportion of these consist of ‘near miss’ injuries, in comparison to permanent outcome injuries. Exploring the reasons for the difference in outcome could yield extremely valuable information.

Nationwide injury prevention programs aim to reduce the incidence of catastrophic injuries and an exemplar program example is New Zealand’s RugbySmart program.^{7,15} South Africa’s national rugby safety program, BokSmart, was initially modelled on the concept of RugbySmart, and has also shown positive results.^{7,16} However, the implementation of wide scale, effective intervention measures in real life situations is not without its challenges.¹⁷ BokSmart is disseminated nationally to all coaches and referees through the provincial rugby unions. The education component of the program is run similarly in all fourteen unions. However, the present study has shown that all fourteen unions do not necessarily have the same level of associated risk, and seemingly also have differing proportional distributions of catastrophic injury types and levels. The sporting landscape in South Africa is extremely diverse with different languages, cultures, socio-economic statuses and levels of education,

making the implementation of an effective intervention across all communities a complex task.^{11,16} This socio-economic disparity translates further into the rugby-playing society, where disparities between playing facilities and levels of coaching poses additional challenges for players from disadvantaged backgrounds.⁹

Various factors could influence the occurrence and outcome of a catastrophic injury. One such factor is the effective and immediate medical management of a seriously injured player, which may play a vital role in the eventual functional outcome.¹⁸ Healthcare in South Africa faces a specific challenge with many underprivileged communities that are often geographically remote.¹⁹ In these rural communities, the medical management of catastrophic injuries is difficult, due to factors such as distance, difficult terrain and limited resources.⁹ A South African study of rugby-related catastrophic injuries noted that 56% of white players recovered fully, compared to only 34% of coloured players and 10% of black players.⁹ This disparity among race groups emphasises the need for adequate treatment and care in previously disadvantaged communities.

A Health and Safety Executive scale which categorises risk in ascending order, from 'negligible' to 'unacceptable' has previously been used to assess the level of risk.⁵ In South Africa, the average annual incidence of rugby-related catastrophic injuries between 2008 and 2011 (2.0 per 100 000 players)⁶ was comparable to the rate reported for Argentina (1.9 per 100 000 players) between 1977 and 1997 and Ireland (0.9 per 100 000 players) between 1995 and 2004.^{5,19,20} A slightly higher average annual incidence was reported in this study for the period between 2008 and 2014 (3.9 per 100 000 players). This is likely attributed to the difference in data for player numbers used to determine the population at risk (denominator), as opposed to an actual increase in catastrophic injuries.

The previously reported average annual incidence of SCI with permanent outcomes between 2008 and 2011 (1.0 per 100 000 players)⁶ was comparable to rates reported in Australia between 1997 and 2002 (3.2 per 100 000 players) and New Zealand (between 0.8 and 1.7, per 100 000 players)^{14,21} and is similarly comparable to the results of this study (1.8 per 100 000 players). The catastrophic injury incidence rates for Boland (7.6 per 100 000 players, 95%CI: 0.0 to 18.6) and Griquas (7.9 per 100 000 players, 95%CI 0.0 to 28.5), and permanent SCI rates in Boland (7.1 per 100 000 players, 95% CI: 0.0 to 17.6) can be

classified as ‘tolerable’ risk⁵, but are nonetheless high in comparison to current and previously reported national rates.

Although the risk of sustaining a catastrophic injury may be classified as ‘tolerable’ or ‘acceptable’, the nature and consequences of these injuries can be devastating and permanently life-changing, making even one case a year as a result of participating in rugby, one case too many.²³ Therefore, catastrophic injuries remain a public concern, and the governing bodies of the sport, the players and rugby’s stakeholders should make every effort to reduce the risk and keep the risk as low as practically possible.⁵ Ongoing research is imperative in ensuring the effectiveness of the approach and, where the interventions could be better tailored to the specific rugby landscape within the different provincial rugby unions. Understanding the available resources, barriers and areas of need that are specific to an area, may further enhance rugby safety as a whole.

Considering the limitations of the study, it is possible that some catastrophic injuries may not have been reported, or that reporting in some provincial rugby unions is more comprehensive than in others. However, BokSmart’s serious injury protocol and the potential benefit of financial, logistical and psychological support that is associated with reporting rugby-related injuries in South Africa, should reduce this possibility. Information dissemination via social media and other more formal communication channels regarding catastrophic rugby injuries would generally pick up any shortfall potentially missed, though this may potentially not always be the case in very rural areas. Player numbers were assumed to constant over the seven years of investigation. Though every effort was made to obtain accurate player numbers for each union, discrepancies may exist in actual player numbers. Incidence rates were calculated as annual averages. However, Poisson regressions were run on incidence rates over the period of 2008-2014, as annual average injury numbers yielded numbers too low for this type of analysis. Thus, exposure data - total player numbers – might have been underestimated, as players are technically at risk of injury every year. However, this approach does not have an influence on the primary research question as an underestimation would be relatively consistent for every provincial rugby union. Poisson regression were only used to compare differences between provincial rugby unions. Catastrophic injury data consist by its nature of small numbers - this resulted in the wide

confidence intervals presented in this study and increases the difficulty of the comparability of these results. This said, conclusions were based on clear patterns within the data, without over-interpretations of smaller between-province trends.

Conclusion

The main finding of this study is that for the period 2008-2014 there were significant differences in the catastrophic injury rates between, and proportional distributions of catastrophic injuries within, the provincial rugby unions of South Africa. Great disparity exists in South Africa with different languages, cultures and socio-economic statuses, making the implementation of a nationwide intervention across all communities a complex task. Future studies should investigate the underlying reasons contributing to these provincial differences. Provinces with higher injury rates may require additional targeted interventions.

Practical implications

- The risk for rugby-related catastrophic injuries varies between the different geographical regions within South Africa.
- These regional injury incidence rate differences are essential information for the implementation of nationwide interventions, such as BokSmart, in South Africa.
- These findings may not be unique to South Africa and could be considered for all nationwide and large- scale intervention programs

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Chapter 3

Players' experiences of rugby-related spinal cord injury

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Abstract

Background

Though rare, rugby union carries a risk for serious injuries such as spinal cord injuries (SCIs), that may result in permanent disability. Various studies have investigated injury mechanisms, prevention programmes and immediate medical management of these injuries. However, relatively scant attention has been placed on the player's experience of such an injury and the importance of context.

Aim

The aim of this study was to explore the injury experience and its related context, as perceived by the catastrophically injured player.

Methods

A qualitative approach was followed to explore the immediate, post-event injury experience. Semi-structured interviews were conducted with forty-eight (n=48) players that had sustained a rugby-related SCI.

Results

Four themes were derived from the data. Participants described the context around the *injury incident*, which may be valuable to help understand the mechanism of injury and potentially minimise risk. Participants also described certain *contributing factors* to their injury, which included descriptions of foul play and aggression, unaccustomed playing positions, pressure to perform and unpreparedness. The *physical experience* included signs and symptoms of SCI that is important to recognise by first aiders, fellow team mates, coaches and referees. Lastly, participants described *emotional experience* which has implications for all SCI first responders.

Significance

All rugby-stakeholders, including players, first responders, coaches and referees may gain valuable information from the experiences of players who have sustained these injuries. This information is also relevant for rugby safety initiatives in shaping education and awareness interventions.

What is already known on this subject:

- Though rare, catastrophic spinal cord injuries do occur in rugby union, most commonly during the scrum and tackle.
- Previous studies addressing spinal injury in rugby union have focused on the biomechanical aspects of injury and the acute medical management after injury.

What this study adds:

- This study emphasises the context around the mechanism of injury that may be valuable to help understand the injury and potentially minimise the risk.
- Participants also described what they perceived as important contributing factors to their injury, which included descriptions of foul play and aggression, unaccustomed playing positions, pressure to perform and unpreparedness.
- Participants described their experience of the physical signs and symptoms of acute spinal cord injury that are important to be recognised by first aiders, fellow team mates, coaches and referees.

Introduction

Rugby union is a collision sport where high-energy impact forces are regularly encountered.¹ Though rare, in some instances, these impacts result in catastrophic cervical spine injuries with life-altering consequences.² In this context, catastrophic cervical spine injury refers to either a fatality due to cervical spinal injury or a severe, non-fatal acute spinal cord injury (SCI) with resultant permanent, functional disability.³ In South Africa specifically, the incidence of permanent outcome SCI has been reported to be between 1.0 and 1.8 injuries per 100,000 players per year.^{4,5}

SCI can result in devastating neurological impairments with profound effects on both the injured player and their family.⁶ Considering these long-term consequences, even one such injury per year is one too many.⁷ Therefore, it remains crucial that rugby's stakeholders strive to eliminate the occurrence of these injuries, for the benefit of all players and their families.⁷ As such, some countries have introduced nationwide rugby safety and prevention programmes. Examples are New Zealand's RugbySmart⁸ and South Africa's BokSmart

programme.⁹ South Africa's BokSmart programme was launched in 2009 by the South African Rugby Union (SARU) in conjunction with the Chris Burger/Petro Jackson Players' Fund (CBPJPF), a non-profit organisation that provides assistance for catastrophically injured players.¹⁰

Several studies have focused on the clinical, biomedical and biomechanical aspects of SCI injury in rugby. The most common types of cervical spine injury in rugby are facet dislocations, in particular, bilateral facet dislocations.^{1,11} Injuries occur most often at the C4/5 and C5/6 motion segments and have been ascribed to buckling of the cervical spinal column during impact loading.^{1,11} Reports prior to the year 2000 indicated that cervical spine injury predominantly occurred either during scrum engagement or scrum collapse.¹¹ However, more recent reports identify that cervical spine injury in rugby now occurs more often during open play, particularly during tackles.¹¹ Nevertheless, the scrum is perceived as a phase of play with considerable injury risk, as a higher proportion of scrum-related SCIs result in permanent neurological deficit outcomes compared with tackle-related SCIs.^{4,12} As noted, injury prevention programmes have been implemented in rugby. Investigations of the effectiveness of these programs in New Zealand and South Africa indicated that these programs are associated with the reduction of disabling spinal injuries.^{13,14} However, in South Africa, this effect was evident only in junior, but not in senior players.¹⁴ Finally, guidelines for on-field management of catastrophically injured players exist. These recommendations include immobilisation in a rigid cervical collar, supportive blocks and a backboard with straps, for optimal management and prevention of secondary injury in suspected SCI.^{15,16} In contrast to these investigations of clinical and management issues, there is relatively little research regarding the player's experience of a catastrophic injury.

A different level of understanding may be gained by viewing the injury from the player's perspective.¹⁷ A qualitative approach has the ability to explore players' perspectives of rugby-related SCI and to provide contextual information that may be important in optimising interventions, including injury prevention and on-field management.¹⁸ Therefore, the aim of this study was to explore the injury experience (including the injury mechanism and other contextual factor related to the injury), as perceived by rugby players who experienced a permanent spinal cord injury on field.

Methods

Design

The study design consisted of a pragmatic, qualitative approach and formed part of a broader study investigating the impact and consequences of rugby-related SCI. Pragmatic qualitative methodology aims to understand a phenomenon and the perspectives of the people involved, offering descriptive information that may inform practice.¹⁹ Ethical clearance for the study was obtained from the University of Cape Town (UCT) Human Research Ethics Committee (HREC REF: 893/2015).

Participants

For the purpose of the broader study, the entire known population (n=113) of rugby-related SCIs in South Africa, as recorded in the CBPJPF database, were invited to participate. Participants were eligible if they were 18 years or older and if at least one year had elapsed since injury (n=102). Ninety (n=90) of the 102 eligible recipients on the CBPJPF database, from around South Africa, agreed to participate and provided informed consent. These participants are referred to as the 'initial sample'. From the initial sample, purposive sampling was used to select 48 interviewees for the current study.²⁰ It has previously been shown that significant differences exist in the catastrophic injury rates between the different provincial rugby unions of South Africa.⁵ It is also evident that South Africa is extremely diverse with regards to factors such as socio-economic status (SES), which poses additional challenges in the management of rugby-related SCIs for players from disadvantaged backgrounds.²¹ Thus, for the purpose of the broader study, a stratification process was used to gather a range of views from players from a variety of SES and geographical areas to provide maximum variation in experiences and richness of information. SES was determined by means of an asset indicator approach with data obtained from questionnaires completed by all participants in the broader study.²² The selection of cases with maximum variation was done to ensure that the knowledge gained is representative of the population from which the sample was drawn and to present the diverse views within the population under investigation.²⁰ Purposive sampling was thus conducted with the aim to find a proportionate representation of each province and SES group. Sampling continued alternately from each

group until saturation was reached. Saturation was determined when no new codes or themes were identified.²³ The sample characteristics are described in Table 1.

Table 1. Sample characteristics.

	Number / Range
Timespan of injuries	1968 – 2015
Age (yr) when injured	15 – 37
Current age (yr)	18 – 68
Level of play	
<i>School / Junior</i>	12 (25%)
<i>Club / Senior</i>	34 (71%)
<i>Correctional services</i>	2 (4%)
Type of play	
<i>Match</i>	43 (90%)
<i>Practice</i>	5 (10%)
Phase of play when injury occurred	
<i>Scrum</i>	24 (50%)
<i>Tackle</i>	18 (38%)
<i>Other</i>	6 (12%)
Functional outcome	
<i>Wheelchair bound quadriplegia</i>	46 (96%)
<i>Ambulant quadriplegia</i>	2 (4%)

Data collection

Individual interviews were conducted with participants at their homes or places of work by MB, a Physiotherapist, trained in qualitative methods. Interviews typically lasted 50 – 90 minutes and were audio-recorded. The interviews did not only focus on the initial experience of the injury, but also included questions regarding other objectives of the broader study, which will be reported elsewhere. The semi-structured, open-ended questions were pilot tested with a person with a rugby-related SCI and modified according to his feedback. Recursive questioning was used to verify the researchers understanding of information being

collected. Interview recordings were entered and organised in Nvivo11™ software (QSR International, 2015).

Analyses

The analysis of this study focused on the introductory part of the interview regarding the immediate on-field management, where participants were asked to describe what happened. This open-ended questioning left it to the participant to decide what aspect of their injury incident was important to share. Interview transcripts were analysed thematically.²⁴ This process started with familiarisation of the data, by listening to the audio files and by writing notes about possible codes and patterns. Thereafter, an iterative process was undertaken to generate codes. Initial codes for the first seven transcripts were generated by MB and JB and discussed until consensus was reached regarding their meaning. The remaining transcripts were then coded by MB. Finally, codes were grouped into categories with similar meanings to create higher-order thematic categories. Codes were collaboratively reviewed by JB, MB and EV until final categories and themes were generated.

Results

Four themes with associated categories were derived from the data. These themes were i) *the injury incident*; ii) *contributing factors*; (iii) *the physical experience* and (iv) *the emotional experience*.

1. The injury incident

This theme relates to the participant's perception of the phase of play or mechanism responsible for injury. (Table 2).

Table 2. The injury incident.

Categories	Substantiating quotes
<p><i>The scrum engagement injury:</i> <i>'I wasn't ready'</i></p>	<p>I broke my neck going into scrum, playing hooker, and for some reason we didn't get my head under the other guys shoulder and I hit my head straight onto his shoulder. And I felt a buzzing sensation...and the scrum broke to let me back in again and I just dropped to the ground...I sometimes think that is where the damage occurred...as I fell, because nobody supported me you know you expect everybody to keep standing but nobody knew what had happened...[P9]</p> <p>In the scrum, I told the referee that the guy I am playing against was engaging skew...He said he will have look. In our next scrum...it was too late for me...I felt the life draining out of me...[P22]</p>
<p><i>The scrum collapse injury:</i> <i>'It just collapsed again'</i></p>	<p>I was in the scrum...and the scrum just collapsed again, and my neck just bent and cracked, and I fell...[P27]</p> <p>The referee that was handling the game had to control it better...If he saw that, that that guy was pulling the scrum down then it would have never happened...I tried convincing the ref that it wasn't me by staying on my feet even though my head was on the ground, while the other guy was flat on his stomach...and I think that is where I made the mistake and placed myself in danger...[P56]</p>
<p><i>The ball carrier's injury:</i> <i>'I didn't see them coming'</i></p>	<p>I was scrumhalf and they tackled me from behind, nothing malicious, I just didn't see him. I couldn't stop my fall, I fell on my neck and was instantly paralysed. [P57]</p> <p>We were playing nicely, we were winning and then a guy tackled me from nowhere and he forced my head down and then I realised</p>

when he got up...I thought no man I am lying skew, I tried to get up, but I couldn't move...[P41]

The tackler's injury:

'He changed direction at the last moment'

I was playing rugby at varsity and then I tackled a guy and I was supposed to go in with my shoulder, but he changed direction at the last moment and I hit him with my head and my neck bent all the way to my chest...and I dislocated my neck...[P90]

The tackle technique injury:
'My neck was in the wrong place'

He got the ball again and I tried to tackle him and hold him up, but my neck was in the wrong place and we both fell with all our weight on my neck and I tried not to, but he was stronger than me...[P35]

I tried to tackle a guy and I went in very low, too low...his knee hit my neck...and well yes that was that...[P52]

Other mechanisms of injury:
'The momentum of the guys kept coming'

There was a maul and the guys pushed me back and I fell over backwards, but the momentum of the guys kept coming and pushed my legs over my head...and then they fell on top of me. It was like a tree branch bending and then breaking...[P8]

I didn't even play really, because I got injured in the first kick-off the match, I jumped for the ball, I am tall, they relied on me, I went up and I didn't get the support from my ranker (front-ranker) and the opponents came as if they were going into scrum! [P67]

1.1) 'The scrum engagement injury: 'I wasn't ready'

The majority of injuries occurred in the scrum and specifically in the scrum engagement phase. At least half of the participants injured during this phase described '*not being ready*' for impact:

As I went down I realised I wasn't ready, I tried to pull up...as I came up my head was still bent, the scrum caught me on top of the head... so I crashed and dislocated, it was instant...I knew instantly what had happened. I just collapsed back onto the locks...[P44]

Most of the participants injured in the scrum engagement phase, were playing in the hooker position. Participants also described '*not being properly aligned*' before impact. Players' heads colliding against the opponents' shoulders was frequently described as the mechanism of injury during engagement:

As we hit in, my head hit the opposition's shoulder and the locks came in slightly late and with that movement I dislocated my neck and severed my spinal cord pretty much straight away...luckily the guy that was scrumming next to me, he felt my body go limp and he held onto me and he lay me down on the ground...[P20]

1.2) The scrum collapse injury: 'It just collapsed again'

Some players described a collapsed scrum causing their injury. A few players specifically mentioned multiple collapsed scrums before the injury occurred.

The scrum collapsed twice. The third time the scrum collapsed, I fell... I didn't know what happened, I was facing down, and I heard the players shouting...[P42]

1.3) 'The ball carrier's injury: 'I didn't see them coming'

The second most common cause of injury reported was the tackle. Injuries sustained during the tackling movement were often when the ball-carrier could not see the tackler. Some players also described being tackled by two players simultaneously:

I was attacking, but two were trying to tackle me, one was coming on the side and one was coming on the back...and my mind was only concentrating on the one coming on the side...you are concerned with the ones in front or on the side, but you don't see the ones behind...[P37]

1.4) The tackler's injury: 'He changed direction at the last moment'

Injuries sustained by the tackler were often because the ball carrier changed direction at the last moment:

I wanted to tackle him, but as I dove...I was already in the air...he side-stepped, and my head connected with his thigh. My neck bent, I fell backwards...and then I felt nothing...[P19]

1.5) The tackle technique injury: 'My neck was in the wrong place'

Additionally, a number of players described incorrect tackling technique as cause of the injury:

I tried to tackle him and hold him up, but my neck was in the wrong place and we both fell with all our weight on my neck and I tried not to, but he was stronger than me...[P35]

1.6) Other mechanisms of injury: 'The momentum of the guys kept coming'

A low number of players sustained their injury during other actions, such as the maul. This often involved other players falling on top of the player.

We started a drive and I kept the ball back...and my team mates went either left or right, but I went straight ahead...straight into the opponents and they drove me back. I fell over my own feet...someone fell on top of me and my head was pushed forward until it couldn't bend anymore...[P76]

2. Contributing factors

This theme encompasses additional factors (apart from actual injury mechanism) that were considered as contributing factors to the occurrence of the injury. (Table 3).

Table 3. Contributing factors

Contributing factors	Substantiating quotes
<i>Aggression and foul play:</i>	The guy that I played against told me before the game that he was going to write me off... I played against him the week before and I gave him a bit of a hard time then...[P56]

'He told me he was going to write me off' It was a dirty game, we were fighting...intimidating each other...they were known for not playing a clean game...and then it happened...[P13]

Pressure to perform: 'No one else could tackle him, except me' The other team were coming for us and I thought if I lose this ball we are going to lose our match. It wasn't easy...the first time played against those guys they beat us 50 - 0...so I told myself we are not going to lose today...[P68]

Unaccustomed playing positions: I usually play number 8, but that morning they put me on as hooker...it was the first time I had ever played hooker...[P29]

'Just come and play' But that day I was only playing 5 minutes, I was an outside centre...but it is not my position...but the guy who is supposed to be there was not there. My usual position is Wing. They just said to no, just come and play that position...[35]

Premonitions and being unprepared: 'I was not supposed to play' Firstly, I must say, I was never, never before so afraid to play as I was that day...you know I said something that I remembered a few months later...I asked one guy who was part of the team to pass a ball to me, because it might be the last time that I handle a rugby ball...[P67]

I was not supposed to play...and then the guys asked me they said we are short of players can't you help us? So, I pitched up...[P41]

2.1) Aggression and foul play: 'He told me he was going to write me off'

A few players mentioned that they felt they were 'marked' and that the opposition was trying to 'take them out'. Some participants perceived foul play to cause their injury:

It was a late tackle...a high tackle...and both guys collided on top of me...so the one who did the high tackle broke my neck...[P37]

In contrast, a player described himself performing an intentionally dangerous tackle, which lead to his own injury:

I had the challenge of tackling this guy, but like rugby players are, you want to write that person off...I tackled him, I speared him...I tackled on the wrong side, wrong technique and his arm was over my neck and as he fell I fell too...[P85]

One player specifically spoke about racial dynamics and associated aggression in rugby and how he perceived it to lead to his injury:

I don't think about it much but there was a bit of racial element there...I don't want to go there because I am past that now, but they knew that our scrum was not set well enough for a proper scrum...they could have stopped...they could have stopped...especially for the fact they heard me scream...you know what I mean, my neck didn't just break immediately. It broke because they continued to push...[P64]

2.2) Pressure to perform: 'No one else could tackle him, except me'

Having more pressure to perform on the day was also reported by some participants as a possible contributing factor:

There was a guy from Butterworth he was a big guy, no one else could tackle him, except me...they told me to just watch that guy...he was so tough...I tried to mark him but then he scored a try and the guys were mad at me, they said how could you let that guy score a try? I thought to myself, what can I do to stop this guy...[P35]

2.3) Unaccustomed playing positions: 'Just come and play'

Another contributing factor identified relates to unaccustomed playing positions. These were particularly evident in the hooker position:

The hooker got a red card and had to go off the field. I was a flank, but they moved me to hooker and 10 minutes after that, I broke my neck. I was never a hooker, I had always played number 6...[P31]

Additionally, a couple of participants mentioned that they felt that they were either too tall or too skinny to play in the hooker position.

2.4) Premonitions and being unprepared: 'I was not supposed to play'

Some participants identified some form of unpreparedness for the game. They were either not actively playing anymore, or were not supposed to play that day and was asked to play at the last minute:

I was focusing on my work, not on sport anymore. But then they said they needed me, and I was a good player. The guys were saying they all wanted me to come, but I didn't want to play. After two tries and a penalty, it happened ...[P29]

Interestingly, some players described a 'premonition' or a feeling that something was going to go wrong:

Basically, I had a weird vibe before I got into field... I was never really a religious...or spiritually inclined person...but basically everything just felt bad, I had a bad vibe throughout my body even my boots didn't feel the same, the uniform didn't feel the same...[P64]

3. *The physical experience*

Participants recalled the physical experience, most often by describing the associated neurological symptoms of an SCI (Table 4).

Table 4. The physical and emotional experience.

The physical experience	Substantiating quotes
<i>Suspecting serious injury:</i> <i>'No one should touch me'</i>	<p>My team mates were with me immediately and I told them not to move me...I knew there was something very wrong, immediately I couldn't feel anything, and I struggled to breathe...[P76]</p> <p>I knew that they shouldn't touch me because I immediately knew something is wrong...there was no feeling in body...[P1]</p>

Confusion about the injury:

‘Why can’t I move?’

I didn’t even know that I had hurt my neck, there was no pain...there was nothing. I just felt myself falling to the ground. But there on the ground I just realised I couldn’t move anything, I am just lying there...[P65]

I fell...and I wanted to stand up and I couldn’t, and I couldn’t understand why I couldn’t stand up, because I was not unconscious! I was fine...? And my team mates said to me get up, stand up and they wanted to try and help me get up, but luckily the people from the ambulance they came on the field and they checked, and they asked me if I am fine, and I still said to them I am fine...I just can’t stand up. [P37]

The signs and symptoms of SCI:

‘Put my legs down!’

All your senses are immediately gone, you can’t see, smell or nothing...I felt like I was lying in a foetal position, but I couldn’t see, I asked a friend and he said no, you are lying with your legs stretched out. [P17]

I thought, no man I am lying skew, I tried to get up, but I couldn’t move, I asked my friends: Guys, pick me up and put me outside of the field. When they tried to pick me up they said no man, you are heavy we can’t lift you...I didn’t know anything about spinal cord injury. I felt my whole body from my chest down, it was burning, burning...I asked them to take my boots and socks off and they said no man, we have already taken it off...I said why am I so hot? [P41]

The emotional experience Substantiating quotes

***The moment of truth:
‘I started crying and I knew’***

I realised in the emergency room things are bad, because I saw a nurse standing with my boots in her hand, but I never felt her take it off...[P74]

They saw my one leg bent under the other and they asked if I could straighten it but I couldn't...they straightened it for me and told me I broke my neck...there lying next to the field, I was praying with my Dad. Later in hospital after x-rays two Doctors came to me told me to just lie very still, then I knew. My dad came and bent over me and I could feel his tears drip on my face and told me, you broke your neck, you are paralysed, and I thought while lying there what am I supposed to do now...[P12]

***Initial Emotions:
'It was terrifying'***

It was the most frightening moment of my life...Here you are lying, knowing you can't do anything...[P49]

That is one thing that was bad, once you are in the ambulance you just want to sleep...but I don't mean normal sleep...you can feel that you just want to go...it was terrifying...like dying...subconsciously...you don't realise it, but yes...[P74]

3.1) Suspecting serious injury: 'No one should touch me'

Some players immediately knew something was wrong:

I could hear it break and I immediately knew it was broken. I started feeling numb from feet and finger tips, I could feel it happening over few seconds. I told them I broke my neck, and no one should touch me...I knew that no one should touch me...[P13]

3.2) Confusion about the injury: 'Why can't I move?'

In contrast, other players were confused about what had happened and what they were feeling. The participants frequently described trying to get up or asking others to help them up:

I fell back...then they took my legs and put it over my head... I said stop don't do this. My teammates didn't understand what was going on, but even me I didn't understand! We have never had something like this...I didn't know my neck was broken...[P35]

3.3) *The signs and symptoms of SCI: 'Put my legs down!'*

Various neurological experiences were described. The majority of participants described an immediate perception of losing feeling in their bodies, not being able to move or feeling 'lame'. Similarly, a couple of players described a feeling of 'life draining out of them'. Participants described pain, burning sensations, 'buzzing', and 'pins and needles':

It was like a branch bending and when it broke...bang, bang...it was very sore. I couldn't straighten my legs and I asked them to please straighten my legs. It was a strange sensation. I had pain in my neck and I felt like someone had poured petrol on me and set me on fire! I asked them to please go get them some water on me and throw it on me, I am burning! [P8]

Additionally, participants described loss of proprioception of their bodies or limbs, which often resulted in them asking team mates to move limbs that felt were in awkward positions:

I just heard the bones cracking...when they got off me I was lying on my stomach. The ball was still under my chest, I was shouting...and I said to my friends just put my legs down my legs are in the air! And they said no man, your legs are on the ground! [P77]

Some players reported no pain, just the inability to move. Difficulty breathing or being unable to talk, were also described by some. A few participants report a flitting inability to see or hear.

4. *The emotional experience*

Some participants described their initial emotional response and moment of realisation of what had happened (Table 4).

4.1) *Initial Emotions: 'It was terrifying'*

One player mentions the sadness of the situation, lying in the rain, waiting for an ambulance. For some participants inadequate management lead to their increased anxiety:

The first-aiders made me very nervous because they were standing there talking about a stretcher and they didn't have one...I tried to lie as still as possible...[P15]

Another describes the terror of feeling that he was dying, while in the ambulance.

4.2) *The moment of truth: 'I started crying and I knew'*

The realisation that something was seriously wrong sometimes occurred on field, in the ambulance or later in hospital:

One of my friends was with me in the ambulance and I told him I wanted to put my arms on my chest, because they were hanging next to stretcher, but I couldn't lift my arms. I actually realised on the field already something was very wrong. I started crying and I knew...my friend asked me why I am so upset, I probably just broke both my collarbones, but later he started crying as well...[P8]

Discussion

This study has identified novel information for the prevention and management of rugby-related SCIs. Participants, who were injured during either the scrum or tackle phase of play, described the specific injury mechanisms in detail. Some also reported additional contributing injury factors, such as foul play and aggression, unaccustomed playing positions, pressure to perform and unpreparedness. This study's findings also provided insight to some of the first signs and symptoms of SCI, which has implications for rugby coaches, referees and medical staff for the early recognition of these injuries.

For the participants in this study, most injuries had occurred during a scrum. Scrumming places high biomechanical demands on players' musculoskeletal structures and exposes front row forwards to the risk of injury.²⁵ Specifically, the scrum engagement was mostly identified as the phase responsible for injury, which reflects the findings of Hendricks et al.¹² New scrum laws were set into place in 2013¹² and only one player described a collapsing scrum causing the injury since the law change. Therefore, the findings of the current study highlight the importance of the modifications to the scrum laws, to make this phase of play safer.¹² Holsgrove et al.¹ stated that further research is required to simulate cervical spine injury mechanisms and how the risk of them occurring can be minimised. The current study emphasises that the context around the injury could be extremely valuable to help minimise the risk. For example, participants described not being ready, or not properly aligned before

impact. These factors are crucial to consider within the complexity of the injury mechanism. Moreover, these findings reiterate the importance of education and execution of proper scrum technique.⁹ Ultimately, teaching a safe technique should enhance overall scrumming ability and therefore team performance.²⁶ Unlike the tackle, the scrum is a more structured phase of play, managed by the referee and therefore more receptive to interventions.^{12,13} Thus, it emphasises the importance of the referee's responsibility in ensuring a safe scrum. It also warrants initiatives such as the Australian rugby union's (ARU) 'Mayday' procedure; a safety technique implemented for players to alert the referee when one of them is in a potentially dangerous position in a scrum.²⁷

The participants identified the tackle, after the scrum, as the phase of play where injury most often occurred. During tackle injuries, participants who were ball carriers often reported not being able to see their tackler before their injury. This supports the findings of Burger et al.²⁸ indicating that ball carriers were less likely to be injured when they were aware of impending contact. It has previously been described that ball carriers are at highest risk for injury from tackles to the head-neck region, whereas tacklers had the highest risk when making low tackles.²⁹ Similarly, participants often mentioned that as tackler, they were performing the tackle too low when injured. Strategies for reducing tackle injuries include continued education of players about safe tackling, better communication between team mates and controlled non-contact and contact drills for the development of peripheral vision.^{26,29,30} Again, the referee plays an important role in tackle safety, as studies have shown that high tackles are often not penalised by referees.^{31,32}

The majority of the participants in this study was playing in the senior age group when injured. The senior age group have previously been shown to have higher incidence rates of permanent outcome SCIs.⁴ Moreover, the BokSmart rugby safety programme has been shown to be successful in reducing catastrophic injuries in junior players, but not in senior players.¹⁴ The authors postulated that there may be some potential contributing factors responsible for the difference between groups. These factors included low numbers of players in the senior group, which could force players to play in unfamiliar positions, other factors such as increased competitiveness and aggression and the risk of injury for the '*weekend warrior*' (adults who play irregularly or only on weekends without sufficient

training, conditioning or coaching).⁴ The participants of this study provided some evidence for these contributing factors previously postulated by Brown et al.⁴ Firstly, participant accounts included descriptions of foul play and aggression. Undoubtedly, intense physical contact is an integral part of many sports, including rugby.^{33,34} However, foul play or acts of unsanctioned aggression, that are likely to cause serious injury, are not a functional part of sport and every effort should be made to eradicate their occurrence.³³ Motivation behind these acts may differ across individuals and circumstances. Coaches are important influencers of player behaviour in rugby³⁵ and can therefore play a key role in this regard.

These findings are critical to the strategies of rugby safety programmes, including BokSmart, which relies on coaches and referees to disseminate their content. Further education with an emphasis on the consequences of unsanctioned aggression and foul play is a consideration for inclusion in the BokSmart program. All factors considered, the choice of behaviour and sportsmanship lies with each player. However, adequate information, awareness and coaching may facilitate this choice. Additionally, for some participants, pressure to perform was an issue. Pressure is an inherent part of sport, but players and coaches should be aware that '*winning against all odds*' and '*putting your body on the line*' may at times have serious repercussions.³⁶ The drive for success must not supersede the welfare of players.^{26,36} This also relates to players playing in unaccustomed playing positions without the necessary training and skill. Hermanus et al.²¹ found 20% of players who sustained SCIs in their survey, reported not playing in their usual positions.²¹ Similarly, the participants in this study indicated that playing in unaccustomed positions, especially in the scrum, is reason for concern. Coaches have a responsibility to ensure that each player in the front row and potential replacements, must be suitably trained and experienced.^{26,33} Some participants mentioned that they were not supposed to play, had stopped playing or had not played for a while, but were asked to play a match at the last minute. The importance of progressive physical conditioning in injury prevention has previously been reported.³⁷ The fact that some of these participants stepped into a game situation unexpectedly might suggest that they were unconditioned and unprepared, increasing their injury risk. A few participants also mentioned fear or a premonition of getting injured shortly before the actual event. This finding may warrant further in-depth investigation of possible reasons for fear and anxiety. One possibility may be that for some reason, the player did not feel fully prepared to play.

Players should feel comfortable enough to raise specific safety concerns, such as these, with their coach. Similarly, coaches should comply with regulations that are concerned with the safety of players and be receptive to players' concerns. These aspects of communication and player welfare may be further highlighted within the BokSmart program.

When SCIs do occur, early recognition of the signs and symptoms can prevent secondary injury and expedite medical management.¹⁶ First responders are generally taught to check for spinal tenderness, restricted range of motion, and bilateral neurologic deficits.¹⁶ The findings of this study offer a comprehensive description of what the player may feel and importantly, verbalise to their team mates, the referee or coach, immediately after injury. All participants described the sudden inability to move. Additionally, neurological sensations such as intense burning, pins and needles and impairment of the senses are described. Several participants reported proprioceptive disturbances. Players asked teammates to move their limbs or put them down, as it felt as if they are floating in the air or bent in awkward positions. Similar proprioceptive disturbances were reported in the qualitative study of Sparkes and Smith³⁸ which comprised of three men who sustained SCI while playing rugby. One of their interviews revealed the player had asked his teammates to '*put my arms and legs down on the floor*'.³⁸ These proprioceptive disturbances are important warning signs for both teammates and first responders. Importantly, players with SCI mostly present with a normal level of consciousness and normal cardio-respiratory function³⁹, as was seen in this study. The seriousness of the injury of a conscious player may be underestimated initially, compared to an unconscious player. This may create confusion and compromise initial treatment. Findings within the broader study indicated that in cases where no first aiders or medics were present, bystanders often handled seriously injured players inappropriately. Some teammates proceeded to move the injured player as they thought he just seemed 'winded', especially in cases where players had difficulty breathing. Additionally, while some players report excruciating pain, others report no pain. Therefore, it is important to reiterate that the absence of pain is not necessarily equal to the absence of injury. Data from the BokSmart serious injury report indicated that the emergency number for suspected head or spinal cord injury, SpineLine, was not contacted in some cases because the severity of the injury was not recognised (BokSmart Serious Injury report, 2014). Thus, especially in amateur games and communities that have less resources and medical support, these signs

and symptoms are important to recognise by fellow team mates, coaches and referees, as they are often the closest and first to respond to an injured player. Coaches and referees are specifically targeted as they are the key decision makers controlling both the game and the players on the field. In many situations within South Africa, the coach may be the only person available to deal with an injury. It is concerning that a recent study reported that some coaches stated that knowing how to deal with a catastrophic injury was not something they had to worry about as coaches.³⁵ It follows that coaches and referees place themselves and others at risk if they are not fully educated or equipped to deal with these injuries.²⁶ The findings of this study regarding the signs and symptoms of SCIs, may be utilised by BokSmart in their mandatory biennial courses to educate coaches and referees in the early recognition of these injuries.

Lastly, an injury of this nature creates a severely anxious and overwhelming situation.⁴⁰ Similar to the work of Ogilvie⁴⁰, participants in this study shared their sense of being physically and emotionally overwhelmed. In the '*moment of realisation*' what was safe and known in their lives changed to what is now unknown in their futures.⁴¹ These immediate experiences of being paralysed serve as a reminder and context for understanding, for all involved in emergency medical management and sport safety.

This study is not without limitations. As part of the broader study, a sampling strategy that was representative of the population of rugby-related SCI was employed. It is likely that a smaller sample with more in-depth interviewing could have yielded additional depth within the findings. The sample also consisted of participants with varied socio-economic backgrounds. As a white, middle-class healthcare professional, the interviewer was particularly aware of the possible power differentials that may arise during interactions with participants from low socio-economic areas.⁴² As a Physiotherapist with work experience in rural areas of South Africa, every effort was made to be mindful of these interactions, to create a relaxed atmosphere that invited unrestricted sharing of experiences. Nevertheless, this relationship may still have determined the sharing of selective information for some participants. Similarly, as a female, discussion around the mostly male dominated game of rugby introduced another dynamic within the interview. As such, the researcher invited as much information from the participants as possible, thereby positioning the participant as

the 'expert'. This may be a strength of the study, as it may have limited assumptions and instead relied on clarification and explanation by the participant. However, the opposite may also hold true and the researcher may not have been able to fully gain their trust. Additionally, the participants in this study were asked to talk about factors that are part of an event that abruptly and traumatically changed their lives and the researcher acknowledges that this may have placed limitations of what some participants were able or willing to discuss. It was also important to take note and reflect on the ways in which the researcher's emotional responses to the participants could shape the interpretations of the interviews. Periodic discussions with the project supervisors and peers were utilised to gain different perspectives and to test assumptions.⁴³ Additionally, to enhance credibility of the findings, coding was performed by two authors, independently of each other and discussed until consensus was reached. Codes were then collaboratively reviewed by three authors until final categories and themes were generated, questioned and refined.

Lastly, It must be noted that it is not necessarily one or two single causes that increases injury susceptibility, but rather combinations of factors that put the person in a vulnerable situation.⁴⁴ Nonetheless, our findings may be transferable to other rugby settings and can be utilised to inform and educate players, coaches and referees in general. Future studies should further explore, amongst others, perceptions of contributing factors reported in this study. The knowledge of players and medical staff regarding catastrophic injuries should also be explored, as this may help shape future interventions.

Conclusion

This study explored the player experience of catastrophic injury in rugby. Participants described the context around the injury, which is valuable to help understand the mechanism of injury which can in turn inform potential prevention opportunities. Participants also reported on perceived contributing factors to their injury, which included descriptions of foul play and aggression, unaccustomed playing positions, pressure to perform and unpreparedness. Additionally, the findings provided insight to some of the first signs and symptoms of SCI. Early recognition of these signs and symptoms can prevent secondary injury, expedite medical management and optimise the outcomes of injured players. Lastly, participants described the traumatic emotional experience which results from an injury of

this nature. The findings of this study have implications for all involved in emergency medical management of rugby-related SCI. This information is also relevant for rugby safety initiatives in shaping education and awareness interventions. Though these injuries are rare, all stakeholders, including players, coaches and referees, should be aware of the possibility of such an injury, be educated to recognise them and be aware of the relevant protocol to follow.

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Chapter 4

Players' experiences of barriers and facilitators of the immediate management of rugby-related acute spinal cord injury

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Abstract

Most contact sports, including rugby union, carry a risk of injury. Though acute spinal cord injuries (SCIs) in rugby are rare, the consequences of such injuries are far-reaching. Optimal management of these injuries is challenging, and a detailed understanding of the different barriers and facilitators to optimal care is needed. In this study, we aimed to describe the perception of players, regarding factors related to the optimal immediate management of a catastrophic injury in a developing country with socio-economic and healthcare inequities. The most frequently reported barriers were transportation delays after injury and admission to appropriate medical facilities. Other barriers included inadequate equipment, the quality of first aid care and barriers within the acute hospital setting. Barriers were more prevalent in rural and lower socio-economic areas. These findings are relevant for all rugby-stakeholders and may help shape education, awareness and future policy around the immediate management of SCIs.

Background

Rugby union, henceforth rugby, is a high-paced, unhelmeted collision sport that is popular across many countries worldwide.¹ As rugby is a full contact sport, there is a relatively high risk of injury, some of which is unavoidable.² However, special consideration should be given to *severe* injuries that have the potential to result in permanent disability.³

A catastrophic injury can be classified as any head, neck, spine or brain injury that is life-threatening, or has the potential to be permanently debilitating.⁴ Acute spinal cord injuries (SCIs) account for the highest prevalence of rugby-related catastrophic injuries.⁴ The incidence of SCIs with resultant permanent neurological deficit, has been reported as 1.0 to 1.8 injuries per 100 000 players per year in South Africa.^{4,5} Catastrophic injuries occur in different phases of play during rugby, but the phases with the highest risk are the tackle and the scrum (a set formation in which eight players from each team bind together). However, a higher proportion of scrum-related cervical injuries result in permanent SCIs, compared to tackle-related cervical injuries.⁶ Though SCIs are rare in rugby, the consequences are far-reaching, for the player, the family of the player and the image of the sport.²

Strategies to make the game safer with regards to such catastrophic injuries have been implemented. These strategies included scrum law changes, which are aimed at lowering the impact of engagement and reducing the number of collapsed scrums⁶ as well as rugby safety programmes, such as RugbySmart in New Zealand and BokSmart in South Africa.^{7,8} BokSmart focuses on injury prevention and management with special attention to catastrophic head and spine injuries. The programme was launched in 2009 by the South African rugby union (SARU) in conjunction with the Chris Burger Petro Jackson Players' Fund (CBPJPF), a non-profit organisation that provides support for seriously injured players.⁹ BokSmart has implemented compulsory, biennial, rugby safety workshops that are aimed at all coaches and referees nationally.⁸ These workshops include education and training on safe rugby techniques and basic medical and injury prevention practices.¹ Apart from the BokSmart Rugby safety workshops, BokSmart also consists of: (i) The BokSmart Rugby Medic programme – a rugby-specific first aid short course, aimed at underprivileged communities and (ii) The BokSmart SpineLine - a toll free number aiding in management and transportation of players who have sustained a serious head or spine injury.⁸ SpineLine

is linked to a privately owned, national emergency service provider, ER24, that fast-tracks the emergency treatment of the seriously injured rugby player by dispatching suitable transportation to the nearest and most appropriate private or public medical facility.¹⁰

Optimal immediate medical management following a SCI should consist of safe and efficient immobilisation (with a rigid cervical collar, supportive blocks and backboard) by trained medical personal, and the expeditious transfer to trauma facilities equipped to deal with SCIs.¹¹⁻¹³ In this regard, optimal management of SCIs may contribute to the functional outcome of the injured player.^{13,14} However, immediate medical care of rugby-related SCIs prior to the launch of BokSmart in 2009 was inadequate, with 34% of players receiving no on-field management.¹⁵

More recently, unpublished data from the 2014 BokSmart serious injury report, indicated that 11% of players received no on-field management for SCIs in the 2008 - 2014 period.¹⁶ Though improvements have been noted, the implementation of a wide-scale intervention such as BokSmart remains challenging in a diverse, developing country such as South Africa.⁸ This is evident in the significant differences in catastrophic injury rates between the different provincial rugby unions of South Africa, suggesting that different geographical areas may have different challenges and requirements for prevention and management of injuries.⁵ It must also be noted that the legacy of Apartheid, which is the period in South Africa's history characterised by enforced racial segregation, has resulted in tremendous inequity and uneven distribution of economic growth between ethnic groups in South Africa that still remain evident today.^{17,18} These challenges are specifically prominent in rural, low-socio-economic (SES) communities.¹ These disparities are also evident in the rugby-playing society, where differences between playing facilities and levels of coaching create additional challenges for players from low SES communities.¹⁵ Additionally, SES disparities are also reflected in the composition of national teams, which are not representative of the composition of the South African population.¹⁹ Players from lower SES are less likely to have the same development opportunities and factors such as nutrition is also likely to be less optimal, which may affect their body mass and stature.¹⁹ Moreover, in low SES, under-resourced communities, the medical management of catastrophic injuries are problematic

due to factors such as distance to hospitals, difficult terrain for transportation, and limited resources.¹⁵

Various guidelines with respect to the immediate management of these injuries are presented in the literature.^{13,20} However, viewing experiences of the immediate management of a SCI through a player's eyes may make all stakeholders (including governing bodies, coaches, referees and medical personnel), more responsive to their needs and, thereby, in a better position to provide optimal care.²¹ The optimal management of such injuries may be influenced by various barriers and facilitators present at the time of injury and these factors need to be understood in their respective contexts. Thus, by applying qualitative methods, we can gain an in-depth understanding of a specific management process and gain insights that may shape future, context-driven interventions.^{22,23} This is the first study to describe players' perceptions of the immediate management of a rugby-related SCIs within the South African context, in both the periods before and after the implementation of BokSmart.

Methods

Design

The study followed a pragmatic, descriptive, qualitative approach, which draws from the most practical methods available to answer a specific research question, to offer a comprehensive summary of events from the perspectives of the people involved.²⁴ This approach was deemed best suited to provide descriptive, practical information to inform professional practices within this area of sports injury management. This study forms an introductory part of a broader project investigating the consequences of rugby-related SCIs.

Participants

For the purpose of the broader project, the entire known population (n=113) of players who had sustained a rugby-related SCI in South Africa in the period of 1968-2015, formed the population of the study. These players were all male. Access to the database of injured players was obtained from the CBPJPF. Participants were eligible to participate if they were 18 years or older and had sustained their injury a minimum of 1 year before the start of the study (n=102). Ninety of the 102 eligible recipients on the CBPJPF database agreed to participate and were included in the broader study. From the 90 interviews of the broader

study, stratified purposive sampling was used to select interviews for inclusion in this study, with the aim to provide maximum variation in experiences and thus enhance transferability.²⁵ The stratification process was used to gather a range of views from players from a variety of SES and geographical areas and is described in detail in Appendix 1. Saturation was determined when no new codes or themes were identified.²⁵ The final sample consisted of forty-eight (n=48) participants (Appendix 2).

Data collection

Individual, semi-structured interviews were conducted at participants' homes or places of work. Interviews typically lasted 50 – 90 minutes and were audio-recorded. Semi-structured, open-ended questions were pilot-tested by a person with a rugby-related SCI and altered according to his feedback. Recursive questioning was used to explore issues, and to verify the researchers understanding of information being collected.²⁶ The interviews did not only focus on the immediate management of the injury, but also included questions regarding other objectives of the broader study, which are not reported on in this study.

Analyses

Interview recordings were organised and transcribed verbatim in Nvivo11 (QSR International, 2015). Thematic analysis was used to analyse data.²⁷ Initial codes for the first seven transcripts were generated and then discussed until consensus about their meaning was reached. Thereafter, the remaining transcripts were coded. The final process involved grouping of codes into categories to create higher-order thematic categories. Codes were reviewed and discussed until final themes were generated. Within this study, it was important to take note and reflect on the ways in which the researcher's emotional responses to the participants could shape the interpretation of the interview data during analysis.²⁵ Therefore, periodic discussions with the project supervisors (co-authors) and academic peers not actively involved in the project, were utilised to gain different perspectives within the analysis of the findings and enhance trustworthiness.²⁵

Ethics

Ethical clearance for the study was obtained from the University of Cape Town (UCT) Human Research Ethics Committee (HREC REF: 893/2015). During the recruitment

process, the study was explained telephonically. Written informed consent was obtained from participants who had agreed to participate, before the start of each interview. Any participant unable to sign the consent form was asked to appoint a representative to sign the form on their behalf.

Findings

Findings were divided between the periods before and after the implementation of BokSmart, where applicable, to provide the necessary context for meaningful conclusions. This was necessary, as players injured pre-BokSmart, often refer to these as the '*old days*' or the '*wild years*' and realised their management was different to what could be expected post-BokSmart, as one participant explains:

Basically, the obvious thing about my situation is that there is now such a programme (BokSmart), while for me there was no such thing...you can see that something like this was needed...I mean we were just coached by someone's Dad...and a teacher that didn't really care...but now you must be an accredited coach.

Three themes with associated categories were derived from the data and are presented in Figure 1.

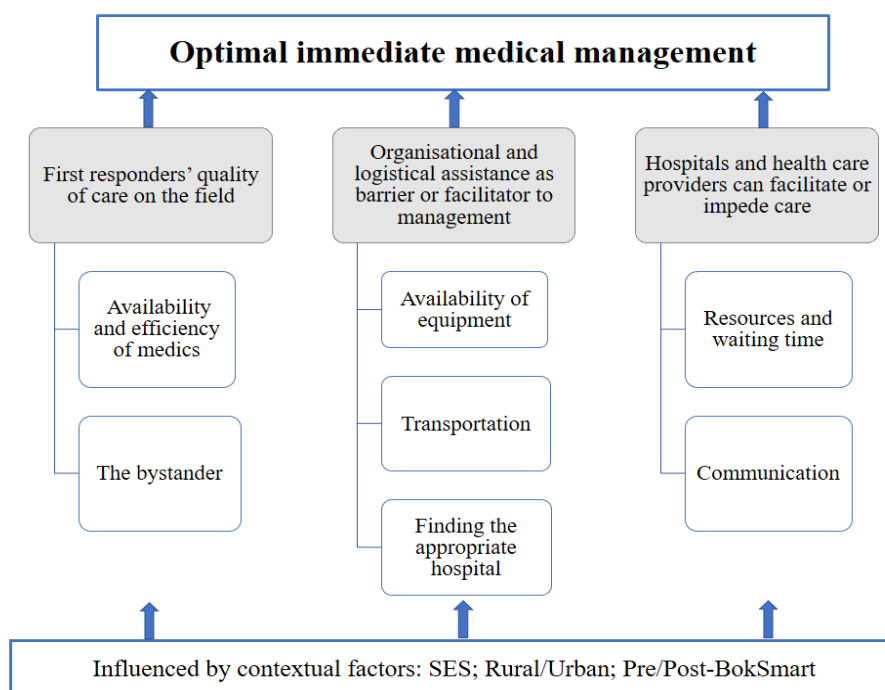


Figure 1. Barriers and facilitators to optimal immediate management of rugby-related SCIs. These themes are described within the sequence of events, from first contact on the field, to management within the acute hospital setting.

1. First responders' quality of care on the field: 'We need a chance to have the best care'

In this study, the term first responder(s) refer to any person(s) providing on-field assistance to the player immediately after injury. These first responders consisted of trained, adult first-aiders, students trained as first aiders at school games, Rugby Medics, qualified paramedics, or bystanders who did not form part of the designated medical personnel. In this theme, the quality of care on the field depended on the availability, skill, knowledge and level of awareness of first responders regarding the possibility of a SCI.

1.1 The availability and efficiency of Medics

Any person designated to provide medical assistance was included under the term 'medic'.

Pre-BokSmart

Participants who had no first aiders or any medical support present, identified this as an important barrier to adequate care in the pre-BokSmart years. This was evident in a substantial amount of cases and describes the lack of resources experienced by many in that period:

No one knew. No one had experienced this kind of thing. Now, these days you watch rugby, they get the stretcher, there are people helping, it is different.

Several players reported that even though medics were present, they felt that the care they received was inadequate. Inadequate care appeared to be linked to insufficient skills or education in dealing with injuries of this kind. For some, their management elicited strong feelings:

My personal opinion is that my management was pathetic...it was ridiculous. Education was the problem...

...I don't know what they thought was going on, they didn't ask me anything...I don't know if they were aware of spinal cord injuries...I don't know...

Additionally, a couple of participants were nervous that the first aiders at their game were students, ill-equipped in knowledge and experience to deal with a serious injury. However, this issue was also raised as a concern with adult first aiders. Some players felt that, because it is such rare occurrence, many first aiders would never have been exposed to an injury this serious before. The anxiety that this event created for the first aider did not go unnoticed. Participants specifically appreciated first aiders or paramedics with the ability to stay in control and keep the injured calm:

He (medic) was quite calm, and I am grateful that he was calm...I got the sense that even the way I was put onto spinal board...he kept me secure.

In contrast, a few players had positive first aid experiences in the pre-BokSmart period. These were often related to rapid assistance and a feeling of *'things being done correctly'*:

I think eight games were going at a time...so something is going to go wrong at some point, so they always had an ambulance. They did everything by the book. I spoke to doctors afterwards. They said they did everything exactly as they should.

While other participants felt that students may not have been equipped to deal with such a serious injury, one participant who himself was still at school, felt that the students managed him well; they knew not to move him and waited for the paramedics. A few participants mentioned that they felt that additional first aiders were needed at try-outs / trials, as these games are *'some of the toughest games you can play'* and players go *'all out to prove themselves'*.

Post-BokSmart

The complete unavailability of medics was described by three participants in the post-BokSmart period, who were all from rural areas and the low SES group. Additionally, only two participants, both from the high SES category, felt that the skills and experience of the first aiders (students, in one case) were lacking in the post-BokSmart period:

There is definitely a need for skills and education, I was watching it on TV and I see the professional guys, how they get handled...I don't think the level of medical care is up to standard at club rugby ...we need a chance to have the best care, it is a 1 in 10 million chance that this happens, but when it does...you want the best care...The Doctor told me to take steps against the on-field medical guys to prevent this from happening again...the whole stabilisation process wasn't right. You don't want to blame anyone, but I do think there was some negligence...and I do still have questions about how it was handled...maybe I would have been injured at least to a lesser extent...because of the way they moved me...

Apart from these participants, the post-BokSmart period was marked by participants who were more satisfied with the care received from the attending medics. In one such example of optimal care, described by a participant from the high SES group, the team had their own medic, who was also BokSmart trained. The participant was immobilised and SpineLine was phoned. He was transferred to a nearby hospital where a spinal surgeon saw him soon after his arrival and operated on him that same night

1.2 *The bystander*

This theme describes the instances in which assistance was provided by bystanders, who were not specifically designated to provide medical care.

Pre-BokSmart

In cases where no medics were present, decisions regarding immediate management were frequently left to teammates, coaches and spectators, often ill-equipped in terms of knowledge. These findings were especially common in the pre-BokSmart period:

The guys came and took me by the arms and tried to pull me to sit up, as they let go, I fell back...then they took my legs and put it over my head. I said, "Stop, don't do this!". The referee and my teammates didn't understand what was going on, even I didn't understand! We have never had something like this...I didn't know my neck was broken...there was a motorcar outside the field, and then they took a desk board...and put me in the back of the car...

Some participants described being carried off without a backboard, as bystanders appeared to not understand the extent of the injury. One participant specifically refers to this as the most fearful moment of his life. In other instances, teammates thought that the injured player was just 'winded', which led them to try and get the player to sit up. Participants often felt that these actions injured them further:

I regret the old style of playing...because when we got injured we liked to pour some water on you and pump your legs, and that is what they did, pumping my legs! That is what I think made my injury worse...they thought I had been winded...

Though bystanders were often seen as barriers to care, they were also one of the most frequently mentioned facilitators to care in the pre-BokSmart period. Often, these bystanders realised the seriousness of what had happened and managed to stop other people from moving the injured player or came forward indicating that they suspected a neck injury. With no first aiders present at his game, a participant described spectators wanting to load him into the back of a van, but a '*lady from the community with some first aid training*' stopped them and persuaded them to phone the ambulance. Importantly, these bystanders who facilitated care often had some form of medical training, which might have explained why

they recognised the seriousness of the situation, instead of the attending referees, coaches or first aiders, who are now targeted by BokSmart to do so. Players remember these bystanders with gratitude:

Fortunately, I don't know how, one of the spectators could see that it was my neck that was broken, and he came running over asking them to leave me alone. He phoned the ambulance. That is one thing I am grateful for, they came quickly because I think that man told them it is a neck injury. I saw him a long time afterwards and I told him I am so grateful, because I couldn't speak, but he spoke for me...

Post-BokSmart

Although these types of experiences were less frequent in the post-BokSmart period, one participant still recounted being carried off the field by his teammates without a backboard:

The scrum collapsed, and I broke my neck, I was playing hooker. Then two guys lifted me up and carried me off the field..and I said to them, no put me down I am not feeling well...If they handled me right, I may have not had something so big, maybe something smaller..but they were rushed to get playing again so they just lifted me and carried me off...

A few players felt strongly that for this reason, awareness and the information acquired from the BokSmart courses should extend beyond coaches:

BokSmart shouldn't be for just the coaches, it should be for the players as well. What does it help if the coach doesn't share this information with his players. People don't realise the seriousness of rugby yet, these things should be practiced more strictly, and the players need to be taught, they need to understand the risks of certain actions...

Bystanders are also mentioned as facilitators in the post-BokSmart period. For example, an ambulant quadriplegic described assistance received from a doctor who was a spectator:

My injury was on the C-field...and the medics were on the A-field. The other fields had scholars as first aiders...and I am not saying they didn't know what they were doing, but if they turned my neck I may not have been able to walk today. I was lucky that there happened to be a Doctor there...so yes there is a fine line...to break your arm is not the

same as breaking your neck...I think there must be someone who knows what it is about on every field. The two guys that were there, were very young and with me at school...so luckily the Doctor ran from the stands to come help.

2. Organisational / logistical assistance as barrier or facilitator to management:

‘Those first six hours are really important’

Organisational and logistic assistance included factors, apart from the first responders, that affected the immediate efficiency of management.

2.1 Availability of Equipment

Pre-BokSmart

Participants perceived the lack of necessary first aid equipment as an important barrier in the pre-BokSmart period. One participant recalls that in the early years, ‘equipment’ mostly consisted of ‘water and *Wintergreen* ointment’. Similarly, another explains:

Ok, that time I mean when you used to get hurt you would just get water...they called it the magic water...you would just get water on your head. And then you go on.

The unavailability of backboards appeared to be a challenge, particularly in the smaller towns and more rural areas of South Africa:

I remember the first-aiders...they made me more nervous than anything because they were standing there talking about a stretcher...they didn’t have one...when I heard that, I was immediately nervous, and I tried to lie as still as possible...they came and carried me off the field without medical equipment. Two guys were on either side of me, their arms were under my knees and behind my back. My neck bent forward and backwards in the process.

Even when equipment was available, some players recount not being strapped in on the board, or not being strapped on correctly (for example, securing the player’s hands that kept dropping from the stretcher with his boot laces). Similarly, the lack of neck braces was a frequently mentioned barrier – participants describe a newspaper, a pair of sneakers and a raincoat being used to ‘stabilise’ the neck. Additionally, players in rural areas also mentioned

safety equipment on the field, such as protective pads around the goal posts, and the condition of the field itself, as areas of concern:

Here where we are, this is something they must change...our grounds, they don't have grass and our field is not secured. There was a fence once, but the people stole it...so the cows and people are just walking over our field. I would say there is an improvement since I was injured, but people like to neglect things. There are cushions around the poles but sometimes they don't use those cushions, they use them only in the big games. They don't do it properly. We need to change the attitudes of the committees and the coaches...we can show them, we got injured here, we are trying to minimise accidents so let us use everything to make it safe for everyone.

Post-BokSmart

In the post-BokSmart period, incomplete sets of equipment were still reported:

We had a struggle before the match because the second team was supposed to play but we had a problem with the first aid kit, it was a struggle to find it, but then we found the stretcher. When I fell I didn't know what happened, I was facing down and I heard the players shouting that someone is injured and that the ref must stop the game. The blocks they were looking for... and the neck brace they were looking for, there was nothing. So we did have a board, but not the neck brace or the blocks..and we didn't have people that were trained to manage the equipment. Luckily my friend had some training and he knew that they had to hold my neck.

However, these accounts were less frequent and appeared to be localised to rural or peri-urban areas. Instead, adequate equipment was mentioned more frequently as a facilitator, than in the pre-BokSmart period:

Their team Doctor stabilised me on the field with a neck brace and blocks...I feel like I was managed incredibly well on the field. The ambulance drove right onto the field, they didn't even have to walk ten steps with me.

2.2 Transportation

Pre-BokSmart

Poor transportation was one of the most frequently identified barriers to swift management in the pre-BokSmart period. Participants in remote areas described slow arrival of

ambulances, with some waiting as long as 3-4 hours. Though much less frequent, these long waiting periods were also mentioned in urban areas:

My dad works further away than the hospital and he got to me before the ambulance did...even through afternoon traffic, he got to me before the ambulance did...it took so long for the ambulance to come, from a hospital that is 5km away...so imagine what it is like for guys who are far away...

A few players mentioned waiting for another injured player, so that both could be taken to hospital at same time. Additionally, players described problematic access of the ambulance onto the field. Poor transportation was also sometimes the result of bystanders' actions. Instead of phoning an ambulance, four participants describe being taken to hospital in a private vehicle.

Post-BokSmart

In the post-BokSmart period, poor transportation remains the most frequently identified barrier. These challenges were particularly evident in rural areas:

I broke my neck 3:30 (pm), the ambulance only came 9:30 (pm) at night...I waited all the time. I don't know, where I live...even when you phone them from your home in the evening and say come now, they only come tomorrow morning...

Participants who waited a long time for an ambulance frequently mentioned that having an ambulance available on the field could solve this problem. However, similar to the pre-BokSmart period, some participants reported that an ambulance was indeed available, but they had to wait for another player to be stabilised or another ambulance to come as the available ambulance couldn't leave the other games unattended. Alternatively, participants emphasised swift transportation as an important facilitator to their management:

The management of the injury was excellent because there were ambulances next to the field, it is most important thing you can have. It wasn't always standard practice, but at every game that I have since been to at our school, there have been ambulances there.

Similarly, a participant who is an ambulant quadriplegic described his perception of the impact of swift management, resulting in an improved functional outcome:

I was treated here (in a town approximately 450km from Cape Town) with an anterior fusion and was then flown to Cape Town for the posterior fusion. So, to me, those first six hours are really important because I believe it has given me a chance to walk...

2.3 Finding the appropriate hospital

In many cases, the time taken to receive treatment is further complicated by the time it takes to get the player admitted to the correct hospital.

Pre-BokSmart

In multiple cases in the pre-BokSmart period participants arrived at the primary hospital, where nothing could be done for them and they had to be transferred to a facility equipped to deal with SCIs:

They then took me from (hospital A) to (hospital B), the Doctor said there I am not supposed to be there I must go to (hospital C) that is a big, big thing...you get a lot of people dying because if you are in (area) you must first go to small hospital before you can go to big hospital like (hospital C) (tertiary hospital), which is wrong!

Travel distance alone to a facility equipped to deal with a SCI may be substantial for players from rural areas. For example, for one participant, the travel distance from the small town where his injury occurred to the nearest hospital was approximately 100km. As this hospital was not equipped to manage him, an additional trip of 1041km was required to take him to Cape Town. This was often the case and at times, multiple transfers occurred before the final hospital was reached. For a few participants, these transfers took a few hours to materialise.

Post-BokSmart

In the post-BokSmart period, organising transfers and the cumulative time to reach the final treating facility was still perceived as a major barrier for the majority of participants. These accounts were more frequent in the lower SES categories where participants make use of public healthcare:

We waited 3 to 4 hours for the ambulance, I was lying on the field...from there they took me to (hospital X) and I waited... to be taken to (hospital Y). I arrived at (hospital Y) and they didn't have traction equipment available so from there was taken to (hospital Z) and there I was finally treated...

A few players specifically mentioned that they felt the difficulties with reaching the correct hospital should somehow be less complicated, as these delays are not acceptable. Only two participants, both from higher SES groups, specifically mentioned SpineLine, the dedicated toll-free number that BokSmart promulgates during their mandatory education courses. However, due to the severe nature of these injuries, it should be acknowledged that the participants may also have been unaware that SpineLine was contacted during their immediate injury management period.

In contrast to these multiple aforementioned barriers, participants mentioned the CBPJPF as facilitator to the immediate management of their injury, by arranging transfers to a hospital with a specialist surgeon or spinal unit. One participant stated:

I have shared this with so many people, and I try to tell people, if something like this happens, don't move the guy, phone SpineLine and the CBPJPF, they know what to do.

Throughout the themes presented thus far, it is clear that in many cases different barriers to care were linked and had cumulative effects on the immediate management of the player, as one participant described:

There was no first aid. The blocks they were looking for and the neck brace, there was nothing...so they put me next to the field and phoned the ambulance, but then my coach said we can't wait anymore, the weather was also starting to change. So, they put me in a car and took me to hospital.

3. Hospitals and secondary healthcare providers can facilitate or impede care: 'They don't understand what we feel'

This theme encompasses the perceptions of care received in the acute hospital. These findings are unrelated to BokSmart and is thus not grouped accordingly.

3.1 Resources, knowledge and waiting time

For some participants, pressure sores and other complications seemed to develop in the time that they waited to be transferred from one hospital to another, causing additional suffering. One participant recounted his experience in the public healthcare system:

I lay there for more than 9 hours before someone came to see me, I was lying the hallway. It took so long there, when I finally got to the right hospital they told me that it took too long to get to them. I have since heard that if you have an operation within 4 hours you may end up having more function, I only arrived at the right hospital after 15 hours, it was too late to do an emergency operation...

Other issues raised included smaller district public hospitals not realising the seriousness of the injury, thus leading to more waiting time before the participants were treated. Finally, weeks of waiting time for surgical intervention was also reported in the public system. Participants mentioned traction equipment not being available in some hospitals. In other cases the hospital appeared to be equipped to manage the injury, but treatment remained problematic. In one such example, the participant described the Doctor on duty struggling to apply the traction equipment. Another Doctor was called to assist, but he only arrived much later:

...I was waiting from 8pm the evening until 2am...I don't think that was right, I think that increased the damage to my spinal cord.

In the private sector, one participant identified waiting for authorisation from private medical insurance, which he felt lead to further complications:

They had to get authorisation from my medical insurance to fly me to hospital, so it took a couple of hours. The game was at 12 in the afternoon and I only flew at night, they put you on that stretcher and you lie tied up like that the whole time...the back of my head became very sore...I had developed a pressure sore...

A few players mentioned that they felt that staff in the immediate hospitals, both public and private, was not accustomed to treating SCIs. In contrast, although logistical problems were evident in reaching the spinal units, all references to the actual spinal units were positive. Participants often discussed this by comparing the excellent and experienced care received at the spinal facilities, to the care received at the immediate/acute hospital:

I think it is about exposure, you can work for 40 years as Doctor or nurse, but it doesn't mean you necessarily know how to work with a spinal cord injury. Small things, like you can't use your own hands to clean yourself, they have to clean you, it is so

undignified because there are other people in the ward also...it is different to rehab because there everyone is the same, but in a normal hospital you just want to be in your own room...they don't understand what we feel.

Participants frequently described staff with experience in treating SCIs as an important facilitator to care:

Fortunate for me, the Doctor that was on duty had 35 years' experience with spinal cord injuries, so he knew it was bad and he knew what to do.

3.2 Communication

Several players perceived the lack of honest and appropriate communication during the initial period in hospital as a barrier that lead to anxiety and uncertainty. Specifically, not understanding the information given, or the implication thereof, caused frustration in some:

Because I had to wait so long I developed complications and was placed on a ventilator...and you wake up and you can't talk, no one tells you what is going on, it is terrible... I didn't know it was a possibility, I thought you could break an arm or leg, I didn't realise it could be so...I thought I would wake up the next day and be fine. So, when I woke up, the Doctor just told me... "you broke your neck". I thought...that must be serious? I didn't understand. You know how Doctors are...

One participant explained that he wanted the Doctor to be frank with him, and even though it was huge a shock, at least he could start processing the injury. Similarly, a participant who occasionally visits newly injured players in hospital, gave his view on honest communication:

You need honesty...but you are not going to want to believe it, you want to believe that you will walk again, and you hold onto that guy that told you will walk. I tell him from the start, listen, there are things I am going to tell you that you don't want to hear, because it doesn't help to be dishonest...I am glad that most people were honest with me.

Discussion

In this study, we present the views of players who have sustained SCIs while playing rugby, regarding their experiences of the facilitators and barriers to the immediate management of their injuries. Transportation delays and admission to the most appropriate medical facility were the most frequently identified barriers to optimal management in both the pre- and post-BokSmart period. These barriers closely resemble the findings of the retrospective case series (1980-2007) of Hermanus et al.¹⁵ and it appears that these challenges persist beyond the period of their study. Collectively, inappropriate transportation, transportation delays and admission to inappropriate medical facilities could be greatly reduced by the utilisation of SpineLine (covered in the mandatory BokSmart course) as a dedicated emergency helpline for suspected catastrophic injuries at the time of injury.¹ However, the persistence of these barriers identified by participants in the post-BokSmart period suggests that SpineLine is under-utilised. This seems plausible, especially since a recent study reported that coaches who attended the mandatory BokSmart course were unable to describe the SpineLine number, a free emergency hotline for rugby-related catastrophic injuries.²⁸ Further investigation around SpineLine's utilisation is required and suggests that more awareness around this important resource is needed among key rugby stakeholders.

The availability and quality of medical facilities and expertise of personnel vary widely between regions and access may depend on whether the patient has private medical insurance or not.²⁰ This is a crucial factor to consider as patients presenting with neurological deficits should be transported to specialised trauma centres, not just to the nearest hospital.¹² If the patient is stable, by-passing smaller district hospitals without adequate facilities should prevent unnecessary delays. However, in a five year review of rugby-related SCIs, an inappropriate primary healthcare facility was the first contact point for 65% of the cases, most of which did not have x-rays facilities.¹² Furthermore, patients with early admissions to spinal units have been shown to have better outcomes and are less likely to develop secondary complications, including pressure ulcers and respiratory problems.²⁹ These delays can affect optimal management, including early reduction or surgery.^{14,30} It has previously been described that permanent neurological damage after rugby-related cervical facet dislocations may be avoided if reduced within four hours of injury.¹⁴ Although the 4-hour window is not based on clinical trials, it is still recommended that these patients are

transferred to an appropriate hospital as soon as possible.^{12,14} Compiling a specific action plan of nearest specialised trauma centres capable of dealing with SCIs, (an aspect covered in the BokSmart course) and sufficient background information on players, including insurance details, would facilitate this process and prevent unnecessary delays.²⁰ Furthermore, the action plan should include the logistics of the ambulance's entrance point to the field.

Delayed transportation and admission to inappropriate medical facilities were more prominent for players from rural areas with lower SES and who utilise public healthcare. In general, these findings portray the challenges that people of lower SES face in public healthcare systems in South Africa,^{17,31} as well as in other low-income settings.³² Challenges within the healthcare system outside of the control of SARU or BokSmart, but play a crucial role in the optimal management of the player. After Apartheid ended in 1994 the public health system was transformed into an integrated and inclusive national service. Yet, healthcare remains problematic.³³ For example, South Africa still has a divided health system with the minority of the population (approximately 16%) using private health services, particularly if they are covered by private voluntary health insurance.¹⁷ In contrast, the national, tax-funded, public health sector, staffed by only 30% of the Doctors in the country, is the sole provider of healthcare for 84% of the population (about 40 million people).³³ Research has shown that poor, uninsured, black South Africans, and rural groups still have inequitable access to healthcare.^{34,35} Ideal treatment depends on having a coordinated healthcare system capable of recognising SCIs as medical emergencies and rapidly transporting them to a SCI unit.¹¹ This said, a recent report found that stabilisation surgery for newly injured SCIs is delayed, with 7 days as the median time to surgery after injury in a tertiary, public sector hospital in South Africa and this delay is associated with an increased occurrence of pressure ulcers.³⁶ Secondary complications such as pressure ulcers, create unnecessary difficulties for both patients and treating facilities and increases the burden on the healthcare system.^{36,37} Additionally, only a few of the nine provinces in the country have the ability to provide comprehensive care for SCIs³¹ and thus specialised services in the public sector are likely to incur added pressure. Strengthening the relationship between public and private healthcare systems in provinces without adequate facilities and resources is likely to reduce the burden on the public healthcare system.¹⁵ Importantly, these

inequities in healthcare may continue to have an influence beyond the acute management phase, as results from within the broader study indicate that compared public healthcare, access to private healthcare, or at least a combination of public and private healthcare, is associated with increased quality of life in the long term.³⁸ Apart from healthcare inequities, factors such as distance to hospitals and difficult terrain for transportation remain problematic in under-resourced communities.^{15,31} However, unlike other causes for traumatic SCIs, the barriers to optimal management of these injuries within the rugby setting could be mitigated, at least to some degree, by the use of SpineLine.

Another issue raised within the healthcare setting was effective communication. Clear information about the nature and prognosis of the condition is important.³⁹ Studies have shown that if the SCI diagnosis and its implications are delivered poorly it can cause confusion, distress and resentment. While if it is done well, it may facilitate understanding and adjustment.⁴⁰ Reasons for inadequate communication may include insufficient communication skills, language barriers or lack of time in an overburdened setting.³⁹ Nonetheless, as this study showed, healthcare providers should not underestimate the effect of poor communication. In this respect, the CBPJPF may play an important role facilitating admission to a spinal unit as well as acting as facilitator and resource between the patient, family and medical staff.

It has previously been shown that inadequately trained paramedics and the lack of first aid care can lead to more severe consequences following a SCI.⁴¹ Patients with SCIs are at risk of neurologic deterioration due to secondary injury to the spinal cord, which may have important consequences for their functional outcome.³⁷ The complete unavailability of first aiders at matches in the pre-BokSmart period was noticeable. This was much less frequent in the post-BokSmart period, with only a few participants reporting that there were no medics present at the time of their injury. These cases were in rural, low SES areas and emphasise that additional interventions are required in these under-resourced areas.

In instances where medics were present, quality of care on the field was identified as a barrier, predominantly in the pre-BokSmart period. It was the perception of many participants that if they had been handled more carefully, the outcome of their injury may

have been less severe. In the post-BokSmart period, the general satisfaction with on-field medical care appeared to be better. First aiders and paramedics play an important role in the pre-hospital management of SCIs by means of fast on-field recognition and early stabilisation.⁴² However, the majority of first aiders is unlikely to deal with catastrophic injuries on a regular basis.⁴³ Nevertheless, first aiders should be knowledgeable about the clinical presentation of these injuries.²⁰ If this is achieved, the seriousness of the situation would prompt actions such as the immediate use of SpineLine, which would prevent incidents in which, for example, the player has to wait for another injured player so that they can both be taken to hospital together. To this extent, schools and clubs should also ensure that there are sufficient medics available, especially on days where multiple games are played simultaneously. BokSmart guidelines stipulate that the minimum medical personnel requirements for school, club or community rugby matches, is the presence of one or two persons suitably trained in emergency field side care: thus, a trained first aider or paramedic.⁴² A BokSmart Rugby Medic is a minimum requirement at matches in communities that are considered socio-economically disadvantaged, where trained first aiders or paramedics are not available. The focus of the Rugby Medic program is mainly on the disadvantaged and under-resourced areas, which do not have any appropriate equipment, training or medical support.⁴² The program provides coaches, referees, players, and any involved person in the rugby community, with the primary skills to be able to identify and manage a potentially serious head, neck, or spine injury. These clubs or schools may be identified by the unions, or they may directly request training from BokSmart. BokSmart would then, within the limitations of their allocated budget, provide the Rugby Medic training at no cost to these schools or clubs.⁴² Therefore, the onus also rests on individual schools and clubs to request training if they do not have adequate medical support. Furthermore, coaches and referees are required to be re-certified on a biennial basis to maintain their BokSmart accreditation. A similar process should be required of first aiders and Rugby Medics, to ensure that they are competent in managing potentially catastrophic injuries, but also to serve as an opportunity for gaining additional experience and knowledge in the management of these injuries.

Having students as first aiders was a concern for some players, however, it was the perception that if a parent or community member with medical training was on hand to

facilitate the management, it may mitigate the possible risk of inadequate management. This is illustrated by the cases where bystanders (often medically trained) stepped in to guide management. This is also an example of how dedicated community involvement can be nurtured within a local rugby community and may be an important avenue for further interventions. However, bystanders can also act as barriers and this finding is likely linked to the absence of first aiders. There will be times when there is little or no medical support available, and this also holds true for practice sessions.⁴² During these times, coaches, referees, players and the immediate rugby community may benefit from knowledge regarding the recognition of suspected serious injury to firstly, ensure no unsafe behaviours take place. For example, they should know that a seriously injured player should not be moved, and the management process can be expedited by calling SpineLine immediately. Coaches and referees are targeted in the BokSmart program as the first line of defence in the prevention of catastrophic injuries⁸ and as such, it re-iterates their management responsibility and plan of action in case such an event occurs. However, it has been reported that some coaches felt that knowing how to deal with a catastrophic injury was not something they had to worry about as coaches.²⁸ This negative attitude needs to be carefully managed to effect change. Coaches and referees must understand that they place themselves and others at risk if they are not fully educated or equipped to firstly, do no harm and to set a swift and organised management plan into action.

Lastly, inadequate equipment restricted efficient management and emerged as a common factor in the pre-BokSmart period. These accounts were less common in the post-BokSmart period, which is a promising sign as game is technically not permitted to start without the adequate safety equipment in place. BokSmart has employed random safety inspections at community level matches which should help to prevent these situations.⁴⁴ However, despite these preventive measures, some participants still mentioned instances of inadequate equipment. Of specific concern is the need for these preventative measures in rural areas, which are often under-resourced. In these areas, added support in terms of provision of equipment, safe-guarding that equipment and having trained people to use it may require additional, targeted interventions. Although immobilisation of the cervical spine after trauma is not supported by high-level empirical evidence, it remains the current recommendation based on biomechanical considerations and clinical experience.⁴⁵ However, immobilisation

must be applied by persons trained to do so⁴² and thus, it remains the responsibility of schools and clubs to ensure that they have the necessary safety equipment and trained responders available.

This study has its limitations. As part of the broader study, a sampling strategy that was representative of the population of rugby-related SCIs was employed. However, it is possible that a smaller sample with more in-depth interviewing could have yielded additional depth within the results. Participants' perceptions of what constituted a barrier or facilitator to care did not obviously differ from what the researchers understood to be current best practice. However, it must be noted that within this study design it was not possible to report on the nuances or finer details of the management process, which could provide additional information on the standard of care.

Additionally, the sample consisted of participants with varied socio-economic backgrounds. The researcher, a middle-class healthcare professional, was aware of the possible power differentials that may arise during interactions with participants from low socio-economic areas.²⁵ Every effort was made to be mindful of these interactions and to create a relaxed atmosphere that invited unrestricted sharing of experiences. Nevertheless, these factors may still have determined the sharing of selective information for some participants. Additionally, the participants in this study were asked to talk about an event that abruptly and traumatically changed their lives and it is possible that certain limitations were placed on what some participants were willing or able to discuss in one interview. Additional, follow-up interviews may have allowed for a relationship with enhanced rapport and trust.

Implication

Recently within the field of sports injury research it has been acknowledged that injuries and their consequences are complex and context based phenomena, which are influenced by interactions between intrapersonal, interpersonal, organisational, community, and societal factors.^{23,46,47} Similarly, in this study we recognised the complex interactions within injury management process. It is important that national sporting federations identify and focus on high-risk groups.⁴⁸ To this extent, the findings of this study painted a concerning picture for players of lower SES, with fewer resources or who live in more rural areas. Thus, 'context'

in this sense, often played a determining role in the way the injury management process would unfold. This process is also driven by human behaviour and is represented in decisions and actions of referees, coaches, medics, healthcare providers and even bystanders. In many cases, various barriers to optimal care were linked and had cumulative effects on the management of the player. For example, the efficiency of the medic may be influenced by the availability of equipment, or bystanders may negatively affect management, if no medics are present at the game.

Although BokSmart has employed random safety inspections at community level, there appears to be a need for a formal monitoring process and investigation into the effectiveness of the immediate management protocol of BokSmart, to ensure that these safety standards are maintained, especially in under-resourced and under-privileged communities. Monitoring alone would not solve the challenges of these communities, as they may lack the resources to meet or maintain these standards and may require additional support in this regard. Both monitoring and support have financial implications and remain a challenge for a governing body in a developing country. However, player safety should not be compromised, and avenues to ensure that it remains a priority should be sought. This study provided a context-driven description of the injury management. Future research should investigate the presence and training of medical personnel, the availability of equipment and emergency protocols, as well as the knowledge of coaches and referees regarding the effective immediate management of catastrophically injured players, in schools and rugby clubs in South Africa.

Although it is outside the control of SARU and BokSmart, this study also points towards implications for the healthcare system. Firstly, when considering healthcare reforms, it is both valuable and vital to understand patient pathways to care and related barriers.⁴⁹ Additionally, the interaction of the wider context, such as SES and environmental factors, and accessibility of healthcare must be linked and mutually considered when interventions that aim to optimise healthcare accessibility are planned.⁴⁹

Conclusion

The initial management of SCIs requires swift and experienced medical treatment, both of which were recognised by participants in this study. Specifically, transportation delays and admission to appropriate medical facilities were the most frequently reported barriers. These barriers, as well as inadequate equipment and quality of first aid care, can all be improved by ensuring that medical personnel are adequately trained and available, applying an appropriate action plan, acquiring correct equipment and determining the correct lines of communication to emergency medical services (SpineLine), all of which are described within the mandatory BokSmart course. These processes are in place in the BokSmart course, but it appears that this knowledge may not be reaching all the end users on the field. The current findings should assist BokSmart to focus their resources on strategies that ensure the dissemination of SpineLine and the translation of knowledge acquired in the BokSmart course into practices on field. Players from lower SES and rural areas, would benefit from additional interventions if BokSmart were to create more equal opportunities for optimal management of serious injuries. Finally, some of the challenges identified in this study, such as those of the healthcare system, are beyond the control of BokSmart. Nonetheless, these findings may be useful for all relevant stakeholders to understand the experiences and needs of seriously injured players and to aid in the design of future interventions. Lastly, a player-centred qualitative approach, as used in this study, can have a positive influence on subsequent intervention development as players can provide useful, first-hand knowledge about the quality of care. As such, healthcare in South Africa could benefit from more interventions that encourage patients to share their perceptions of healthcare.

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Chapter 5

Quality of life among individuals with rugby-related spinal cord injuries in South Africa

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Abstract

Objectives

Rugby-related spinal cord injuries are rare, but life-altering and traumatic events. Little is known about the long-term consequences and outcomes of players who have sustained these injuries. This study investigated current quality of life (QoL) and factors associated with QoL, among individuals with rugby-related spinal cord injury (SCI) in South Africa, by using the International Classification of Functioning, Disability and Health (ICF) framework.

Design

Descriptive cross-sectional study.

Setting

Rugby-related SCI population of South Africa, as captured in the BokSmart/Chris Burger Petro Jackson Players' Fund (CBPJPF) database.

Participants

Ninety (n=90) of the 102 eligible players on the database agreed to participate in the study.

Main Outcome Measure

The relationship between QoL, as measured with the World Health Organization Quality of Life questionnaire (WHOQOL-BREF) and specific independent variables (demographic information, level of independence and participation in various activities and life roles) was investigated. Variables that were significantly associated with QoL in bivariate analyses were included in multiple linear regression analyses.

Results

The mean score and standard deviation (SD) of the WHOQOL-BREF was 15.1 ± 2.3 arbitrary units (AU). *Participation* (an ICF framework construct) and income were significantly associated with Overall QoL ($p < 0.001$). *Participation* was the only variable significantly associated with all QoL sub-domains ($p < 0.001$). Additionally, number of health concerns, type of healthcare (public vs private) and level of education were significantly associated with various QoL domains ($p < 0.001$).

Conclusions

On average, these individuals with rugby-related SCI presented with higher QoL scores than other comparable SCI studies. However, lower levels of *participation* and income, certain levels of education, increased health concerns and use of public healthcare, were associated

with lower levels of QoL. Sporting bodies have a responsibility to optimise player welfare, by acting upon the modifiable factors associated with QoL.

Strengths and limitations of this study

- This study addresses the paucity of knowledge of the long-term consequences of catastrophic sporting injuries.
- The results from this study is a first step in describing specific factors associated with QoL in Rugby-players who sustain SCIs. Future studies should further investigate the relationships identified in this study.
- Based on criticisms of existing objective *participation* measures, this study used a *participation* measure that assesses *participation* limitations that are meaningful and important to the individual (subjective experience).
- Although some of the modifiable factors in this study may be South African specific, concepts such as *participation* may be important for all individuals with SCI.
- This study considered only certain variables and their association with QoL, while other factors, such as coping strategies, self-esteem and athletic identity, may also contribute to QoL.

Introduction

Sport plays a role in the aetiology of spinal cord injury (SCI) in various countries.¹ Rugby union specifically, is a popular team sport, characterised by frequent exposure to physical contact and high impact collisions.² Compared to other sports, rugby has been identified as one of the individual sports with highest risk for SCI.³ Though the actual risk is low, serious and potentially disabling injuries are associated with the sport.⁴ In 2009, a nationwide injury prevention programme, ‘BokSmart’, was launched in South Africa in conjunction with the Chris Burger Petro Jackson Players’ Fund (CBPJPF) to reduce these catastrophic injuries.⁵ The CBPJPF is a non-profit organisation that provides support for rugby players who have sustained a catastrophic injury.⁵ Although catastrophic injuries such as spinal cord injuries (SCIs) are rare, the outcome remains a life-altering event for the player and their family.⁴ In South Africa, the overall annual incidence rate for permanent outcome SCIs between 2008 and 2014 was reported as 1.8 injuries per 100 000 players (95% CI: 0.3–3.4).⁶

The consequences of such an injury can be assessed by the World Health Organisation (WHO)’s International Classification of Functioning, Disability and Health (ICF).⁷ The ICF contains three components of human functioning; (i) Body functions and structures

(physiological, psychological and anatomical functions), (ii) *Activity* (execution of tasks) and (iii) *Participation* (involvement in life situations). Disability, in this context, refers to the interaction of *impairments* in body structure and function, limitations of *activity* (difficulties an individual may have in executing tasks or activities) and restrictions in *participation* (problems an individual may experience in involvement in life situations) (Figure 1). Instead of focusing on the physical injury as the main determinant of functional outcome, the framework considers the influence of other factors, such as personal factors and the individual's environment.⁷

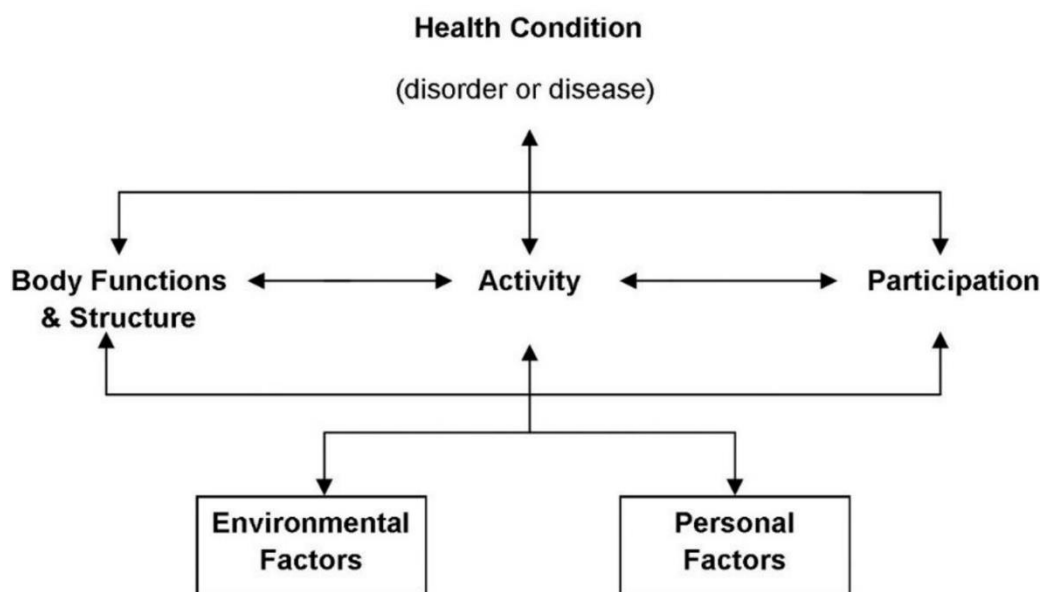


Figure 1. The International Classification of Functioning, Disability and Health, from WHO (2001)

A concept not incorporated in the ICF is Quality of Life (QoL).⁸ The WHO defines QoL as an individual's perception of their position in life in the context of their culture, value systems, standards and concerns. Subsequently, a revision of the ICF diagram (the ICF-CR) has been proposed to enhance its biopsychosocial content, by depicting QoL as the largest component of human functioning, with contributions of each of the other subsystems.⁸ The incorporation of QoL allows the impact of any given health condition, its effect on daily life and the experience from the personal perspective of those affected, to be appreciated more

comprehensively.^{8,9} Measuring QoL after SCI is important, as the purpose of SCI rehabilitation includes functional recovery and independence, community reintegration and ongoing enhancement of QoL.¹⁰ QoL has been found to be diminished following SCI and may be affected by personal factors, such as socio-demographic and psychological factors, or cultural factors such as race and ethnicity.¹¹⁻¹³ QoL may also be affected by economic and environmental factors, such as accessibility to healthcare, quality of education, adequacy of housing, and opportunities for employment.^{11,14} Specifically, paid employment and time since injury has previously emerged as important cross-cultural predictors of QoL after SCI.¹⁵ Additionally, participation in home, social and leisure activities have been shown to have a positive effect on QoL.^{15,16}

SCI has been described as one of the most devastating neurological impairments an individual can face, with profound effects on both the injured person and their family.¹⁷ Qualitative studies of the experiences of people who have suffered a SCI through playing rugby have shown that the lives of these individuals can change from being highly active and positive, to being severely restrictive and unfavourable for their psychological and social health.^{18,19} International Sporting Federations have an obligation to protect the health of their athletes.²⁰ As is evident from the various injury prevention programmes in rugby⁵, prevention of serious spinal injury seems to be a key priority, but less attention is given to the consequences for players who sustain SCIs playing rugby. To our knowledge, no studies have investigated factors associated with QoL in individuals who have sustained rugby-related, or other sports-related SCIs. Identification of these barriers and facilitators to optimal QoL is an essential first step in establishing strategies to enhance QoL. Therefore, the aim of this study was to investigate current QoL and factors associated with QoL, among individuals with rugby-related spinal cord injury, by using the ICF framework.

Methods

Participants and data collection

The entire group of rugby players who had sustained rugby-related SCIs in South Africa (n=113) formed the population of this study. The group included players of all age groups and level of proficiency (amateur to professional). Access to this population was obtained through

the CBPJPF/BokSmart database.⁵ The database is managed jointly by the BokSmart programme and the CBPJPF. According to BokSmart's serious injury protocol and reporting process, all potentially disabling or life-threatening head, neck or spine injuries, sustained by any player at any level of rugby union, is reported to the serious injury case manager (SICM) of the CBPJPF who makes key decisions regarding the injured player's management. The SICM records the final diagnosis on the database one month after injury, during a follow-up visit or consultation with the Medical Doctor in charge of the case. Though it is possible that some catastrophic injuries may not have been reported, the potential benefit of financial, logistical and psychological support that is associated with reporting rugby-related injuries in South Africa, should reduce this possibility. Players were eligible to participate in the study if they were 18 years or older and spoke either Afrikaans or English. Additionally, players were only eligible if at least 1 year had elapsed since their injury, to minimise possible psychological burden.²¹ Eligible players (n=102) were contacted telephonically and invited to participate in the study. Players who agreed to participate and provided informed consent were included in the study (n=90). Data collection visits were conducted at their homes or places of work, throughout South Africa. Data collection consisted of two parts; the collection of questionnaire data for this study, followed by semi-structured interviews investigating the long-term consequences of SCI in this population. Questionnaires were completed individually by participants with sufficient writing ability. The researcher assisted with completion of questionnaires for participants who were unable to write.²²

Patient and Public Involvement

The research objectives and study design of this study was formulated in consultation with a person with a SCI, who is also the CEO of Quad/Para association of South Africa (QASA), and with the CBPJPF. Persons with SCIs were not further involved in the recruitment or conduction of the study. Study findings will be disseminated to both QASA and the CBPJPF. Findings will also be summarised in a plain language report. This report will be sent to the participants by e-mail, post or discussed via telephone, depending on their preference.

Dependent variable

QoL was assessed using the abbreviated version of the World Health Organisation Quality of Life questionnaire (WHOQOL-BREF). The WHOQOL-BREF is a cross-culturally valid

questionnaire that consists of 26 items within 4 QoL domains: physical health, psychological health, social relationships, and environment.^{22,23} Higher scores indicate greater perceived QoL in that domain. The psychometric soundness of the use of WHOQOL-BREF in a SCI population has been confirmed and it has been described as the most established instrument to assess QoL after SCI.^{24,25} The frequency distribution of the 4 domains of the WHOQOL-BREF was found to be nearly symmetric and showed no floor or ceiling effects. All domains showed good internal consistency (Cronbach's $\alpha=0.74-0.78$), with the exception of the social relationships domain ($\alpha=0.54$). It has been noted that the social relationships domain calculation is based only on 3 items, whereas those for the other domains are based on 6 to 8 items, thus affecting the alpha value.²⁵ The WHOQOL-BREF was also shown to correlate in appropriate domains with other QoL measures such as SF-36 ($r_s=0.33-0.78$).²⁶

According to scoring guidelines, each domain's score was calculated by multiplying the mean score by 4, to make domain scores comparable with the scores in the WHOQOL-100.²² The score for each domain therefore ranges from 4 to 20. The overall QoL score was obtained by summing the mean score of each domain.²⁷ The overall score ranges from 4-20 and higher scores indicate greater perceived overall QoL. The procedure for missing values described by the WHOQOL-BREF scoring guidelines, was applied in one case. The guideline stipulates that where an item is missing, the mean of other items in the domain is substituted, provided no more than two items are missing from the domain and with the exception of domain 3, where the domain should only be calculated if < 1 item is missing.²² The case had complete data after this substitution and was retained in the analysis.

Independent variables

Demographic data

Personal information collected included age, marital status, education level, employment status, income and time since injury. Environmental factors included the residing Province, type of transport most often relied on, and type of healthcare accessed (public, private or both). An asset indicator approach was used to determine a proxy of socio-economic status (SES) by formulating a composite score from the presence of assets such as electricity, indoor flushing toilet, indoor running water, television, satellite dish, computer, internet, motor vehicle, refrigerator, microwave, washing machine, radio and method of cooking.²⁸ The asset indicator

scores were used to divide the sample into low, middle and high socio-economic groups, based on percentile cut-off points.²⁸

Impairment, Activity and Participation measures

Impairment was measured by three variables, injury level, completeness of SCI, and the presence of health concerns or complications such as pressure ulcers, spasticity, contractures, urinary tract infections, bowel problems, blood pressure problems and pain. The number of health concerns indicated by the participant were summed and presented as a numeric value. The injury level was obtained from the records of the SICM of the CBPJPF and confirmed during interviews with the participants. For the purpose of this investigation, injury level was categorised based on functional capabilities, into high quadriplegia (C3-C4, using chin-control wheelchairs), low quadriplegia (C5-C8, using hand-control or manual wheelchairs), paraplegia and ambulant quadriplegia.

Activity / level of independence was measured with the third version of the Spinal Cord Independence measure (SCIM). The SCIM is a widely used instrument designed to measure functioning in activities of daily living in persons with SCI.²⁹ The SCIM has 19 daily tasks grouped into three subscales. Item scores are weighted according to their clinical relevance and are graded according to difficulty. Each item has between 2 and 9 grades and the total SCIM score ranges from 0 to 100. Higher scores indicate greater levels of independence. The subscales assess the areas of self-care, respiration and sphincter management and mobility. The SCIM has been shown to be valid and reliable in multi-centre studies.²⁹

The inclusion of *participation* in disability studies is important, but the subjective nature of *participation* can cause challenges with measurement.^{30,31} The Craig Handicap Assessment and Reporting technique (CHART) is one of the most widely used measure of *participation* in research.³² However, CHART is classified as an *activity*-focused, objective measure of *participation* (outsider's perspective) and is based on the ICIDH framework (International Classification of Impairment, Disability and Handicap), which is an outdated version of the ICF.³³ The ICF's focus on difficulty of *participation* reflects the outsider's view of what is important and has been criticised for not including subjective aspects of *participation*.³³ Issues of choice and control, importance, belonging, and satisfaction have been included in recent definitions of *participation*.^{34,35} The value of *participation* is evident in life situations that are

meaningful and important to the individual (subjective experience), as opposed to factors of *participation* that are considered important by the healthcare professional or researcher.³¹

Based on these criticisms of existing objective *participation* measures, a relatively new concept and measure of *participation* was used.³¹ *Participation Enfranchisement* assesses the subjective experience of *participation* and is a reflection of the meaning that individual's attach to participation across life domains.³⁶ Enfranchisement is defined as active engagement, choice and control, access and opportunity, fulfilling responsibilities, having an impact and supporting others, and social connection.³⁶ This construct is a reflection of the individual's perception of the communities in which they *want* to participate and the extent to which their communities are perceived to be valuing, respecting and inclusive.³⁶ Enfranchisement can also reflect personal factors, such as cultural background and socio-economic status, as well as environmental factors, such as varying opportunities between rural and urban communities.³⁶ Heinemann et al.³⁶ developed the Community Participation Indicators (CPI), which consists of separate components to measure *participation enfranchisement*. *Importance of participation*, which consists of 13 items (e.g., 'I do important things with my life') and *control over participation*, which consists of 14 items (e.g., 'I participate in activities that I choose'). Rasch analyses of the two item sets from a diverse disability sample demonstrated adequate internal validity (person separation = 2.66 and 2.28; item separation = 15.50 and 14.81 for *importance of* and *control over participation*, respectively).³⁶ Residual principle components analyses have suggested that the two item sets are one-dimensional. The two enfranchisement measures share 44% of their variance.³⁶ The CPI has previously been used to measure *participation* in a SCI population.³⁷

Statistics

Descriptive statistics for socio-demographic and lesion-related variables were performed. Apart from the usual scoring of the WHOQOL-BREF, the five items of the WHOQOL-BREF (WHOQOL-5) that cover overall quality of life, satisfaction with health, daily activities, relationships, and living conditions were also calculated separately. This allowed for comparison with WHOQOL-BREF data from the only other SCI QoL study that could be found for South Africa.¹⁵ All independent variables presented in Table 1 and Table 2 were included in the bivariate analyses to assess their association with the dependent variables (Total QoL, and the four QoL domains). *Participation*, number of health concerns, current age, age when

injured, years since injury and level of independence were treated as quantitative variables. The remaining variables were treated as categorical variables. The categories of each categorical variable are presented in Table 1 and was coded as such for analysis. Variables that were significantly associated with QoL were included in the multiple regression analysis to examine the factors related to overall QoL. The same procedure was performed for each of the four QoL domains. Akaike Information Criterion (AIC) was used to find the most parsimonious model of overall QoL as well as each QoL domain.³⁸ A *P* value of $\leq .05$ was considered statistically significant for all independent variables. During analysis, listwise exclusion of cases with missing values was applied.³⁸ Thus, if a participant had a missing value for any variable, then the whole case was excluded from any analysis that included that variable. The assumption of independence of errors were met for all models. The models exhibited no influential cases, no multicollinearity, no heteroscedasticity and the residuals were normally distributed.

Results

Ninety (n=90) of the 102, eligible rugby-related SCIs in the CBPJPF database were included in the study after they had agreed to participate. The participants were all male. Injuries were sustained over the period of 1968 – 2015. Twenty-nine (32%) of the injuries had occurred at school level, 56 (62%) at club/senior level, 3 (3%) within correctional services, and 2 (2%) were social rugby-related (social game). Forty-one injuries were sustained in the scrum (46%), 33 (37%) in the tackle, 12 in the ruck (13%) and the remaining 4 (4%) in other phases of play. Table 1 presents the general characteristics of the sample. The participant's ages ranged from 18 to 68 years, with a mean age of 40 years. The majority the participants were unmarried (69%). The mean time since injury was 18 years, with a minimum time of 1 year.

Table 1. Socio-demographic and lesion-related variables of participants (n=90)

Quantitative variables	Mean	SD	Min	Max
Age				
Current age	40	11	18	68
Years since injury	8	10	1	48
Age when injured	22	6	14	40

Table 1. Continued

	Median	Min	Max
Number of health concerns	4	1	10
Categorical variables	N	%	
<hr/>			
Race			
African	15	17	
Mixed ancestry	28	31	
Caucasian	47	52	
Marital status			
Unmarried	62	69	
Married	21	23	
Divorced	6	7	
Separated	1	1	
Province			
Eastern cape	20	22	
Free state	2	2	
Gauteng	12	13	
Kwazulu-Natal	5	6	
Limpopo	1	1	
Mpumalanga	2	2	
Northern cape	3	3	
Northwest	5	6	
Western cape	40	44	
Level of injury			
High quadriplegia: (C3-C4)	7	8	
Low quadriplegia: (C5- C8)	71	79	
Paraplegia	1	1	
Ambulant quadriplegia	11	12	
Completeness of injury			
Complete	37	41	
Incomplete	53	59	

Table 1. Continued

Current employment		
Unemployed	37	41
Employed	43	48
Student	8	9
Correctional services	2	2
Education		
Primary level	7	8
Secondary (high school not completed)	30	33
Secondary (high school completed)	23	26
Tertiary level	30	33
Income*		
Very low (R1-R2500)	33	37
Low (R2501-R8000)	20	22
Medium (R8001-R20000)	14	16
High (more than R20000)	14	16
Not provided / missing data	9	10
Asset indicator score (SES)		
Low SES	32	36
Medium SES	17	19
High SES	41	46
Type of residence		
Care facility: dependent	12	13
Care facility: independent	2	2
Private house	65	72
Block of apartments	3	3
Wendy house/ room in back yard	4	4
Townhouse	2	2
Correctional services	2	2
Transport		
Has own transport	48	53
Relies on others / paid transport	32	36
Relies on care facility transport	10	11

Table 1. Continued

Type of Healthcare		
Public healthcare	42	47
Private healthcare	37	41
Both	11	12
Exercise*		
None	39	43
1-4 times / week	17	19
More than 5 times /week	33	37
Missing data	1	1

* -variable with missing data

The study population included eleven (n=11) SCIs who presented with permanent neurological deficits, but who could walk (ambulant quadriplegia), either with assistance, crutches or ankle-foot orthoses (AFOs). One-way ANOVA revealed no significant differences between the mean QoL scores of the high quadriplegic and low quadriplegic (p=0.68), high quadriplegic and ambulant quadriplegic (p=0.23) or low quadriplegic and ambulant quadriplegic groups (p=0.33). The ambulant quadriplegia group was therefore retained in the sample for the full analysis. Thirty-seven (41%) of the sample was unemployed and subsequently the highest percentage of the sample (37%) had a very low monthly income (R1-R2500). Thirty-seven (41%) of the participants had not completed high school. According to the asset indicator score, 36% was grouped into low SES and 46% into high SES. Forty-seven percent made use of public healthcare, 41% of private and 11% of both. Table 2 presents the questionnaire scores of the sample. The mean score and standard deviation (SD) of the WHOQOL-BREF was 15.1 ± 2.3 AU. The domain scores ranged from 14.6 to 16.1 AU.

Variables that showed an association with one or more of the dependent variables in the bivariate analyses are presented in Table 3. Variables that showed no association with any of dependent variables were omitted from this table. Independent variables that were significantly associated with outcomes of the WHOQOL-BREF were included in the multiple regression (Table 4). In the final model, *participation: control* (B:0.09; 95%CI:0.07-0.12), very low

income (B: -1.65; 95%CI: -2.70- -0.60) and low income (B: -1.45; 95%CI: -2.60- -0.30) were most strongly associated with overall QoL (Table 4). This model explained 50% of the variance in QoL (F=18.2, p<0.001).

Table 2. Quality of life, level of independence and *participation* scores

	Mean	Median	SD	Min	Max	Interquartile Range
Quality of Life						
Total QOL (out of 20)	15.1	14.8	2.3	7.9	19.8	3.3
* Missing data n=3						
<i>Physical domain*</i>						
4-20 transformation	14.7	14.3	2.6	9.7	20.0	4.6
0-100 transformation	66.9	64.3	16.5	36	100	29
Missing data n=1						
<i>Psychological domain*</i>						
4-20 transformation	16.1	16.7	2.6	7.3	20.0	3.3
0-100 transformation	75.6	79.2	16.4	21	100	21
Missing data n=1						
<i>Social domain*</i>						
4-20 transformation	14.6	14.7	3.2	5.3	20.0	4.0
0-100 transformation	66.0	66.7	20.2	8	100	25
Missing data n=3						
<i>Environmental domain*</i>						
4-20 transformation	14.9	15.0	3.0	6.5	20.0	4.5
0-100 transformation	68.4	68.8	18.9	16	100	28
Missing data n=3						
WHOQOL-5*	19.7	20.0	2.8	13.0	25.0	4.0
Missing data n=3						

Table 2. Continued**Participation***

CPI: Importance	57.1	54.7	11.9	29.6	100.0	15.8
CPI: Control	67.3	63.6	15.6	37.1	100.0	20.5
Missing data n=3						
Level of independence						
SCIM	34.8	24.0	23.2	3.0	97.0	23.0

* -Variable with missing data

For the Physical health domain, *participation: control* (B:0.07; 95%CI:0.03-0.10), very low income (B: -2.47; 95%CI: -3.89 - -1.04), low income (B: -2.25; 95%CI: -3.79- -0.71) and number of health concerns (B: -0.34; 95%CI: -0.59- -0.09) were significantly associated with QoL. The model explained 38% of the variance in Physical health QoL (F= 9.0, p<0.001). *Participation: control* (B:0.08; 95%CI:0.04-0.12) and *participation: importance* (B:0.05; 95%CI: -0.00- -0.10) were the only variables included in the final model of the Psychological domain, explaining 39% of the variance (F=27.8, p<0.001). This was also the case for the Social domain where *participation: control* (B:0.08; 95%CI:0.03-0.13) and *participation: importance* (B:0.07; 95%CI:0.00-0.13) explained 32% of the variance in this domain (F=19.7, p<0.001). *Participation: control* (B:0.08; 95%CI:0.05-0.11) and the use of private healthcare (B:2.66; 95%CI:1.36-3.86), or both private and public healthcare (B:2.61; 95%CI:0.94-4.37) compared to public healthcare only, were positively associated with increased Environmental QoL. Uncompleted secondary level schooling (B: -2.47; 95%CI: -4.61- -0.33) and completed secondary level schooling (B: -3.02; 95%CI: -5.34- -0.69) was negatively associated with environmental QoL (F=16.6, p< 0.001).

Participation's strong association within all the regression models prompted further exploration of this variable. All variables were again assessed in a bivariate analysis with participation as the dependent variable. Three variables showed associations with *Participation: control* at p <0.01 level. These variables were level of independence ($r_s = .376$,

$p < 0.001$), number of health concerns ($r_s = .306$, $p = 0.004$) and exercise frequency ($r_s = .321$, $p = 0.002$).

Table 3. Bivariate analysis: Association between dependent and independent variables (ANOVA and Spearman's correlation)

	Total QoL	Physical QoL	Psychological QoL*	Social QoL*	Environmental QoL
Quantitative variables					
CPI: Control	$r=.657$; $p<0.001$	$r=.492$; $p<0.001$	$r_s=.654$; $p<0.001$	$r_s=.541$; $p<0.001^*$	$r=.441$; $p<0.001$
CPI: Importance	$r=.518$; $p<0.001$	$r=.259$; $p=0.02$	$r_s=.558$; $p<0.001$	$r_s=.535$; $p<0.001^*$	$r=.360$; $p=0.001$
SCIM	$r=.292$; $p=0.01$	$r=.281$; $p=$ 0.01	$r_s=.185$; $p=0.08$	x	x
Number of health concerns	$r=-.239$; $p=0.03$	$r=-.380$; $p<0.001$	$r_s=-.248$; $p=0.02$	x	x
Categorical variables					
Province	x	x	x	x	$p=0.001$
Injury level functional level	x	x	x	x	x
Current employment	x	x	x	x	$p=0.02$
Education	x	x	x	x	$p=0.001$
Income	$p=0.001$	$p=0.01$	x	x	$p<0.001$
Asset indicator score (SES)	x	x	x	x	$p<0.001$
Transport	x	x	x	x	$p<0.001$
Type of Healthcare	$p=0.03$	x	x	x	$p<0.001$
Exercise	x	$p=0.04$	x	x	x

* *Psychological and Social domains not normally distributed*

r = *Pearson's correlation coefficient*

r_s = *Spearman's correlation coefficient*

Table 4. Multiple regression models for Quality of Life

Model	R	R- Square	Adjusted R- square	Independent variables	Unstandardized	95%	Confidence		P value
					Coefficients B	Interval Lower Bound	Upper Bound		
Overall QoL	0.70	0.50	0.47	Participation: Control	0.09	0.07	0.12	<0.001	
				Income					
				Very low income	-1.65	-2.70	-0.60	0.001	
				Low income	-1.45	-2.60	-0.30	0.02	
				Medium income	-0.52	-1.77	0.74	0.42	
High income	<i>Base variable</i>								
Physical domain	0.62	0.38	0.34	Participation: Control	0.07	0.03	0.10	<0.001	
				Income					
				Very low income	-2.47	-3.89	-1.04	0.001	
				Low income	-2.25	-3.79	-0.71	0.01	
				Medium income	-1.21	-2.88	0.47	0.16	
				High income	<i>Base variable</i>				
Health concerns	-0.34	-0.59	-0.09	0.01					

Psychological domain	0.63	0.40	0.38	<i>Participation: Control</i>	0.08	0.04	0.12	<0.001	
				<i>Participation: Importance</i>	0.05	-0.00	0.10	0.05	
Social domain	0.57	0.32	0.30	<i>Participation: Control</i>	0.08	0.03	0.13	0.002	
				<i>Participation: Importance</i>	0.07	0.00	0.13	0.04	
Environmental domain	0.71	0.51	0.47	<i>Participation: Control</i>	0.08	0.05	0.11	<0.001	
				Education					
				Secondary level: uncompleted	-2.47	-4.61	-0.33	0.03	
				Secondary level: completed	-3.02	-5.34	-0.69	0.01	
				Tertiary level	-1.12	-3.47	1.23	0.355	
				Primary level	<i>Base variable</i>				
				Healthcare					
				Private	2.66	1.36	3.86	<0.001	
Combination: Private and Public	2.61	0.94	4.37	0.003					
Public	<i>Base variable</i>								

Discussion

This study investigated the QoL and the factors associated with QoL in individuals with rugby-related SCIs. It has previously been reported that people with disabilities in South Africa have lower QoL than people without.³⁹ The current sample had higher QoL scores compared to the only WHOQOL-BREF score data that could be found for a South African SCI population.¹⁵ This sample scored higher, in all four domains, than a comparable study in a Taiwanese SCI population.²⁷ Except for the Environmental domain, this sample also scored higher than an Australian study sample.¹⁶ Instead, these QoL scores were similar to those reported for healthy adults.⁴⁰ These comparisons are limited to studies that utilised the WHOQOL-BREF or WHOQOL-100. Nonetheless, the present study population appears to possess unique characteristics potentially affecting their QoL. Further research is needed to explain this finding, but possible influencing factors may include the population type (active individuals with a similar mechanism of injury) and the assistance provided to these injured players by a dedicated organisation (CBPJPF).

The findings of the study indicated that *participation* and income were significantly associated with overall QoL. In addition to these two factors, the number of health concerns, type of healthcare and level of education were significantly associated with the various QoL domains. Previous research has indicated that participation in home, work, social and community activities, was highly related to QoL.^{16,41} Importantly, *participation* was the only ICF component that was significantly associated with *all* QoL domains in this study. Similarly, the Taiwanese study found *participation* to be consistently associated with all domains of the WHOQOL-BREF.²⁷ The significant relationship of *participation* with QoL reiterates its importance as a modifiable factor for individuals with SCI. To improve the *participation* of persons with SCI, it is important to understand how potentially modifiable factors, such as exercise, are associated with *participation* in this population. Physical activity has been shown to be associated with better QoL in healthy adults as well as persons with SCIs.^{42,43} Additionally, reviews have proposed that sports and recreational activities improve self-confidence and performance of activities of daily life in people with SCI.⁴⁴ Compared with non-active persons with disabilities, those who engage in organized sports have decreased depression and anxiety, and increased opportunities for employment.⁴⁵ In

this study, exercise was not directly related to QoL in the final regression models. However, it was indirectly related to QoL through its association with *participation*. The importance of exercise in this sample of previously active rugby players before their injury may be far reaching. Individuals who identify as athletes are more likely to maintain, or find the need to maintain, sporting behaviour over the long term.⁴⁶ Qualitative research has examined the experiences of people who have suffered a SCI through playing sport.^{18,19,47,48} These studies have revealed that individuals with strong athletic identity before the SCI can have adaptation difficulties after their injury.¹⁹ However, athletic identity has also been reported as factor that can promote recovery, and is considered as means to enhance long-term adjustment to disability.⁴⁹ This may be explained by research that has shown athletic identity to be a predictor of sport participation among individuals with acquired physical disabilities.⁵⁰ Sports participation has also been associated with improved QoL.⁴³ Certain barriers may impede exercise or sporting behaviour, such as cost, level of disability, health complications, lack of facilities, difficulties with transport and accessibility.⁵¹ It is important to overcome as many of these barriers as possible, as exercise participation may be an essential component of the player's identity.⁵⁰ This requires an in-depth individualised assessment to understand the specific *participation* components which are perceived as important to the individual.⁵²

Among the other components of the ICF, the only *impairment* variable that was significant in the final model was the number of health concerns. This agrees with other studies that found lower QoL in persons with SCI reporting secondary health problems.^{53,54} Health concerns and complications are important areas of focus for interventions as apart from affecting QoL, these issues may also increase healthcare costs due to re-hospitalisations. Furthermore, health concerns in SCI population might create greater barriers to employment, thereby affecting both income and *participation* in general.⁵⁵ In contrast, level of injury was not associated with QoL in any of the final models. This finding is also consistent with other literature which showed that *impairments* do not affect QoL directly, but rather via their impact on *activities* and *participation*.^{15,16} In the present study, *activity* (i.e. level of independence) was also not directly related to QoL. It was, however, indirectly related to QoL through its association with *participation* (Figure 2). For a person sustaining an SCI, most self-care activities and wheelchair mobility tasks require specific skills development to

reach higher levels of functioning.⁵⁶ An improvement of these skills is likely to have a substantial impact on level of independence.⁵⁶ In South Africa, rehabilitation services are inaccessible to the majority of people as they are concentrated at tertiary institutions or provided by private service providers.^{57,58} This could mean that those with an SCI in rural areas of South Africa are less likely to receive specialised rehabilitation, which may inevitably affect their independence.⁵⁷ The findings of a South African household survey confirmed that poor, uninsured, black Africans and rural groups still have inequitable access to healthcare.⁵⁹ These disparities are particularly evident when considering that the poorest quintile of South Africans receives less than 10% of the country's health benefits despite requiring close to 40% of these services.⁶⁰ Disability further impedes accessibility to healthcare.^{57,61} The associations of the type of healthcare being utilised with QoL, may be specific to the nuances of the South African healthcare system. Results from this study indicate that private healthcare, or at least a combination of public and private healthcare, was associated with increased QoL. It is most likely that based on these health inequities, additional external support is necessary for those individuals living with an SCI. In effect, support from the CBPJPf for individuals with rugby-related SCIs, is likely to distinguish them from other SCIs in South Africa.

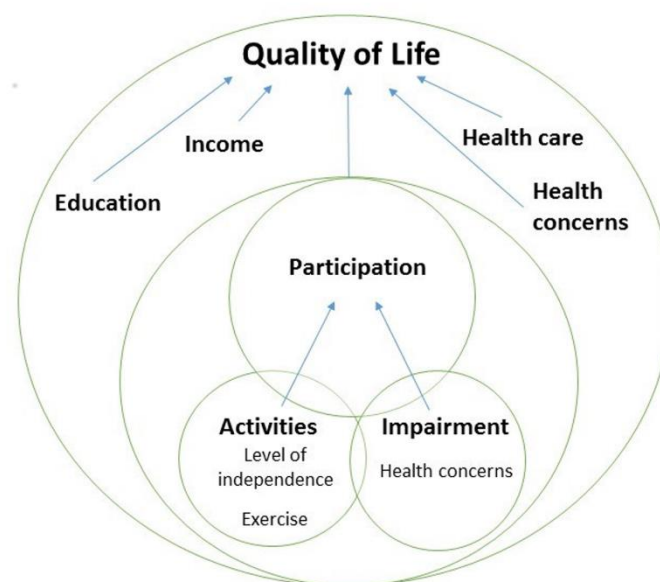


Figure 2. Factors associated with QoL based on the ICF-CR framework (based on Ravenek et al, 2013)

Owing to difficulties in the quantification of SES in South Africa, we considered many different proxies of SES.²⁸ The asset indicator score was not significantly associated in any of the final models and it is possible that other variables, such as income and education, were better proxies of SES in this sample. Low income was negatively associated with QoL. Sufficient income of either the patient or the household is crucial when considering the lifetime cost, care and equipment needs of SCI. A 10-year longitudinal study reported that people with SCI with lower household income had experienced more dissatisfaction, worsening health problems and environmental barriers compared to persons with higher income.⁶² Marginalisation of people with disabilities may result in loss of productivity and opportunities to generate income, which again is linked to health and QoL.⁶³ Apart from the monetary gain from employment, this activity would also improve *Participation*, which our study has shown to be associated with QoL. Indeed, productive work has been described as amongst the most important ‘participation activities’ for adults with disabilities and being employed is regarded as a key indicator to social integration.^{15,64} Unfortunately, the South-African Census of 2011 showed low overall absorption rates of disabled people in the labour market.⁶⁵ Apart from employment opportunities, lack of skills and education are also important barriers to successful employment for people with disabilities in South-Africa.⁶⁵

The highest level of education attained by participants showed specific associations in the environmental domain. Compared to primary level education, secondary level education was associated with significantly lower Environmental QoL scores, while tertiary education was not. This finding is difficult to interpret, as it would have been expected that QoL would increase as the level of education increases. It is possible that the level of education before sustaining the injury may have been low and not necessarily due to the injury. As is the case with healthcare, South Africa still bears the burden of an unequal education system and the children of poor parents attend, for the most part, low-quality schools with high dropout rates.⁶⁶ This limits learners’ opportunities for tertiary education and subsequently restricts them to low-level jobs.⁶⁷ Moreover, for a player injured while studying or at school, continuation of their education post-injury can be challenging in a country with inequitable access to education, and even more so for persons with disabilities.⁶⁶ Another possible explanation is based on the country’s political past and Calman’s definition of QoL, as the gap between expectation and experience.^{9,68} Calman’s theory argues that when faced with a

new experience, if the experience matches expectation, there would be no significant decrease in QoL. The Environmental QoL of participants with low levels (primary level) of education may have not been influenced to an extent that resulted in further loss of Environmental QoL, while for participants with higher than primary level education and possibly higher expectations, this balance was potentially not maintained post-injury.

Limitations

Although all participants were fluent in either English or Afrikaans, some nuances of the WHOQOL-BREF and CPI measures may have been lost for participants whose first language was neither Afrikaans nor English. Other factors relating to adjustment and mental health after SCI, such as coping strategies and psychological resources were not investigated in this study but may explain the remaining variance in the regression models. Furthermore, this study comprised a special population of previously active individuals who became disabled playing their sport. It is possible that this ‘athletic identity’ contributes to the perception of QoL and may thus not be representative of the general SCI population. Further investigation in this regard is warranted. Due to the cross-sectional study design, we were unable to identify factors predicting QoL, but could only show associations between the investigated variables. Our study was exploratory and the first study in a South African SCI population to investigate factors associated with QoL. Statistical methods such as Path analysis or directed acyclic graphs (DAGs) may be used in future studies in this population, to further investigate the relationships identified in this study.

Conclusion

This is the first study to present QoL data for rugby players who have sustained SCIs. On average, this group mostly had higher QoL scores than other comparable SCI studies in non-sporting populations. This could be a consequence of the support given by a dedicated organisation, or due to the identity of the group as active rugby players before their injuries. Sporting bodies have a responsibility to optimise player welfare by acting upon the modifiable factors associated with reduced QoL, following a sport-related injury. The study indicated that persons with lower levels of *participation* and income, certain levels of education, increased health concerns and those who make use of public healthcare, experienced low levels of QoL. It follows that these individuals may benefit most from

tailored and specific interventions. Assisting in strategies to create alternative forms of financial self-sufficiency may be one such opportunity where sporting bodies could show their support. Further, the strong association between *participation* and QoL in this study emphasises the need to measure this concept in those with SCIs. Although some of the modifiable factors in this study (such as type of healthcare) may be South African specific, concepts such as *participation* may be important for all individuals with SCI. Studies of a qualitative nature could provide further understanding of the factors associated with QoL.

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Chapter 6: Barriers and facilitators to healthcare in individuals with rugby-related spinal cord injury in South Africa

Prepared for submission

Introduction

Rugby is a fast paced, full-contact sport that is popular worldwide.¹ Rugby-related injuries that result in permanent disability (catastrophic injuries) are not common, but they do occur.² Amongst these catastrophic injuries, acute spinal cord injuries (SCI) account for the highest proportion of injuries.³ To date, substantial efforts have been made to make the game safer. In 2009, a nationwide injury prevention programme, 'BokSmart', was launched in South Africa in conjunction with the Chris Burger Petro Jackson Players' Fund (CBPJPF) to reduce these catastrophic injuries.⁴ The CBPJPF is a non-profit organisation that provides physical and emotional support for rugby players who have sustained a catastrophic injury. Despite these prevention efforts, when such an injury sustained on the field results in permanent disability, the negative physiological, psychological, social and economic consequences are profound for both the player and his family.⁵⁻⁸ Sporting bodies have a responsibility to maintain the health and welfare of their athletes.⁹ This responsibility does not stop at the development and advocacy of effective preventive approaches, but extends to the player whose life has been irrevocably changed by playing their sport. The various injury prevention programmes in rugby^{10,11}, demonstrate that rugby administrators prioritise the prevention of serious spinal injuries. However, less attention is applied to the consequences, and thus, long-term quality of life (QoL) of players who sustain SCIs playing rugby.

The consequences of a SCI can be assessed by the WHO's International Classification of Functioning, Disability and Health (ICF).¹² A conceptual revision of the ICF diagram (the ICF-CR) was proposed to enhance its biopsychosocial content. The revision represented QoL as the largest component of human functioning, with contributions of the other subsystems.¹³ The incorporation of QoL contributes to a more comprehensive understanding of the impact of the health condition and the experience from the perspective of those affected.^{13,14} QoL after sustaining a SCI may be affected by various factors.¹⁵ These include personal factors, such as sociodemographic and psychological factors, or economic and environmental factors, such as education, adequacy of housing and opportunities for employment.¹⁵⁻¹⁸ Studies have also shown that secondary health problems negatively affect QoL in persons with SCI.^{19,20} Health-related problems may directly affect a person's ability to participate in the community or to be employed.^{16,21-23} Therefore, good health may be

seen as the foundation to successfully participate in everyday life and various life roles and thus, overall QoL.²¹

However, maintaining good health is more difficult in individuals with SCI.²⁴ Not only do health concerns and complications increase healthcare costs and affect QoL, the presence of several secondary health conditions also increases the risk for diminished life-expectancy after SCI.²⁵ Therefore, acute care, rehabilitation services and ongoing health maintenance are essential for prevention and management of these conditions and may play a determining role in maintaining health.^{21,26,27} The ability to maintain good health will depend, in part, on the accessibility of healthcare.²⁸ However, people with disabilities have unequal access to healthcare services, experience poorer levels of health and have more unmet health needs compared to people without disabilities.^{29–31}

Accessibility has been defined as the “opportunity and freedom to use services and encompasses the circumstances that allow for appropriate service utilisation, plus a sufficiently informed individual or household, empowered to exercise choice within the health system”.³² The ‘degree of fit’ between the individual / household and the healthcare system determines the degree of access attained.³³ In South Africa, approximately 16% of the population uses private health services, often covered by private, voluntary health insurance (also known as medical aid).³⁴ Over and above the basic health insurance contribution, members are also required to make out-of-pocket payments for the costs of services or consumables not covered by insurance, for co-payments of specialists, or paying for services once the annual benefits or savings component of the health insurance plan have been exhausted.^{35,36} On the other hand, the remaining 84% of the population relies on the national, tax-funded, public health sector, staffed by only 30% of the Doctors in the country, as their sole provider of healthcare.²⁷ South-Africa’s pre-democracy healthcare system was characterised by racial segregation and discrimination.³⁷ Apartheid ended in 1994 and the right to healthcare is now an important part of the South-African Bill of Rights. However, the health system is still faced with massive challenges, partly due to the persistence of economic inequalities between races, resulting in inequitable health access for poor, uninsured, black South Africans and rural groups.³³ In fact, South Africa classically mirrors

the inverse care law, where those with the greatest need for health services benefit from fewer services compared to those with relatively less need for such services.³⁸

The contribution of good health to overall QoL, makes it an important factor to consider for long-term well-being of players who have sustained these injuries. This would require an enhanced understanding of the healthcare needs and challenges that individuals with SCI in South Africa are facing. There is limited research on factors associated with access to healthcare in persons with disabilities in South Africa. Though some barriers and facilitators may be similar for all persons with disabilities, SCI-specific barriers and facilitators may be present. This information will firstly educate health planners and caregivers about creating circumstances that will enable people with SCI to achieve optimal health and healthcare, and secondly address factors that may be specific to this population of injured rugby players. Successful removal of barriers and improvement in access to health services requires input from the persons with SCIs who access these services, who are most familiar with, and who are affected by such barriers.³⁹ Therefore, the aim of this study was to describe barriers and facilitators to healthcare, in individuals with rugby-related SCI in South Africa.

Methods

Design

The study followed a pragmatic, descriptive, qualitative approach, drawing from the most practical methods available to answer a specific research question. This approach facilitates a comprehensive understanding of a phenomenon or process from the perspectives of the people involved⁴⁰, and was deemed best suited to provide descriptive, practical, information to all stakeholders with vested interest in the long-term healthcare needs of these injured players. This study forms part of a broader project investigating the consequences and long-term impact, of rugby-related SCI. Ethical clearance for the study was obtained from the University of Cape Town (UCT) Human Research Ethics Committee (HREC REF: 893/2015).

Participants

For the purpose of the broader project, the entire known population (n=113) of players who

have sustained a rugby-related SCI in South Africa in the period of 1968-2015 formed the population of the study. Access to the database of injured players was obtained from the CBPJPF. Participants were eligible to participate if they were 18 years or older and had sustained their injury a minimum of 1 year before the start of the study (n=102). Ninety of the 102 eligible recipients on the CBPJPF database agreed to participate and were included in the broader study. From the 90 interviews of the broader study, stratified purposive sampling was used to select interviews for inclusion in this study, with the aim to provide maximum variation in experiences and thus enhance transferability.^{41,42} The stratification process considered socio-economic status (SES) and geographical areas to ensure that views from all these strata were equally represented. SES was grouped as high, medium or low SES (Appendix 3). Saturation was determined when no new codes or themes were identified.⁴³ The final sample consisted of thirty-one (n=31) participants (Table 1).

Data collection

Individual, semi-structured interviews were conducted at participants' homes or places of work by the first author, a Physiotherapist with training in qualitative research methods. Interviews averaged between 50 – 90 minutes and were audio-recorded. The interviews focussed on health and healthcare, but also included questions associated with the objectives of the broader study, which are not reported on in this study. Semi-structured, open-ended questions were pilot-tested by interviewing a person with a rugby-related SCI and altered according to his feedback. Recursive questioning was used to explore issues, and verify the researchers' understanding of information being collected.⁴⁴

Analyses

Interview recordings were organised and transcribed verbatim in Nvivo11 (QSR International, 2015). Thematic analysis was used to analyse data.⁴⁵ This process started by listening to the audio files and writing notes about possible codes and patterns. Initial codes for the first ten transcripts were generated by the first and final authors, and then discussed until consensus about their meaning was reached. The remaining transcripts were coded by the first author. The final process involved grouping of codes into categories to create higher-order thematic categories. Codes were reviewed and discussed by the first and final authors until final themes were generated. Reflection included the ways in which the researcher's

personal background and emotional responses to the participants could shape the interpretations of the interview data.⁴² Thus, periodic discussions with the project supervisors and peers were utilised to gain different perspectives and to test assumptions.⁴²

Table 1. Sample characteristics (n=31)

	Min	Max	Mean	Median
Years since injury	31	48	37	36
Current Age (years)	20	68	17	16
	Frequency			
	(%)			
Monthly income				
Very low (R1 -R2500)	32			
Low (R2501-R8000)	19			
Medium (R8001-R20 000)	26			
High (More than R20 000)	23			
Education				
Primary	10			
Secondary (not completed)	26			
Secondary (completed)	22			
Tertiary	42			
Socio-economic status				
Low	32			
Medium	36			
High	32			
Health system accessed				
Public	42			
Private	45			
Both	13			

Findings

Four themes with associated categories were derived from the data; (i) *Healthcare for QoL*, (ii) *The public system - issues of access and quality*, (iii) *The private system – balancing income, cost of care and health insurance*, (iv) *Factors that play a role across systems*. The first theme highlighted the meaning and importance that participants placed on healthcare as a component of QoL. The remaining themes described the participants' experiences of barriers or facilitators present within the private, public or both healthcare systems.

1. *Healthcare for QoL*

Good healthcare meant, at the time of the injury, a chance at survival. However, participants also describe long-term, accessible, affordable, quality healthcare as an important determinant for their QoL through its effect on health:

QoL is the most important factor and if these guys (healthcare providers) can't look after me, then my QoL won't be what it should be...and the danger that I see then...because the guys that I know that are quadriplegics...they died over a couple months...they got bitterly sick and I don't want that, that is not for me.

Medical care...if you don't have that worry...if you have a good medical aid and your primary needs are met, like your wheelchair...and you don't have to worry about it every day...and your catheters and bags...I think it will be really difficult if you have to worry about that everyday...I think that is very important...that you know that is covered.

Healthcare was seen as a primary need that had to be in place. Moreover, good healthcare facilitated good health, which was crucial in facilitating participation in everyday activities and life roles:

The less your disability comes in the way of the things you want to do...and have to do...that is QoL, for that your health must be taken care of. Like my medication...my QoL has improved drastically since I managed to go on the correct medication...

Participants also described the importance of the initial rehabilitation process after injury and identified it as a phase that facilitated mobility and functionality. The rehabilitation

phase was regarded as a process that taught endurance and an important part of the road to recovery and adjusting to a new life. However, participants also emphasised the importance of continued rehabilitation:

You never actually stop. I still do rehab now...I tell people it never really stops, because you go through different phases in your life and at every new phase, you have to learn to do something differently, or like I am getting older now, and less independent, so I have to learn to do some things differently now as well. It is all part of rehab and it is important for my life. I see a Physio once a month.

For some, continued rehabilitation was important not just from a prevention and promotion point of view, but also because being active is something that they have also enjoyed as rugby players:

I think most rugby guys enjoy going to the Physio...because it is like gym. I mean, you used to be an active guy, so going and being active is not a punishment...it helps me a lot... I know it helps to maintain what I have and keep me healthy. Without Physio I would have been much stiffer...and have blood clots and things like that...

2. The public healthcare system: issues of quality and access

Quality of care

Several participants were concerned about the quality of care received in the public health system. Some participants felt that public health Doctors are often young or inexperienced, or that the care received while admitted to the hospital was not adequate:

I don't want to sit in a public hospital, when I get a job I will get a medical aid because the public hospitals are bad...so bad...the young Doctors are not so experienced.

Even the care in that hospital...I remember one of the quads I went to visit while he was there. He was lying in the bed, there was not even a pillow...nothing to protect the heels...even me, I have a big mark from a pressure sore I got in that hospital.

This led at times, to participants who usually accessed public healthcare, opting for private healthcare instead, with additional cost implications:

The hospital in (-) town is not nice, like the time I was still living there, I got an infection. They took me the local hospital, there I got worse...I said no, I need a Doctor, so I hired a car to take me to the private Doctor who gave me the right medication and then I got better, I had to pay the private Doctor to get better.

I went there, and they changed the catheter, I was on my way back to the taxi rank. I started to feel dizzy, luckily, I had friend that recognised something was wrong. They paid for me to go to the private Doctor...there was a lot of blood even on my wheelchair cushion. I don't know, maybe they don't care... I am not sure...so for me, since then, I hate to go there. I now use the condom catheter, it is better. For other things, I also rather pay to go the private Doctor in town than go there.

Several participants were also unsatisfied with the quality of rehabilitation services and treatment received outside of specialised spinal units. This dissatisfaction was often related to student Physiotherapists who had less knowledge and experience:

The Physios are very good, but there are also students that are still learning...if you get someone that is there permanently you will feel like, yes I did something today...if you get a student ..who doesn't know how to do this...you must still teach this person how to do exercises...they ask you, what do you usually do when you come here? It is helpful when you get people who know what to do.

I don't like a Physio that only do what they have to do...they just stretch you. Give me something to do...give me something to work on my core...because that is what I need, it is most important...I am an incomplete quad. So that would really work on my nerves...I am competitive and there are things I want to do, so like the one guy gave me nice stuff like transfers. If you want to do Physio, you want to help him to do better...to make him feel better...now that is what I want.

Waiting time and availability of healthcare providers

In the public system long waiting periods was an important and consistently mentioned challenge. These waiting periods referred to both waiting for treatments, appointments,

equipment or availability of services, or physically waiting in the out-patient department and the difficulties associated waiting for prolonged periods of time:

In the clinic they do give you medicine and so on and if it is very severe they do send you to hospital but even in these public hospitals, it is always full there...you go there now but you will only get a Doctor tomorrow morning, it is like that. It always full, you wait there in the line...even if they are going to admit you still have to wait there in line for the bed. It is not easy for a person in wheelchair to just sit and wait.

Some participants expressed concern that their condition would deteriorate while having to wait these prolonged periods for care:

I go to private (healthcare) then because I can't wait that long...six hours...and then my infection can turn how bad...I know I have infection, so I just go to the private Doctor but that is an expensive consultation fee...

Similarly, the most commonly mentioned barrier to continued rehabilitation in the public system was the availability of these services. These included a shortage or complete absence of rehabilitation therapists such as Physiotherapists or Occupational Therapists to visit care homes, or the shortage of rehabilitation therapists at day hospitals:

My neck gets really stiff...and this arm too...because there are no Physios here that can help us...

The workload of Physiotherapists in the public system meant that it was difficult to be seen regularly:

I went once a month...and maybe you can you persuade your Physio to take you twice a month...but they have a lot of people they must look after, too many.

Participants described their need for rehabilitation and how the lack thereof affected their functioning. It was especially problematic to find these services in a rural area:

Really the one thing that is worrying me, I don't care about this leg, I don't have run again, I have made peace with that one. But I don't know why I can't straighten this arm, especially the fingers...it is completely closed (flexed)...and it is stinky...

Interviewer: After (specialised rehab centre) did you ever have Physio or OT again?

Participant: No that was the only time...that is the problem. never again. So, the exercises I am doing I am just doing by myself, sometimes I get tired...

I need to get a Physio to try and move my arms and legs...it is not good they don't move. So, in the wheelchair what happens...I have straight legs in my wheelchair. That makes it difficult to move...yes and you see how difficult it is to move on these roads.

Interviewer: Did you have any Physio after hospital?

Participant: No, no one, I had a friend who helped me a bit but nothing after that...I never did anything after that...

Participants also felt that it would be easier to continue rehabilitation exercises if there were spaces in the community where they could exercise, or if more Physiotherapists and Occupational Therapists (OT) were available in the community to assist:

You see, I am living in this facility, if the government can get to these facilities...if they can build a hall for exercising and all that stuff...there are spaces also in the clinics, we need spaces to exercise, it can very helpful. Even in the communities, there are community halls...it would be nice if government could step in and build some place where people can get together and exercise.

I think with more rehab I can improve, I last had OT while I was still in hospital. It was, so bad, the day I was discharged... my mother cried, she said, why God...because she saw I couldn't eat, or push myself, I couldn't even do anything I couldn't even wipe a fly away. If government can see the challenges we have, especially us who are needy, if they can train more Physios and OTs to go into communities, into our communities, I think it will be 100% better.

The care provided by students was seen as a barrier for some, though they were also seen as a facilitator for people who had no options for accessing further rehabilitation and appreciated any help they received:

Luckily some students from the University come here to help. There is a lot of need here! You can never get too much help. We only have two carers here in the day to help, so let's say I want to do some exercises, I will call them to come and help me, but just

as you start someone else will call them for help. If only we had more help here...if we could get more Physio, that will also be good.

Attitudes of staff and patients

Negative or unhelpful attitudes of healthcare providers were also identified as a barrier to receiving necessary healthcare:

The Doctor isn't really interested. In the out-patient department and emergency department, I have sometimes found Doctors that care and that will talk...but there have been times where I have arrived at the emergency department and decided to rather go home, I would rather die than battle with this Doctor. It was a disappointment...maybe it was a coincidence that I also saw the young Doctors, doing their hospital year...

Some participants also reported hostility from other patients waiting in the out-patient department, if they got preference to be seen before them:

If you come to hospital, and you are supposed to be helped first but you need to have someone to stand there and see that you are going to be helped...they must stand there they can't walk away or someone will walk in before you...they feel; just what you have, I have... my daddy knows where to go, we just walk through...sometimes people get mad when we just go through, but I understand some people have been sitting there since six in the morning.

Some participants also expressed a lack of shared decision making and autonomy:

I went to hospital to fetch my stomach bags the other day. I went to ask for a plaster, I am using a condom catheter, they say what are you going to do with the plaster? I say I am going to put my condom and then put the plaster around they said no you are not supposed to that...I am listening to this sister...I saw when she was coming to me she had that attitude in her face...ok its fine, just cool down, then she said you put the condom like this, you put the plaster like this, I said ma'am, I am living with this condom for ten years...I did this like how you tell me, it didn't work for me, every time I did that I wet myself. So even the people in Cape Town, they put the plaster on me when they changed me to the condom. Then she says; no all of you who stay in Cheshire you don't want to be told all this stuff...I said it is not about being told what to do, it is about doing what is going to be the best for yourself, because I am the one that is going to sit wet

and then I am the one with bedsores...no...I will rather use what I know is right and works for me. She said, well you are not going get any plasters from us.

Transport

The availability and cost of suitable transport for participants utilising public healthcare, was an important barrier to access:

Challenges, number one, it is transport, because Physios are in hospital, and to go there, you can't take public transport...I have to hire a private car, it is about 12km..you know how much they charge me, it is R500 and I have to pay it, and what can I do, sometimes I need to go hospital 3 times a week and I don't have the money.

I go to hospital in (in town), I have to arrange a car...and then how much you pay depends on if the guy that is fetching you, whether he is good or bad guy...

For some, living in a care home with its own transport had facilitated access to healthcare:

When I lived at home...before I lived here (care home) ...transport was always a problem, transport to get to the day-hospital. You have to find a driver and pay him and pay for his petrol too...but here where I am living now, it is really nice because the home has their own buses, with ramps that you ride in on, you don't have to struggle like when getting into a car...your body just doesn't want to do that.

Availability of Stock

Another substantial concern of these participants was the availability of consumables, such as catheters, linen savers and medication, collected at public health centres. Often, the stock would not be enough to last for the whole month and patients would have to make another trip to the health centre, at a later stage, with additional transport costs:

Sometimes for instance when I am there in hospital, you get some things and other things you won't get...and you always get people shouting at you, it is not pleasant. They don't have all the things that we use there. There's just linen savers and urine bags and gloves, that is all. Some other stuff they don't have, like Lioresal, all the medication I am using, you won't find there.

Participants also described not getting the specific items requested (items substituted with other types or brands), or items of lower quality. For some, this meant buying additional stock, or the specific stock or medication they want privately, and therefore incurring additional costs:

But the day-hospital doesn't always have the catheters that we use, those silicone ones, they give you those ones that stay in for a week...I think the quality of the things we get at the day hospital is not that good anymore. And there are different things you need to get, at the day-hospital you only get 15 linen-savers a month...what can you do with that? And 15 gloves...you have to buy the extras yourself, that is why we are so grateful for the Fund (CBPJPF), because we can order some of that from them.

Although various barriers were described in the public healthcare system, some participants of low SES who were unable to access private healthcare, were satisfied with the quality of care they received. Transport, however, remained problematic for these participants. One participant, of higher SES, also described that some procedures that were not paid for by health insurance and that are expensive, such as *in vitro* fertilisation (IVF), were done at a public hospital and that they were happy with care received.

3. The private health system: balancing income, cost of care and health insurance

Income as facilitator

The ability to access private healthcare and private insurance was the most frequently identified facilitator to healthcare. This was strongly linked to a good income, facilitating the ability to pay for care or afford adequate health insurance:

So, well now I have good income so it is not that much and I have good medical aid, though they don't cover things such as wheelchairs and such...I have been very fortunate in that I have been able to buy good wheelchairs...but it is very expensive...like these wheels that I have on now that help me go all over the place, they cost about R80 000, so for ordinary person not earning a very good salary, it is not easy.

The man in the middle

There was a group of participants who were between the participants that could afford private healthcare and participants who definitely could not afford private healthcare (and thus had no choice but to use public healthcare). This group of participants chose to use private healthcare, but struggled to afford the related costs. For these participants the costs of private healthcare, health insurance and out-of-pocket payments were substantial barriers to healthcare. One participant mentioned that because of the expense he would delay seeking medical care when he was ill or would try and solve the problem without seeking professional care. Not being able to afford health insurance was a worrying long-term prospect:

The scariest thing is to not have medical aid (health insurance), and I think to myself, who can help with that...any person with a disability must do a job where medical aid is included...but then again, that is a dream, no will do that, enforce that...it is my biggest source of worry...where am I going to get long-term care...So I just live...and I am not an idiot...but I just live day from day to day, because it is so challenging. But obviously I am worried about the long-term, not just for me, but also for my parents who don't have medical aid.

Participants also spoke of the reality that the private health system offers more procedures or treatments. Therefore, patients are more likely to make use of these services, but also at additional cost:

With medical aid, you almost have more costs. When you have medical aid you won't say: I am not going to do this procedure because there will be a co-payment, you are going to try and do everything...and that places a n big financial burden on you...the one thing, medical aid doesn't pay for IVF at all, so it is already a challenge to try and have children, how do you cope with that if you don't have a good income...to even start phase one...you won't even get there...it is a terrible imbalance.

The cost of consumables was often not covered by health insurance plans, which resulted in additional costs, especially if the type of health insurance plan only paid for admissions to hospital. Participants also described the depletion of the medical savings component of the health insurance plan, which then resulted in out-of-pocket costs:

Yes see, my medical aid is completely depleted...so I had to do fundraising...all the players that played with me...I live off that fund for my medical things now...if it wasn't for that it would be chaos! It costs a lot to buy all the bags and stuff.

Additionally, participants experienced problems getting medical aids to pay or authorise or certain procedures or medications:

I have two pay for two of medications, they don't want to pay for it...and those two together alone costs R2000 a month...we have been battling with the medical aid so long...we pay them so much...but they don't want to pay what they have to...so what does it help...we are still busy fighting...catheters and things like that, that I pay myself too...they only pay half of things..

Though there were fewer barriers to rehabilitation mentioned in the private system, one prominent barrier that emerged was the cost of rehabilitation and the additional costs related to prolonged rehabilitation:

I had private Physio, and yes it was a lot of money...at least she gave me a little bit of discount so that I didn't have to pay everything.

In many instances, rehabilitation out of hospital was not covered by health insurance and if additional rehabilitation was needed, this became an out-of-pocket expense.

My medical aid stopped paying after the first year already, they couldn't anymore...they had already paid for three operations...and that depleted everything. When I needed extra rehab, they didn't want to pay...

Participants also mentioned having difficulties to get some Doctors to motivate for additional rehabilitation payment from health insurance.

4. Factors that play a role across sectors

Awareness of healthcare professionals in dealing with SCI and SCI specialists

Although the private system was generally associated with enhanced quality of care, participants identified a need for skilled professionals with specialist SCI knowledge to manage their health in both the private and public system:

I feel like no one really specialises in spinal cord patients...there must be guys who know what happens to us and how to handle us...who can look at the symptoms...that is what I would like to see. Instead, every time I go to the Doctor they tell me that I probably know more about what is wrong with myself than they would.

Participants also described a lack of knowledge and awareness of healthcare providers on how to care for people with SCI, especially when admitted to hospital:

I broke my kneecap, I was exercising...and then the guy stretched me very hard, I felt something is wrong and they took me to hospital and took x-rays because I could see my knee was swollen, they said it is crack in the knee cap, they put a cast on the back of my leg...and then the Doctor they say pick up your leg and put it there. I said, come on guys I am in wheelchair. I need to ask someone to put it there. Imagine if you have to put this leg straight in a wheelchair...they said you must put this leg straight I said how must I do that? They didn't help me with any of that to organise how to put this leg straight, I had to find a box and figure it out myself...

I didn't want to be there at all, because they don't know how to work with a person in wheelchair, they don't know how to do your bowels, they actually don't know anything...I can use my arms, but I can't press that help button...if you need help you must pray someone walks by...

Specialised spinal units and rehabilitation specialists

In contrast, a substantial number of participants mentioned specialised spinal units with good knowledgeable staff, across the public and private system, specifically Physiotherapists and Occupational Therapists, as important facilitators to rehabilitation.

The Physios and OTs were very knowledgeable, they had years of experience. The Physios also really helped me, they have their own job, but they can also tell you, like when you are having problems with your bladder...do this or that...they really went above and beyond, it helps when you have that extra knowledge.

Information and education

In both systems, participants reported receiving insufficient information about their conditions, both initially and in the long-term:

I got sick...autonomic dysreflexia...and it is a really horrible thing...even in hospital...it is not something they prepared me for...even my dad. He is medical, he didn't know what it was. Later I googled it...I wasn't even aware of the possibility...now afterwards...after time, you know how to handle it. It is important to manage it well

For instance, if I can get something in place with my bladder management, if I can maybe get a bit more support...or maybe I don't have enough of the right information on what to do...there must be a way, I need help for this...

Information and guidance on what exercises to continue doing, or what exactly to do at home was also problematic for some. Participants also identified a lack of support and education around sexual function and fertility:

Another big thing, when a young guy gets this injury, they need to get to place that can test his fertility...I waited too long...now it is too late for me. They have to do it...my parents were also useless...we didn't go to the right Doctors...if you take your son to the Doctor, go outside...he wants to talk about his own things with the Doctor...even if he is still a boy, there are things that you can't say in front of your parents. No one ever spoke about sex with me...so I assumed it wouldn't work and I just left it at that...

No, we have never had any real counselling...except a bit in hospital...If I could have saved sperm...I could have had a family...we haven't been to Doctors, it is so expensive...so we have given up...but the young guys must really think about...when you are young you don't think about it...but later you regret it. It should be the norm...

Cost

The cost of equipment and consumables was experienced as barriers in both the private and public healthcare system. These costs were incurred when the health insurance did not cover the items, or the items were not easy to obtain in the public healthcare system. Maintenance of wheelchairs and replacing wheelchair cushions were often paid for from the patient's own pocket:

So yes you really need a lot of finance when you are in a wheelchair, like a grant is not enough, for instance, the government gives you the wheelchair, but you need to maintain the wheelchair, something happens to your wheelchair and you go back to government to repair it and they say we can't, the budget has died.. you have to use your own money or your grant...you see...you have to use this grant money to fix this chair, but it is too expensive...it is expensive to live this life.

Additionally, specialised equipment, such as commodes, orthotics, special wheels, or gloves were identified as facilitators to healthcare, but is recognised as costly and difficult to afford.

I mean a wheelchair like this, you know you can buy a small car for that price...and look cushions, gel cushion the maintenance of the chair...new batteries, special wheels, yes...expensive...

External support structures

Several participants mentioned the assistance provided by the CBPJPF for consumables, equipment or rehabilitation and as an important facilitator:

Like for linen savers, we get money from the fund (CBPJPF)...because sometimes they don't have at the hospital.

I get support from fund (CBPJPF). The fund makes it easier for me, for my equipment...like my wheelchair...they support me...to add onto the DG (disability grant) I have...because I can tell you... I don't have any money in the bank.

The difference that the CBPJPF's assistance has made, was often highlighted by the participants:

It is not cheap to be disabled...if I didn't have the fund (CBPJPF) I would be in trouble...you would be pushing me in a wheelbarrow...financial...medical supplies...all those things.

External support from other avenues, such as fundraising by the rugby community, were also identified:

My medical aid was completely depleted, so we had a fundraiser...all the rugby guys that played with me...I depend on that money for medical things...and it is amazing, someone from an anonymous company pays money into my account every month...if it wasn't for that, it would be chaos! It costs a lot to buy all the things you need for this...

Discussion

To our knowledge, this is the first study that explored perceived barriers and facilitators to healthcare within both the South African public and private healthcare system, for persons with rugby-related SCI, (or SCI in general). Participants described long-term, accessible, affordable, quality healthcare as an important contributor to their QoL. If participants could afford it, private health insurance and private healthcare were perceived as facilitators to healthcare. External funding sources, such as the CBPJPF, often acted as a facilitator to bridge the gap between the cost and access to healthcare. Additionally, specialised spinal units and rehabilitation specialists were seen as facilitators to rehabilitation. However, there were many identified barriers to receiving healthcare. In the public system, quality of care, waiting time and availability of healthcare providers, transport and availability of stock were identified as the main barriers. Across both sectors, cost of health-related equipment and products, the awareness of healthcare professionals in dealing with SCI and information and education provided to the injured individuals and their families acted as barriers. These findings concur with a household survey of individuals with disabilities living in Africa, which indicated as important barriers; lack of transport, unavailability of services, costs associated with the visit to the health facility, insufficient medication or equipment and negative experiences or inadequate skills of healthcare providers.⁴⁶ Similarly, a recent study that conducted a secondary analysis of data from the South African General Household Survey (2014) found that persons with disabilities were more likely to have poorer physical accessibility to healthcare in terms of having no health insurance, using public healthcare

facilities, walking to the health facility and taking longer travelling time, compared to persons without disabilities.³⁰

Within the ICF, health systems can be considered as an environmental factor.¹² Personal factors, such as income, SES and health insurance may intersect with health systems to influence healthcare access. In turn, healthcare access can modify disability and health status.²⁸ Healthcare access includes issues of affordability, availability, accessibility, accommodation and acceptability or satisfaction with services.²⁸ These factors resemble the themes and associated categories presented in this study and influenced the extent to which participants were able to manage their access to healthcare. Previous quantitative findings within the broader research project indicated that, amongst other factors, income, health concerns and type of healthcare accessed were significantly associated with the various QoL domains.⁴⁷ Specifically, access to private healthcare, or at least a combination of public and private healthcare, compared to public healthcare only, was associated with increased QoL.⁴⁷ The findings of this study may help to explain some of these previous findings. Numerous public system barriers were identified. In contrast, private system barriers were mostly cost-related and thus participants with sufficient income were able to overcome these cost-related barriers. As such, the ability to access private healthcare and private insurance was the most frequently identified facilitator to healthcare and rehabilitation access and importantly, was considered to contribute to QoL. Although the private health system was seen as a facilitator to healthcare, affordability was one of the key underlying factors that determined whether this system would be used. Therefore, the personal factors; SES and income (as a proxy of SES), determined whether private healthcare would be affordable and was thus one of the key factors influencing healthcare access in this study.

Though private health insurance could be considered as a facilitator for accessibility to adequate healthcare, the costs related to both insurance and private healthcare itself are substantial.^{35,36} Membership and cost of private health insurances have become increasingly unaffordable for the middle-income group compared to the high income group in South Africa⁴⁸ and this was demonstrated by the participants in this study. Participants were required to make considerable out-of-pocket payments for the costs of services and consumables not covered by health insurance, or when annual benefits were exhausted.^{35,36}

For some, affordability of private healthcare affected the utilisation thereof to the extent that participants delayed or avoided seeking healthcare. Health insurance schemes are therefore not necessarily providing adequate financial protection for middle-income members who incur the substantial cost of care and rehabilitation of SCI.³⁶

In general, the cost related to SCI is substantial.³⁹ Specialised equipment, such as commodes, orthotics, special wheels, or gloves were identified as facilitators to healthcare. Such equipment is, however, also costly. As was presented in this study, these costs are incurred when health insurance fails to cover the specific items, equipment or services, or if these were not obtainable in the public healthcare system. These costs were often mitigated by the assistance provided by the CBPJPF and in a few instances, by external funding provided by the rugby community. The important difference that the assistance of these external funding sources made to the lives of the participants, highlights the inadequacies of both the public and the private healthcare systems to care for people with SCIs with income disparities.

In the public system, availability of services or healthcare professionals was a substantial barrier. Similarly, the availability of stock or preferred medication was identified as a barrier. Continued rehabilitation was especially problematic in rural areas. These barriers included the lack of rehabilitative therapist stationed at day-hospitals, visiting care homes or patients in the community. South Africa has well developed health professions and well-established training institutions.³⁴ However, the country is experiencing a serious shortage of healthcare professionals in the public sector and rural areas, compared to the well-resourced private sector and urban areas.^{27,34} These factors are a remnant of the country's political past, with policies of racial segregation and exclusion that are still visible in the unequal distribution of human resources in healthcare, creating unremitting barriers and shortfalls in the public system.³⁴ Additionally, the emigration of health professionals to developed countries further weakens the effectiveness of the public health system.^{34,49} Participants identified in-patient rehabilitation in the acute phase as an important facilitator to regaining health and functioning, but follow-up and care once discharged into the community was inadequate and at times, non-existent. Maintenance rehabilitation plays an important role in preventing or decelerating the decline in functional ability, but in many instances the emphasis instead remains only on acute medical needs.⁵⁰

The need for rehabilitation spaces and community-based rehabilitation (CBR) was evident in this study. South Africa adopted United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007, which includes the right to the highest attainable standard of health, without discrimination for people with disabilities. The convention requires that necessary accommodations in existing policies and services are made to realise these rights (UNCRPD). Rehabilitation is defined by the UNCRPD as “a set of measures that enable people with disabilities to achieve and maintain optimal functioning within their environments” (UNCRPD). Rehabilitation is also a core component of primary healthcare⁵¹ and as such South Africa’s National Rehabilitation Policy (NRP) was published in 2000. The goal of the NRP is to improve accessibility to all rehabilitation services to facilitate every person’s constitutional right to have access to healthcare services.⁵² However, access to rehabilitation for people with disabilities remains problematic in South Africa⁵¹ and was highlighted in the present study. CBR aims to provide services outside of institutions, but also adheres to the philosophy of inclusion and full participation of people with disabilities in all aspects of community life.⁵¹ Though CBR is currently one of the guiding policies in South Africa⁵³, other authors similarly indicated a high percentage of unmet rehabilitation needs for people with disabilities in South Africa, with inadequate finances and transport problems as main barriers.⁵⁴

The experience of the public health system in the study, reflected a system that is not accommodating to SCI patients’ individual needs and preferences.²⁸ This was evident in the long waiting periods to see healthcare providers or the unavailability of preferences such as a certain catheter or a specific medication. Similarly, attitudes of healthcare providers were not always favourable and also affected autonomy and decision making in care. Participants also related a feeling of the healthcare professionals *not caring enough* about looking after them. Ethically, healthcare professionals are obliged to place the interests of the patient first and to respect patients’ personal autonomy.⁵⁵ Autonomy can be enhanced by caring partnerships between healthcare providers and patients, supporting patients’ ability to consider all reasonable options and to participate in their own care. The absence of these relationships may result in fragmented healthcare, leaving patients with unresolved problems and needing to solve these problems on their own.⁵⁵⁻⁵⁷ Patients with long-term SCIs have

often figured out what works for them and healthcare providers need to listen to, respond to, negotiate and respect the patient's own knowledge, experience and wishes.⁵⁸

Apart from the barriers experienced within the public healthcare system, participants who made use of public healthcare also reported physical accessibility / transport to healthcare facilities as a major barrier. Accessibility was restricted by travel distance to facilities, availability and affordability of suitable wheelchair-accessible transport. These barriers were magnified for participants from rural areas and of low SES. Indeed, many underprivileged communities in South Africa are often geographically remote.¹ Similarly, Vergunst et al.³¹ described a “triple vulnerability” of poverty, disability and rurality that affects access to healthcare; this was also evident in this study. Additionally, in their study, persons with disability had significantly more access barriers than persons without disabilities.

In both the public and private health systems, sub-optimal quality of care was reported, although substantially more often in the public healthcare system. Issues related to quality of care mostly described the general experience, awareness and knowledge of healthcare providers in dealing with people with SCI. These factors were also evident during hospital admissions and also suggest that policies designed and developed for one particular group of patients may not meet the needs of others.²⁸ Additionally, participants identified a need for skilled professionals with specialist SCI knowledge to manage complex SCI-related health problems. The prevalence of SCI may be low and thus healthcare providers outside of specialised SCI units may not see SCI patients on a regular basis. However, the management and care options for SCI patients are often complex.⁵⁹ Therefore, successful health management and promotion requires a primary care provider who can offer an informed service for SCI-related issues.⁵⁹ This is not always the case and similarly other studies have shown that primary care physicians do not always meet the care expectations of patients with SCI.^{60,61} In contrast, several participants mentioned that the experienced and knowledgeable staff in specialised spinal units, across the public and private system, specifically rehabilitation therapists, were important facilitators to rehabilitation. Specialised in-patient rehabilitation is perceived to be high quality, but once participants were discharged into the community, follow-up and continued rehabilitation was problematic or non-existent for some. Similarly, insufficient information and guidance about their condition, both

initially and in the long-term was reported by participants in both the public and the private system. Participants also specifically identified this need around sexual function and fertility. Sexual health has been identified as an important priority for men following traumatic spinal cord injury, however, it continues to be a neglected topic by healthcare providers.⁶² As was shown by Lee et al⁶³, healthcare providers should not just focus on problems related to the physical disability, but also show greater concern for problems related to sexual activity.

When dealing in issues of healthcare accessibility the focus is often on supply and demand, rather than aspects of behaviour change, or motivation. However, some of the challenges experienced within this study with regards to the choice of which health system to use (for those participants in a position to choose), can be described by the mechanisms of free public health service seeking proposed by Robert et al.⁶⁴ According to these authors, the choice to seek free public healthcare will be determined by, among other things, trust and acceptability.⁶⁴ Patients' trust in healthcare providers will influence this choice⁶⁴ based on their perceptions of those providers' qualifications, professionalism and past interactions. Trust is also built on healthcare provider's ability to communicate and listen, and an honest concern for patients' well-being.⁶⁵ The findings of this study also reflects the work of Castiglione et al.⁶⁶ that described the perceptions and uses of public and private healthcare in a lower SES area of Brazil, indicating that patients' perceptions of the one system affect not only their willingness to use the other system, but also the ways in which the other system is used. Utilisation of healthcare was influenced in various ways in this study. Firstly, due to issues with quality in the public healthcare system, patients would opt for private healthcare instead, but with problematic associated costs. Additionally, participants who were having difficulties affording private healthcare, still opted for private healthcare due their negative perceptions of the public healthcare system. However, not all participants were able to exercise their choice if they simply couldn't afford it. Although private healthcare may be preferred, the cost implication forced the utilisation of public healthcare for the acquisition of consumables, equipment and medication for some.

With these barriers aside, once access to the public system has been gained, it is free of cost for persons with a disability and some participants also experienced what they perceived to be good quality service. This was especially evident from some low SES participants, who

reported no barriers to healthcare except for barriers outside of the health system, such as the availability and cost of transport. People evaluate their health-related quality of life by comparing their expectations with their experience.¹⁴ Psychological, socioeconomic, environmental and cultural differences between individuals will affect their experiences in different ways.¹⁴ It is possible, that for these low SES participants with no prior experiences of 'better' healthcare, their expectations and of healthcare quality may stay accordingly low.

Implication

SCI is a life-altering event with substantial consequences, irrespective of where one is in the world. However, in a country with substantial healthcare disparities, such as South Africa, these consequences are likely magnified. The participants in this study, who sustained their injury whilst playing rugby, are distinguished from the general SCI population by the assistance provided by a dedicated organisation. However, it magnifies the inadequacies of both health systems to provide affordable, quality care for persons with SCI. Therefore, this study has a number of implications. Firstly, the issues of quality and availability in the public health system must be addressed for persons with SCI, especially for those who have no other option or choice of care. If these issues are addressed, it is less likely that persons who struggle to afford private healthcare would continue to incur additional costs that are essentially unaffordable and that places them in a position of financial hardship. However, this study has also shown that there is a need to reduce health disparities by making both the public and the private healthcare system more inclusive, both for general healthcare issues as well rehabilitation in person with SCI. Given that multiple factors limit access to healthcare for people with disability, actions are needed in all components of healthcare systems, including improving governance and increasing levels of awareness, knowledge and research.³⁹

The findings of this study have further shown why a move towards universal health coverage is likely necessary. As such, South Africa has been in the process of planning a transition towards universal health coverage by implementing national health insurance (NHI). It has been envisaged that by 2030 significant strides towards this goal should have been made.⁶⁷ The aim of the NHI would be to reduce the cost related to private healthcare while improving the quality of public healthcare, by providing free, equal healthcare regardless of SES. The

NHI will be a tax-funded system, requiring all individuals who earn above a certain amount to contribute. The NHI will enter into contracts with private and public hospitals, practitioners and public clinic to provide services to all citizens. Additionally, public facilities will be required to upgrade their facilities.⁶⁷ Though the NHI will eliminate out-of-pocket payments, the funding disparities of the private and public sectors, the large number of additional healthcare professionals required and issues of governance and corruption may make its implementation both difficult and time-consuming.^{49,68} Importantly, barriers to accessibility were not just related to the healthcare system itself, but are also closely related to SES. We have to consider social determinants of health, including living and working conditions, education and income.⁶⁹ The interaction of context (personal and environmental factors) and factors directly related to accessibility of healthcare, must be linked and mutually considered when interventions that aim to optimise healthcare accessibility are planned. Additionally, people-centered health systems are being promoted.⁷⁰ Therefore, we should look beyond merely supply and demand, to other important aspects of the healthcare experience.⁶⁴

Health-related factors have previously been identified as an important contributor to QoL.^{16,21,47} Health is also the basis for every person's participation in society, including the right to education, employment, and social participation.^{51,71} Therefore, as health status influences SES and vice versa, and also the inter-generational transmission of SES, access to quality healthcare may play a role in perpetuating inequality in a country with vast socio-economic disparity.^{26,72,73} Every effort should be made to facilitate healthcare to optimise QoL in SCI patients. Similarly, from a sports medicine perspective, a recent editorial promoted the duty of care that clinicians, clubs and governing bodies have in the long-term health outcomes of professional football players.⁷⁴ The findings of this study, in our view, extend this responsibility and duty of care to amateur athletes and especially, athletes who suffer a permanent, life changing disability by playing their sport. Sporting bodies have an opportunity to improve the QoL of these athletes by considering the myriad of healthcare factors requiring intervention, as was presented in this study. However, as Carmody et al.⁷⁴ pointed out, there is a need for defined roles of sporting bodies, clubs and player associations in this regard, as well as a consensus on how interventions addressing long-term player health should be managed and funded. Nonetheless, improving transportation to access

services may be one such area where a formal intervention may make a considerable difference. The issue of health insurance for all players sustaining a catastrophic injury (including SCIs) also requires consideration. However, assisting in strategies to create alternative forms of financial self-sufficiency may be the most crucial to create relief from at least some of the healthcare barriers experienced and importantly, to provide choice and financial independence.

Limitations

We used a sampling strategy that was representative of the population of rugby-related SCIs. It is possible that a smaller sample with more in-depth interviewing could have produced additional detail within the results. Future research should investigate the knowledge, attitudes and practise of healthcare professionals managing persons with SCI in South Africa. The sample also consisted of participants with varied socio-economic backgrounds and as a healthcare professional, the researcher was aware of the possible power differentials that may arise during interactions with participants from low socio-economic areas.⁷⁵ The researcher was mindful of these interactions and aimed to create a relaxed atmosphere that invited unrestricted sharing of experiences. Nevertheless, these factors may still have determined the sharing of selective information for some participants. Additionally, these findings likely reflect some of the barriers and facilitators experienced by the general (non-rugby-related) SCI population. However, this study only included males and can therefore not be generalised to include barriers and facilitators experienced by women and children with SCI, especially since females and children have been reported to experience additional health disparities.^{39,51} Instead, these findings do reflect some nuances that are specific to the rugby playing population such as the assistance of a dedicated non-profit organisation.

Conclusion

This is the first study to provide a comprehensive description of the perception of healthcare related barriers and facilitators, as an important component of QoL in a South African rugby-related SCI population. The interactions between personal factors such as SES and environmental factors demonstrated that even though public healthcare is accessible from a cost point of view, quality of care and factors such as affordability and availability of adequate transport remain a barrier for lower socio-economic groups. Additionally, private

healthcare was associated with cost-related barriers and challenges. This population was unique, as the support from a dedicated organisation enabled participants to overcome some healthcare barriers, highlighting the inadequacies of the healthcare system in maintaining the health of people with SCI. Good health is a facilitator of participation in various activities and life roles. Therefore, every effort should be made to create equitable access to healthcare to all persons with SCI in South Africa.

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Chapter 7

General Discussion

General Discussion

The purpose of this thesis was to investigate *risk, immediate management* and *current QoL* of rugby-related SCI in South African rugby union players. The topics presented in this thesis are aligned with these main themes, for which the main findings from five results chapters are summarised and discussed here. Additionally, the limitations of the project as well as recommendations for future research are discussed.

1. Identifying high risk areas and the context around rugby-related SCI in South Africa

Regional differences

The first objective of this thesis, as presented in **Chapter two**, was to determine if the incidence and distribution of catastrophic injuries in South Africa differed by geographical rugby areas ('unions'). Indeed, this Chapter showed substantial differences in injury rates, as well as relative differences in distributions of types of catastrophic injuries between unions. The highest catastrophic injury incidence rate among the provincial rugby unions was in Boland (7.6 per 100 000 players) and Griquas (7.9 per 100 000 players). Additionally, Boland had the highest incidence of SCI with permanent outcomes (7.1 per 100 000 players). In contrast, the incidence of SCI with permanent outcomes in unions such as Griquas was much lower, at 2.0 per 100 000 players. Boland, Bulldogs, and Bulls had proportionately more permanent SCIs, while the Lions, Kings and Cheetahs had proportionately more TBIs.

It is difficult to draw conclusions on the reasons for the regional differences in these injury rates and proportions. What is clear, is that the sporting landscape in South Africa is extremely diverse with different languages, cultures, socio-economic statuses and levels of education, making the implementation of an effective intervention across all regions and communities an intricate task.¹ This socio-economic inequality also translates into rugby-playing society, where disparities between playing facilities and levels of coaching create further challenges for players from disadvantaged backgrounds², which could translate to an increased risk of injury. The role of the coach is indeed an important factor to consider. For example, an association has recently been shown between the quality of coach and team staff

communication and injury risk.³ This said, various factors could influence the occurrence of a catastrophic injury. Investigations of the aetiology of sports injuries and related prevention strategies have mostly assumed a reductionist view in which the injury phenomenon has been simplified into units and have also been analysed as such.⁴ This approach has been limited in its ability to successfully identify predictive factors as well as in the effectiveness of injury prevention programs.^{4,5} Sports injuries, as with most human health conditions, are multifactorial and complex phenomena that arise from the interaction between several determinants.⁴ Therefore, we require knowledge about the settings, the cultures, and the infrastructures in which they injury occur.⁶ It is clear that the need for alternative approaches is warranted, such as qualitative methods that take complexity into account.

Contextual factors from the player's perspective

With this complexity in mind, the aim of **Chapter three** was to describe the injury experience, including the injury mechanism and other contextual factors related to the injury, from the player's perspective, with the aim to provide information that may be important in optimising injury prevention strategies. For the participants in this study, most injuries had occurred during a scrum. The scrum places high biomechanical demands on players' musculoskeletal structures and exposes front row forwards to the risk of injury.⁷ Specifically, the scrum engagement was mostly identified as the phase responsible for injury, which reflects the findings of Hendricks et al.⁸ Twenty scrum-related catastrophic injuries were recorded between 2008-2012.⁸ After the new scrum laws were set into place in 2013⁸, only one player described a collapsing scrum causing the injury since this law change. Scrum-law changes have indeed been associated with a reduction in scrum-related cervical spine injuries.^{8,9} However, when scrum related injuries do occur, they are more likely to cause permanently debilitating SCIs.⁸ It is clear that simple, linear injury prevention approaches⁴ such as scrum law changes and BokSmart, have been successful in reducing injury rates in rugby, however, these interventions may be further enhanced by investigating contextual factors and designing interventions that have taken these factors into account.

The findings of this Chapter provided context that could be an extremely valuable asset to incorporate in preventative strategies. For example, participants described not being ready for impact, or felt that they were not properly aligned within the scrum or had experienced

multiple scrum collapse incidents within the game. In comparison to other phases of play of the game, the scrum is more structured and better managed by the referee, and therefore more receptive to interventions.^{8,10} Thus, these findings also highlights the importance of the referee's responsibility in ensuring a safe scrum, especially by means of clear communication on his/her own side, as well as on those of the players. Open play injuries, such as tackle-related injuries are more difficult to control. However, the reduction of scrum-related injuries since the implementation of the new set of scrum laws means that the tackle components of rugby now carry a higher proportion of cervical spine injuries^{8,9} and should be an important priority in injury prevention strategies. The findings of this study provide context that may be useful to consider within these strategies, such as being unaware of the impending tackle, dealing with a ball-carrier that suddenly changes direction or player perceptions of tackling with an incorrect tackle technique. This practical information from the player's point of view sheds light on some of the decisions and actions within a tackle situation that eventually resulted in a SCI.

The players' accounts of the factors, that they felt to contribute further to the occurrence of their injury, are also presented in **Chapter three**. These contributing factors provide some evidence and insight into the contributing factors previously postulated by Brown et al.¹¹ In their study, the senior age group, the hooker playing position and the scrum phase of play was associated with an increased risk of catastrophic injury. Furthermore, the study found that BokSmart was successful in reducing catastrophic injuries in junior players, but not in senior players.¹² The authors postulated some contributing factors responsible for the difference between these groups. These factors included low numbers of players in the senior group, which could force players to play in unfamiliar positions, other factors such as increased competitiveness and aggression and the risk of injury for the '*weekend warrior*' (adults who play irregularly or only on weekends without sufficient training, conditioning or coaching).¹¹ The findings of Chapter three indeed indicated that playing in an unaccustomed position without the necessary training and skill, especially in the scrum, is a reason for concern. Additionally, some participants mentioned that they were not supposed to play, had stopped playing or had not played for a while, but were asked to play a match at the last minute, which raises questions around adequate physical conditioning and readiness to meet match demands. The importance of progressive physical conditioning in

injury prevention has previously been reported.¹³ The fact that some of these participants stepped into a game situation unexpectedly might suggest that they were unconditioned and unprepared, increasing their injury risk. Importantly, the findings also included additional factors such as descriptions of foul play and aggression, and for some participants, pressure to perform was perceived to contribute to the circumstances that caused the injury.

2. Injury management of rugby-related SCI

Recognising the injury

Just as it is not necessarily one or two single causes that increase injury susceptibility^{4,14}, various factors may also influence the outcome of a catastrophic injury. One such factor is the effective and immediate medical management of a seriously injured player, which may play a vital role in the eventual functional outcome.¹⁵ The first factor to consider is that when a SCI does occur, early recognition of the signs and symptoms can prevent secondary injury and expedite medical management.¹⁵ In this regard, contextual information, as described by the player, may be important in optimising interventions, including on-field management. First responders are generally taught to check for spinal tenderness, restricted range of motion, and bilateral neurologic deficits.¹⁵ However, the findings of **Chapter three** offered a more detailed description of what the player may feel and importantly, verbalise to their team mates, the referee or coach, immediately after injury. Importantly, the majority of players reported the immediate inability to move and intense burning, buzzing sensations or pins and needles were reported. Participants also described proprioceptive disturbances. It is especially important to educate players, referees and coaches about these signs and symptoms, as players often asked the people around them to move their limbs as they felt that they were bent in awkward positions or floating in the air. It is also important to note that, although some participants realised what had happened, others didn't; they were often the ones to ask teammates to help them sit up. As was seen in this study, players with SCI mostly present with a normal levels of consciousness and cardio-respiratory function.¹⁶ Thus, compared to an unconscious player, the seriousness of the injury of a conscious player may initially be underestimated. Furthermore, some players did not experience pain, which may create confusion regarding the nature or severity of the injury and thus compromise initial treatment. Collectively, these signs and symptoms are important warning signs for both teammates and first responders and must be communicated as such.

Barriers and facilitators to injury management

Further contextual barriers and facilitators may be present with regards to the immediate management of these injuries. In **Chapter four**, players' experiences of these barriers and facilitators were explored. The most frequently reported barriers were transportation delays after injury and admission to appropriate medical facilities, in both the pre- and post-BokSmart period. These barriers were more prominent in low SES, rural areas and for those who use public healthcare and closely resemble the findings of the retrospective case series (1980-2007) of Hermanus et al.², emphasising the persistence of these challenges over the last two decades. Collectively, inappropriate transportation (transporting a player in a private vehicle instead of waiting for an ambulance), transportation delays and admission to inappropriate medical facilities could be greatly reduced by the utilisation of SpineLine. SpineLine is a dedicated emergency helpline for suspected catastrophic injuries and is one of the aspects covered in the mandatory BokSmart course to coaches and referees.¹⁷ However, the continued presence of these barriers identified by participants in the post-BokSmart period suggests that SpineLine is under-utilised and that more emphasis should be placed on successfully implementing this important resource, especially in rural and low SES areas.

Other barriers included inadequate equipment and the quality of first aid care. Inadequately trained paramedics and the lack of first aid care can also have important consequences for the functional outcome of players who sustain a SCI.^{18,19} First aiders and adequate equipment were often not available at matches played in the pre-BokSmart period. This was less frequently described in the post-BokSmart period, but was still reported by some participants injured in rural, low SES areas. These findings further emphasise that additional interventions are required in these under-resourced areas. It was the perception of many pre-BokSmart participants that if they had been handled more carefully, the outcome of their injury may have been less severe. This aspect appeared to be improved in the post-BokSmart period and was an important contributor to participant satisfaction, and thus, an important consideration for first-responders. The manner in which first-responders deal with the injury will likely leave lasting impressions on a player, which will have life-long injury consequences. Therefore, every effort should be made to equip first responders with education and practical training to manage catastrophic injuries in a calm, confident and efficient manner.

3. Consequences of rugby-related SCI in South Africa

Quality of Life (QoL)

Chapter five investigated the factors associated with QoL in individuals with rugby-related SCI. On average, these individuals with rugby-related SCI presented with higher QoL scores than other comparable SCI studies. It is possible that this sample possessed some unique characteristics affecting their QoL, one of which may be the support of a dedicated organisation such as the CBPJPF.

However, lower levels of *participation* and income, certain levels of education, increased health concerns and use of public healthcare were associated with lower levels of QoL. Moreover, the findings of this study emphasised the importance of participation in various life roles and activities. As such, *participation* was the only ICF component that was significantly associated with *all* QoL domains in this study. Previous research has similarly highlighted the importance of participation in home, work, social and community activities, in relation to QoL.^{20,21} Furthermore, the associations of the other two ICF components, i.e. *impairment* and *activity*, were important to note, due to their role in *participation*. The number of health concerns reported by participants was the only *impairment* variable that was directly associated with QoL, which is in agreement with other studies.^{22,23} Secondary health complications is an important area of focus for intervention strategies as, apart from affecting QoL, these issues may also increase healthcare costs. Furthermore, health concerns may create barriers to employment, thereby affecting both income and *participation* in general.²⁴ Various authors have emphasised the negative effects of secondary health conditions.^{24,25} In contrast, level of injury as well as level of independence was not associated with QoL. This finding is also consistent with other literature, which showed that *impairments* did not affect QoL directly, but rather through its impact on *activities* and *participation*.^{21,26}

Low income was another factor negatively associated with QoL, which is especially relevant as 41% of the participants of this study was unemployed. Sufficient income is crucial when considering the life-time cost, care and equipment needs of SCI. Similarly, loss of productivity and opportunities to generate income is again linked to health and QoL.²⁷

However, employment opportunities, lack of skills and education are important barriers to successful employment for people with disabilities in South-Africa.²⁸ From a health and healthcare perspective it was important to note that related factors, such as income, health concerns and the type of healthcare accessed, were significantly associated with the various QoL domains.²⁹ Specifically, access to private healthcare, or at least a combination of public and private healthcare, compared to public healthcare only, was associated with increased QoL.²⁹ Healthcare in South Africa is problematic in the many, geographically remote and underprivileged communities.¹⁷ In these rural communities, the medical management of catastrophic injuries is difficult, due to factors such as distance, difficult terrain and limited resources.² As previously mentioned, in the acute phase, delayed transportation and admission to inappropriate medical facilities were more prominent for players from rural areas with lower SES and who utilised public healthcare. However, these findings also portray the challenges of the public healthcare system and related resources in South Africa in general.^{30,31}

Barriers and facilitators to healthcare

The challenges present within the South African healthcare system are not within the control of SARU or BokSmart, but nonetheless play a crucial role in the optimal management of the player. After 1994, the public health system was transformed into an integrated and inclusive national service, yet healthcare access remains problematic.^{32,33} In general, access to healthcare is inequitable, greatly affecting poor, uninsured, black South Africans, and rural groups.³⁴⁻³⁶ Regardless, ideal treatment of an acute SCI depends on having a coordinated healthcare system capable of recognising SCIs as medical emergencies and rapidly transporting them to an SCI unit.³⁷ Unfortunately, only a minority of the nine provinces in the country have the ability to provide comprehensive care for SCIs³⁰ and, thus, specialised services in the public sector are likely to incur added patient-load pressure. Although healthcare inequities and factors such as distance to hospitals and difficult terrain for transportation remain problematic in under-resourced communities,^{2,30} unlike other causes for traumatic SCIs, the barriers to optimal transportation and admission of these injuries within the rugby setting could be mitigated, at least to some degree, by the use of SpineLine.

The consequences of healthcare disparities continued beyond the acute phase and played an important role within the long-term health management of persons with rugby-related SCI. **Chapter six** explored perceived barriers and facilitators to healthcare within both the public and private healthcare system. Participants described long-term, accessible, affordable, quality healthcare as an important contributor to their QoL. If participants were able to afford it, private healthcare and private health insurance were perceived as facilitators to healthcare. Furthermore, specialised spinal units and rehabilitation specialists were seen as facilitators to rehabilitation. However, participants identified many barriers to healthcare. Specifically, the experience of the public health system in the study reflected a system that is not accommodating to the patients' individual needs and preferences.³⁸ This was demonstrated by the long waiting periods to see healthcare providers, the unavailability of rehabilitation services or preferred items such as specific catheters or medications. Similarly, attitudes of healthcare providers were not always favourable and also affected autonomy and decision making in care. Apart from the barriers experienced within the public healthcare system, participants who made use of public healthcare also reported the availability of suitable wheelchair-accessible transport to healthcare facilities, distance, and importantly, the costs related to transport, as a major barrier. These barriers were especially evident for participants from rural areas and of low SES and concur with barriers reported in other studies of individuals with disabilities living in Africa.^{39,40}

Though private health insurance could be considered a facilitator for accessibility to adequate healthcare, the costs related to insurance and private healthcare are substantial.^{41,42} Compared to high income groups, membership and cost of private health insurances have become increasingly unaffordable for the middle-income group⁴³ and this was clearly demonstrated by the participants in this study. Participants were required to make significant out-of-pocket payments for the costs of services and consumables not covered by health insurance, or when annual benefits were exhausted.^{41,42} For some, affordability of private healthcare affected the utilisation thereof to the extent that participants delayed or avoided seeking healthcare. Health insurance schemes are therefore not necessarily providing adequate financial protection for middle-income members who incur the substantial cost of care and rehabilitation of SCI.⁴²

In general, the cost related to SCI is extensive.⁴⁴ Specialised equipment, such as commodes, orthotics, special wheels, or gloves were identified as facilitators to healthcare, but are costly. As was seen in this study, these costs were incurred when health insurance failed to cover the specific equipment, items or services, or if these were not available in the public healthcare system. However, this population was also unique, as the support from a dedicated organisation enabled participants to overcome some healthcare barriers, highlighting the inadequacies of the healthcare system in maintaining the health of people with SCI, both in the private and public healthcare systems.

In both the public and private health systems, quality of care was a concern for participants, although it was substantially more prominent in the public healthcare system. The experience, awareness and knowledge of healthcare providers in dealing with people with SCI was identified as an important barrier. These factors were also evident during hospital admissions and also suggest that general hospital policies may not meet the needs of person with SCIs.³⁸ Additionally, participants identified a need for skilled professionals with specialist SCI knowledge to manage complex SCI-related health problems. Other studies have similarly shown that primary care physicians do not always meet the care expectations of patients with SCI.^{45,46} In contrast, a substantial number of participants mentioned that the staff in specialised spinal units, across the public and private system, were experienced and knowledgeable in dealing with SCIs and was an important facilitator to quality rehabilitation. However, once discharged into the community, follow-up and continued rehabilitation was problematic or non-existent for some. A lack of sufficient information and guidance regarding their condition, including issues such as sexual function and fertility, was also reported in both the public and the private system. Sexual health has been identified as an important priority for men following traumatic SCI, however, it continues to be a neglected topic by healthcare providers.⁴⁷

Utilisation of healthcare was influenced in various ways in this study. Firstly, due to issues with quality in the public healthcare system, patients would opt for private healthcare instead, but with substantial additional costs. Furthermore, participants who were having difficulty affording private healthcare, still opted for private healthcare due their negative perceptions of the public healthcare system. However, not all participants were able to

exercise their choice. Although private healthcare may be preferred, the cost implication forced the utilisation of public healthcare for the acquisition of consumables, equipment and medication for some. However, once access to the public system has been gained, it is free of cost for persons with a disability and some low SES participants also experienced what they perceived to be good quality service. These participants reported no healthcare barriers, except for barriers outside of the health system, such as the availability and cost of transport. People assess their health-related quality of life by comparing their expectations with their experience.⁴⁸ This process will also be affected by psychological, socio-economic, environmental and cultural factors.⁴⁸ It is possible, that for these low SES participants with no prior experiences of 'better' healthcare, their expectations and of healthcare quality may have stayed correspondingly low.

The ICF-CR, disability and the South African context

The ICF's development was based on the integration of medical and social models, creating a 'biopsychosocial' approach to functioning.⁴⁹ The biopsychosocial approach, upon which the ICF is based, was also constructed as an alternative to the reductionist view of the biomedical model. Ravenek's⁵⁰ revision of the ICF, as adopted in thesis, incorporated elements of general systems theory to enhance the clarity of biopsychosocial principles and to better understand health and disability within the ICF. A general systems approach describes components of systems interacting with one another and with the surrounding environment to influence the whole, as opposed to a simple addition and subtraction of its components.⁵⁰ As Ravenek⁵⁰ points out, general systems theory is an appropriate way to assemble the components of the ICF because as humans we interact with our environment, and our functioning is influenced by biological, psychological and social factors. A person is part of the larger environment, and QoL is seen as the largest and most complex component of human functioning to which each of the other subsystems, including health, contributes.⁵⁰ Furthermore, in the ICF-CR, the overarching component was changed from 'health condition' to 'health', as it was described in the ICF.

Health in this sense, is based on the WHO's definition as a state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity'.⁵¹ However, it must also be noted that some authors describe this definition as unattainable for real people

living in an imperfect world, and instead suggest that health can be seen as the ability to flourish without being unduly impeded by illness or disability or, if necessary, by overcoming illness or disability.⁵² Nonetheless, a health condition or injury (such as a SCI) may likely play an important role in health and finally QoL. In the fields of sport medicine and injury prevention it has been proposed that injuries and their consequences are complex and context based phenomena and are influenced by interactions between intrapersonal, interpersonal, organisational, community, and societal factors.^{4,5,53} Injuries do not occur in a vacuum. Similarly, within the ICF-CR, the person is part of his environment and affected by various sub-systems. The ICF-CR characteristics of interactivity, multidimensionality and non-linearity associates well with the shift away from reductionist science. In essence, the ICF-CR reflects similar theoretical underpinnings of complexity.

The ICF-CR as conceptual framework can be used to understand the findings of this thesis in the South African context. As often mentioned within this thesis, South Africa is characterised by socio-economic disparity which affects an array of factors. For the player sustaining a rugby-related SCI, personal factors (such as SES) and the environmental context (geographical location, resources and infrastructure within that area) often played a determining role in the way the injury management process would unfold. Barriers to optimal injury management were especially evident for players of lower SES, with fewer resources or who live in more rural areas. Delayed transportation and admission to inappropriate medical facilities were more prominent for players from rural areas with lower SES, who also due to their SES, would utilise public healthcare. Importantly, these inequities in healthcare continued to have an influence beyond the acute management phase and eventually played a role in QoL, as findings indicated that compared public healthcare, access to private healthcare, or at least a combination of public and private healthcare, is associated with increased quality of life and that multiple barriers were experienced by participants accessing public healthcare. Similarly, as another proxy of SES, low income levels and certain levels of education were also negatively associated with QoL.

The importance of SES in this study reflects features of the social model of disability, which describes disability as a condition that is completely socially imposed and includes a degree of social oppression.⁵⁴ It calls on society to change its attitude and the environment, as a

person will only be as ‘disabled’ as his/her environment and society forces them to be.⁵⁴ Similarly, critical disability theory describes the challenges of disabled people as a product of an unequal society, where social oppression and discrimination have a greater restrictive effect on people’s lives than their actual impairments.⁵⁵ The theory highlights a social transformative perspective that includes the struggle for social justice and diversity on a social, economic and political level, but also on psychological and cultural level.⁵⁵ This view excludes the role of the body and impairment in disability, but instead consists mainly of society’s role in creating a world characterised by exclusion and inequality for a person with a disability.⁵⁶ These models of disability have also been criticised, as Vehmas & Watson⁵⁷ argue; a society without group differences is probably not a realistic possibility.

From a pragmatic stance, some middle-ground can be found in the work of Shakespeare & Watson⁵⁸, who argue that disability is constructed by both impairment and social exclusion, thereby re-instating the importance of the body and impairment, but maintaining society’s role as significant. Recognising the effect of impairments, such as secondary health conditions / complications in SCI, is necessary to secure good treatment and social provisions that enhance people with disabilities’ participation in various activities and roles (including education and employment) and overall QoL.^{21,29,59–61} The findings of this thesis highlights the role of health and healthcare in QoL, as well as the barriers to healthcare and rehabilitation for people with SCIs. Addressing these barriers is critical when considering disability within the South African context, as health status influences SES and also the inter-generational transmission of SES.^{62–64} Thus, access to quality healthcare may play a role in perpetuating inequality, especially for people with disabilities, in a country with vast socio-economic disparity.^{62–64}

The strong relationship between *participation* and QoL in this cohort emphasises its importance as a modifiable factor for individuals with SCI. *Participation* is a crucial resource for persons with SCI, as it may buffer the potential negative effects associated with SCI on mental health and QoL.⁶⁵ Interventions aimed at, for example, improving social skills or self-efficacy may facilitate the negotiation of participation restrictions.^{66,67} However, interventions aimed at *participation* within the population of this study would require further contextual considerations.

The findings of chapter 5 emphasised the importance of assessing the subjective experience of *participation*, and thus *participation* that is meaningful and important to the individual. This should include an understanding of what *participation* means to the individual and by taking their specific context into account. In Chapter 5, exercise is identified as potentially modifiable factor due to the association shown with *participation* in this population. The benefits of exercise and sport in persons with SCI is well described.⁶⁸⁻⁷¹ However, the importance of exercise in this sample of previously active rugby players before their injury may be an important motivation for exercise interventions. Individuals who identify as athletes are more likely to maintain, or find the need to maintain, sporting behaviour over the long term.⁷² Athletic identity has also been reported as a factor that can promote recovery, and is considered as means to enhance long-term adjustment to disability.⁷³ Nonetheless, an in-depth, individualised assessment to understand the meaning of *participation*, as well as the specific *participation* outcomes that are important to a previously active individual is needed.⁷⁴

A recent qualitative study in community-dwelling people with SCI in South Africa, described participants views of becoming ‘re-involved’ in pre-injury activities and roles.⁷⁵ Reclaiming *participation* required the negotiation of barriers along the path of recovery as well as ‘dealing with the new self’ as the first aspect to negotiate on the journey of re-establishing meaning.⁷⁵ However, once participants had imagined a possible life that included living with the injury, they then described a seemingly endless ‘journey dominated by obstacles’, especially within their environment.⁷⁵ Herein lies an important consideration for disability in the South African context. Environmental barriers have been shown to be negatively associated with *participation* in the SCI population.^{76,77} These barriers may include the physical area and infrastructure, assistive technology, transportation, information and technology access, social support and attitudes, systems, policies, and economics.⁷⁸ Addressing issues of participation would require the consideration of the individual context, keeping in mind that certain barriers may be accentuated for persons with SCI who live in rural areas and who are of low SES.⁷⁹ Nonetheless, the impact of the environment on the possibility of participation in the immediate, community and societal levels is crucial to consider as part of a potential intervention.⁸⁰ This includes assessing environmental

facilitators and barriers to participation both within rehabilitation and community settings and advocating for system and policy changes to target these environmental barriers.^{76,80} It must also be considered that cultural beliefs and attitudes are different; therefore, addressing *participation* requires contextually sensitive interventions.⁷⁵

Methodological reflections and limitations

Considerations of quality and rigor are central to the credibility of any research project, quantitative as well as qualitative.^{81,82} Where quantitative approaches tend to employ objectifiable and delineated criteria for quality, in qualitative research criteria are more lucid. In order to value the quality of the studies described in this thesis, first one must consider the qualitative research philosophy taken in this thesis; i.e. pragmatism. The goal of pragmatic research is not theory development, as is the case in grounded theory, or the high-level interpretive understanding of a phenomenon as gained through phenomenology.⁸³ Pragmatists' also do not aim to find ways to most accurately represent or 'mirror' reality, but instead aim for research that values context, that is useful, descriptive and practical for the people who intend to use it.⁸² This includes understanding the importance of participants' perspectives in the context of their lives, and representing participants accounts accurately.⁸¹

The first consideration for judging the quality of the project was the worthiness of the topic.⁸⁴ The CBPJPF was an important driving force behind the initiation of this project. The paucity of research in this population informed the importance of the research questions, firstly as rugby players experiencing a catastrophic injury, and secondly as persons with SCIs within the South African context. Research questions were considered in the ways that they could practically contribute to rugby safety and the management of rugby-related SCIs in South Africa, as well as in welfare of players who do suffer these injuries. For some objectives of this thesis, a quantitative approach was deemed to be most useful, while other questions required the voice of a rugby player, or the voice of a person who lives with a SCI. As such, the qualitative methodology employed in this thesis is one of its most important strengths. This approach allowed for the description of contextual factors that are crucial in the field of injury prevention, injury management and long-term player welfare. Specific limitations and reflections within each chapter will be discussed according to each approach.

Qualitative methodology

Rigor within a research project may be enhanced by using a sample appropriate for the aims and objectives of the study⁸⁴, that would produce data that was meaningful and practical and in line with the pragmatic approach of the study. Ninety (n=90) of the entire known population (n=113) of rugby-related SCIs in South Africa, as recorded in the CBPJPF database, agreed to participate in the study. Upon request of the CBPJPF, individual, face-to-face interviews and completion of questionnaires were conducted with all 90 participants in their respective provinces.

During the data analysis phases for the Chapters that used a qualitative approach (**Chapters three, four and six**), a sampling strategy that was representative of the population of rugby-related SCI was employed. Sampling was conducted for maximum variation and included a stratification process of low, medium and high SES participants. This was done to ensure that a range of views was covered and to yield tangible findings that could inform the practical care of this population. However, a limitation of this approach is likely the depth in findings that could be achieved. It is possible that a smaller sample with more in-depth interviewing could have generated additional depth within the findings. Furthermore, socio-economic diversity was an important requirement, but it also held certain implications. The researcher was aware of the possible power differentials that may have arisen during interactions with participants from low socio-economic areas.⁸⁵ However, every effort was made to be mindful and sensitive to these interactions, to create a relaxed atmosphere that invited unrestricted sharing of experiences. Nevertheless, this relationship may still have determined the sharing of selective information for some participants. Similarly, an important part of the qualitative methodology was to reflect on the ways in which the researcher's own biases and emotional responses to the participants could shape the interpretations of the interviews. This was facilitated by periodic discussions with the project supervisors and peers to gain different perspectives and to test assumptions.⁸⁶ Additionally, as part of an audit trail aimed at enhancing credibility and transparency of the findings, coding was performed by two authors, independently of each other and discussed until consensus was reached.⁸⁴ Codes were then collaboratively reviewed by three authors (the researcher and project supervisors) until final categories and themes were generated, questioned and refined. All four supervisors of the project were involved in previous

research that evaluated the effectiveness of the BokSmart program. It has to be considered that this may have biased their own views in certain ways. This concern is balanced by the pragmatic design of the study, in which the researcher remained close to the data and the findings were descriptive and not subjected to high-level interpretations.⁸³ Regardless, the researcher valued discussions with her peers (scholars within a disabilities studies group) who acted as ‘critical friends’, completely removed from the rugby context. These discussions were valuable to gain different perspectives and encourage reflexivity during the analysis process.⁸⁷

In **Chapters three and four**, the participants in this study were asked to talk about factors that were part of an event that traumatically changed their lives and the researcher acknowledges that this may have placed limitations of what some participants were able or willing to discuss. Additional, follow-up interviews may have allowed for a relationship with enhanced rapport and trust. The sensitive nature of the expected content informed early decisions around recruitment and as well the psychological burden for the participants. Participants were only recruited if they incurred their injury more than a year before recruitment began. This factor in itself was not expected to comprehensively mitigate the risk of negative psychological outcomes. As such, it was important to explain to participants at the beginning of the interview that they did not have to answer any questions they did not want to and were encouraged to stop the interview at any time if they wished not to proceed further.

An important consideration of this study is that the participants were well-known and supported in various way by the CBPJPF. In the proposal phase of the study it was agreed (and participants were informed of this during informed consent), that the CBPJPF would facilitate the provision professional psychological support, should the interview elicit any negative psychological experiences. The CBPJPF naturally remained in contact with all participants which facilitated this process. No negative experiences were reported, however, one cannot be sure that they did not occur. Similarly, no participants asked to stop the interview or declined to answer any questions. This may in part be due to the response of the researcher to the participants’ emotional state while progressing through the interview. The researcher was sensitive to not probe a topic extensively, if the participant seemed

uncomfortable or distressed. However, this possibly affected the depth of information gained in some situations and can be regarded as a limitation of the chosen methodology. Nonetheless, it was decided by the researcher to be the ethical choice for a once off interview with no possibility of follow-up opportunities to build rapport or trust. These issues aside, the researcher was surprised by the level of trust and rapport that was gained within the interviews. It is likely that this trust was enabled due to recruitment via an organisation that the participants were very familiar with (CBPJPF) and should be considered an important strength of the thesis.

Furthermore, it is important to note that the findings of Chapter 3 and 4 were not able to provide pertinent explanations for the regional differences in catastrophic injury rates described in Chapter 2. One reason may be that the questions posed in Chapters 3 and 4 were not specifically designed to answer this question. Nonetheless, Chapter 4 provided important evidence that players from rural areas, lower SES and with fewer resources experienced more immediate medical management barriers, which was a potential reason postulated in Chapter 2. It became clear in the analysis of these Chapters, that the exploration of the potential reasons for these differences specifically in and between Unions would require a different research question and methodology, which was beyond the scope of this study.

In **Chapter four**, participants' perceptions of what constituted a barrier or facilitator to care did not obviously differ from what the researchers understood to be current best practice. However, it must be noted that within this study design it was not possible to report on the nuances or finer details of the management process, which could provide additional information on the standard of care. From a pragmatic stance, further investigation of the injury incident could draw on methods such as incident analysis using the systems approach^{88,89}, which would require a shift in the epistemology and ontology of the current research question and thus, the knowledge that is produced.

In **Chapter six**, the findings likely reflect the barriers and facilitators experienced by the general (non-rugby-related) SCI population. However, this study only included males and can therefore not be fully generalised to include barriers and facilitators experienced by women and children with SCI, especially since females and children have been reported to

experience additional health disparities.^{44,61} Instead, these findings do reflect some nuances that are specific to the rugby playing population such as the assistance of a dedicated non-profit organisation.

Quantitative methodology

When considering limitations in **Chapter two**, it is possible that some catastrophic injuries may not have been reported, or that reporting in some provincial rugby unions may have been more comprehensive than in others, which may have affected the injury incidence calculations. However, BokSmart's serious injury protocol and the potential benefit of financial, logistical and psychological support associated with reporting rugby-related injuries in South Africa, should reduce this possibility. The 2013 SARU census employed a telephonic nationwide survey over the course of 1 year.⁹⁰ A verification process was used to check the accuracy of the data by physically and randomly performing spot checks in approximately 5% of all respondents (in line with other national Census verifications). At the end of the survey period all unions were sent lists of clubs and schools, which had been surveyed, in their region. They were asked to check the addresses and names of the schools/clubs and to provide feedback on any missing institutions. Missing institutions were contacted, and the survey process was repeated. The use of the player census data is regarded as a strength of the study as it was thought to provide a more accurate representation of player numbers compared to estimations of player numbers. However, it must be acknowledged that discrepancies with actual player numbers may still exist.

Additionally, player numbers were also assumed to remain constant over the seven years of investigation and every effort was made to obtain accurate player numbers for each union. However, the possibility exists that discrepancies may be present within actual player numbers. By its nature, catastrophic injury data consist of small numbers and as such, resulted in the wide confidence intervals, which in turn increases the difficulty of the comparability of these results. Nevertheless, conclusions were based only on clear patterns within the data, without over-interpretations of smaller between-province trends.

Chapter five also comprised of quantitative methods. The study was considered to be powered for the number of variables explored in the multiple regression, as a common rule is to have at least 10 participants per variable.⁹¹ However, a few limitations were present.

All questionnaires were translated and back-translated into Afrikaans. Although all participants were fluent in either English or Afrikaans, some nuances of the WHOQOL-BREF and CPI measures may have been lost for participants whose first language was neither Afrikaans nor English. Importantly, the remaining variance in the regression models may be explained by other factors relating to adjustment and mental health after SCI, such as coping strategies and psychological resources, which were not investigated in this study. Furthermore, this study comprised a special population who were all male, previously active individuals, who acquired a disability whilst playing their sport. It is possible that factors such as ‘athletic identity’ contributes to the perception of QoL and may thus not be representative of the general SCI population. Furthermore, previous studies have reported no significant differences between gender and QoL in people with SCI^{26,92,93}, however, it is important to consider that some factors that determine or predict QoL may still be different between genders.⁹⁴ Due to the cross-sectional study design, it was not possible to identify factors predicting QoL, but only associations between the investigated variables. It will be valuable to further explore these associations and the complexity of QoL.

Practical implications

Implications for BokSmart

Injury prevention

The implementation of wide-scale, effective interventions in real life situations is challenging.⁹⁵ BokSmart is disseminated nationally to all coaches and referees through the provincial rugby unions. The education component of the program is run similarly in all fourteen unions. However, **Chapter two** has shown that all fourteen unions do not necessarily have the same level of associated risk, and also have differing proportional distributions of catastrophic injury types. Ongoing research is imperative to ensure the effectiveness of the approach and, where the interventions could be better tailored to the specific rugby landscape within the different provincial rugby unions, as well as within specific teams. Understanding the available resources, barriers and areas of need that are specific to an area or team, may further enhance rugby safety. Identifying high-risk groups is an important risk-mitigating strategy in sport.⁹⁶ Thus, the findings of **Chapter two** can be

utilised by SARU and BokSmart to direct further investigations around injury patterns within high risk provincial rugby unions. Additionally, these findings may not be unique to South Africa and could be considered for all nationwide, large-scale intervention programs.

The findings of **Chapter three** emphasised the importance of the referee's responsibility in ensuring a safe scrum. Initiatives such as the Australian Rugby Union's 'Mayday' procedure; a safety technique implemented for players to alert the referee when one of them is in a potentially dangerous position in a scrum⁹⁷, should be a consideration for inclusion in the BokSmart program. Additionally, coaches are important influencers of player behaviour in rugby⁹⁸ and can therefore play a key role in contributing factors identified in this Chapter. Further education with an emphasis on the consequences of unsanctioned aggression and foul play is a consideration for inclusion in the BokSmart program. Although the choice of positive behaviour and sportsmanship lies with each individual player, adequate information, awareness and coaching may facilitate this choice. Similarly, pressure is an inherent part of the sport, but players and coaches should be aware that '*winning against all odds*' and '*putting your body on the line*' may at times have serious repercussions.⁹⁹ The drive for success must not supersede the welfare of players^{99,100} and coaches have a responsibility to ensure that each player in the front row and potential replacements must be suitably trained and experienced.^{100,101} Players should feel comfortable enough to raise specific safety concerns, such as these, with their coach. Similarly, coaches should comply with regulations that are concerned with the safety of players and be receptive to players' concerns. All these aspects of communication and player welfare may be further highlighted within the BokSmart program.

The experience and context surrounding a rugby-related SCI from the player's perspective has implications for all involved in emergency medical management of rugby-related SCI. This information is also relevant for rugby safety initiatives in shaping education and awareness interventions. Though these injuries are rare, all stakeholders, including players, coaches and referees, should be aware of the possibility of such an injury, be educated to recognise them and be aware of the relevant protocol to follow. Participants provided context around injury which is valuable to help understand the mechanism of injury and which can in turn inform potential prevention opportunities. Early recognition of these signs and

symptoms can prevent secondary injury, expedite medical management and optimise the outcomes of injured players. Thus, especially in amateur games and communities that have less resources and medical support, these signs and symptoms are important to recognise by fellow team mates, coaches and referees, as they are often the closest and first to respond to an injured player. Coaches and referees are specifically targeted as they are the key decision makers controlling both the game and the players on the field. In many situations within South Africa, the coach may be the only person available to deal with an injury. The findings of this study regarding the signs and symptoms of SCIs, may be utilised by BokSmart in their mandatory biennial courses to educate coaches and referees in the early recognition of these injuries. These findings may also be transferable to other rugby settings and can be utilised to inform and educate players, coaches and referees in general.

Injury management

Chapter four indicated that participants of lower SES, with fewer resources or who live in more rural areas experienced more barriers to optimal immediate management. Although BokSmart has employed random safety inspections at community level, there appears to be a need for a formal monitoring process and investigation into the effectiveness of the immediate management protocol of BokSmart. This will ensure that these safety standards are maintained, especially in under-resourced and under-privileged communities. Monitoring alone would not solve the challenges of these communities, as they may lack the resources to meet or maintain these standards and may require additional support. In rural areas, added support in terms of provision of equipment, safe-guarding that equipment and having trained people to use it may require additional, targeted interventions. These interventions have financial implications and remain a challenge for a governing body in a developing country. However, the safety of players should not be comprised, and avenues to ensure that safety remains a priority should be continually pursued.

The importance of a specific action plan that includes the utilisation of SpineLine (as described in the BokSmart programme), information of the nearest specialised trauma centres capable of dealing with SCIs, the logistics of the ambulance's entrance point to the field and sufficient background information on players, (including insurance details), should be emphasised more loudly and possibly included as part of a formal monitoring process.

Additionally, BokSmart guidelines stipulate the minimum medical personnel requirements for school, club or community rugby matches. It is also the responsibility of individual schools and clubs to request training if they do not have adequate medical support and thus this responsibility should also be advocated more widely. To this extent, schools and clubs should also ensure that there are sufficient medics available, especially on days where multiple games are played simultaneously. Having students as first aiders may be a concern. If a parent or community member with medical training was on hand to facilitate the management, the possible risk of inadequate management may be mitigated. This is illustrated by the cases in Chapter four where bystanders, who were often medically trained, needed to step in to guide management. Thus, nurturing dedicated community involvement within a local rugby community may be an important avenue for further interventions. There will be times, such as during practice sessions, when little or no medical support will be available.¹⁰⁰ During these times, coaches, referees, players and the immediate rugby community may benefit from knowledge regarding the recognition of suspected serious injury, so that they may ensure that SpineLine is called and that no unsafe behaviours take place.

Coaches and referees are targeted in the BokSmart program for the prevention of catastrophic injuries¹ and as such, it re-iterates their management responsibility and plan of action in case such an event occurs. However, it has been reported that some coaches felt that knowing how to deal with a catastrophic injury was not something they had to be concerned about as coaches.⁹⁸ This has serious implications for delivery of the educational content within the BokSmart courses and the perceptions that may drive certain behaviours. In public health for example, efforts concerned with changing health behaviour have had limited success.¹⁰² Kelly & Barker¹⁰² argues that it is not enough to give people information and expect a change in their health behaviour. Instead, it requires a new way of thinking that includes identifying the network of factors associated with the behaviour and the people involved. True change occurs when the links between parts of the activity or practice and its networks are broken and changed.¹⁰² Similarly, the field of rugby safety may require a multilevel approach to better understand ways to successfully effect change within the rugby community. Ultimately, we need to change coaches' perceptions around their responsibility to manage the process efficiently, which includes having the SpineLine number at hand.

Furthermore, coaches and referees are required to be re-certified on a biennial basis to maintain their BokSmart accreditation. A similar process should be required of first aiders and Rugby Medics, to ensure they are competent in managing potentially catastrophic injuries, and also to serve as an opportunity for gaining additional experience and knowledge in the management of these injuries.

Implications for the CBPJPF

The positive role that the CBPJPF plays in the lives of the participants becomes especially evident in the healthcare support that they provide. When considering the long-term consequences of SCI in **Chapter 5**, the findings indicated that persons with lower levels of *participation* and income, certain levels of education, increased health concerns and those who make use of public healthcare, experienced low levels of QoL. These individuals may benefit most from additional and specific interventions. Furthermore, the strong association between *participation* and QoL in this study emphasises the value of assessing and addressing this concept in those with rugby-related SCIs. Notably, *participation* was the only variable associated with overall QoL as well as all the QoL domains and thus provides important motivation for interventions to enhance *participation*, as this would likely have an important effect on the QoL. It is also important to consider, is that for these previously active individuals, exercise and or participation in sport may be one of the important areas of *participation* to cultivate. Not only is it likely to improve health, it may also improve functionality; both aspects which are important for employment and self-sufficiency.^{70,71} Although healthcare is a basic need that cannot be compromised, ‘upstream’ interventions that are likely to improve SES and general health, would likely have positive downstream effects in terms of healthcare needs. However, it must be remembered that the CBPJPF is a non-profit organisation, reliant on public donations, which will place limitations on what they can realistically provide.

Implications for the South African healthcare system

Chapter six identified modifiable factors to improve healthcare access and quality for individuals with SCI. There is a need to reduce health disparities by making both the public and the private healthcare system more inclusive, both for general healthcare issues as well rehabilitation. Given that multiple factors limit access to healthcare for people with

disability, actions are needed in all components of healthcare systems, including improving governance and increasing levels of awareness, knowledge and research.⁴⁴ A “triple vulnerability” of poverty, disability and rurality affects access to healthcare¹⁰³, and was especially evident in the findings of this thesis. Additionally, the financial implication and out-of-pocket costs of persons with SCI who utilise private healthcare also affects access to care and financial hardships. These costs were often mitigated by the assistance provided CBPJPF and in a few instances, by external funding provided by the rugby community and highlights the inadequacies of both the public and the private healthcare systems to care for people with SCIs with income disparities.

South Africa has been planning a transition towards universal health coverage by implementing national health insurance (NHI).¹⁰⁴ The aim of the NHI is to reduce the cost related to private healthcare while improving the quality of public healthcare, by providing free, equal healthcare regardless of SES. The NHI will eliminate out-of-pocket payments, but the funding disparities of the private and public sectors, the large number of additional healthcare professionals required and issues of governance and corruption may make its implementation both difficult and time-consuming.^{105,106} Additionally, barriers to accessibility were not just related to the healthcare system itself, but were also closely related to SES. We have to consider the social determinants of health, including living and working conditions, education and income.¹⁰⁷ The interaction of context (personal and environmental factors) and factors directly related to accessibility of healthcare, must be linked and mutually considered when interventions that aim to optimise healthcare accessibility are planned. Additionally, people-centred health systems are being promoted.¹⁰⁸ Therefore, the health system should also look beyond supply and demand to the dynamic dimension of users’ experience.¹⁰⁹ South Africa adopted United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007, which includes the right to the highest attainable standard of health without discrimination for people with disabilities. However, the participants of the study repeatedly emphasised the need for rehabilitation spaces and access to community-based rehabilitation and is an important point of consideration for health policy developers.

Implications for the national and international governing bodies of rugby

Every effort should be made to facilitate healthcare and optimise QoL in players who sustain SCI. Assisting in strategies to create alternative forms of financial self-sufficiency may be one such opportunity where sporting bodies could offer support. The duty of care that clinicians, clubs and governing bodies have in the long-term health outcomes of professional football players has recently been promoted.¹¹⁰ It stands to reason that this duty of care should be emphasised even more for athletes who suffer a permanent, life-changing disability whilst playing their sport. If sporting bodies, specifically the international governing body of the sport, wish to stay true to their vision and duty of care as displayed in the various injury prevention or player development programs, finding avenues to assist these players with life-changing injuries in developing, low and middle-income countries, in the various challenges they face, should be a priority. For instance, sporting bodies have an opportunity to improve the QoL of these athletes by considering the myriad of healthcare factors requiring intervention, as was presented in this study. However, there is a need for defined roles of sporting bodies, clubs and player associations in this regard, as well as a consensus on how interventions addressing long-term player health should be managed and funded.¹¹⁰ Nonetheless, assisting in transportation to access services may be one such area where a formal intervention may make a considerable difference. The issue of health insurance for all players requires consideration. Assisting in strategies to create alternative forms of financial self-sufficiency may be the most crucial, to create relief from at least some of the healthcare barriers experienced and importantly, to provide choice and financial independence.

Future research

The reasons for the difference in injury rates and injury outcomes could yield valuable information and thus need to be explored. This requires an in-depth investigation and comparison of provincial rugby unions. To this extent, a case study approach that explores the complex nature of rugby safety and its application within a specific context, in this case specific provincial rugby unions, may be useful. Provincial rugby unions such as Griquas and Eagles had a high rate of catastrophic injuries, but a large proportion of these consisted of “near miss” injuries, in comparison to permanent outcome injuries. Lessons could be

learned from provincial rugby unions with lower injury rates or proportions. It is perhaps time to move away from a “one-size fits all” approach, towards a rugby-safety initiative that is tailored to each specific provincial union and that takes into account the communities, the infrastructures and resources within that union. Investigations such as these may aid the conceptualisation of such an initiative.

Future studies should further investigate the contributing factors to injury reported in this study. The next step should also include investigations of the presence and training of medical personnel, the availability of equipment and emergency protocols, as well as the knowledge of coaches and referees regarding the effective immediate management of catastrophically injured players, in schools and rugby clubs in South Africa. Further investigations around the awareness, perceptions and utilisation of SpineLine is required.

The population presented in this study appeared to possess unique characteristics potentially affecting their QoL. Further research is needed to explain this finding, including the potential influence of the special population type (active individuals with a similar mechanism of injury), athletic identity, and the role of personal factors on QoL. This specific study (Chapter 5) was exploratory and the first study in a South African SCI population to investigate factors associated with QoL. Statistical methods such as Path analysis or directed acyclic graphs (DAGs) may be used in future studies in this population, to further investigate the relationships identified in this study. Additionally, a qualitative approach could provide important additional insight into the factors associated with QoL. As such, the strong association of *participation* with QoL warrants future research to explore barriers and facilitators to participation in various life roles, as well education and employment.

In both the public and private healthcare systems, the knowledge, awareness and attitudes of healthcare providers dealing with SCI patients in South Africa should be further explored. In general, the ‘how’ and ‘why’ questions of real-world problems cannot be answered through quantitative research alone.¹¹¹ To this extent, qualitative approaches are especially valuable. More studies should move towards examining injury risk, prevention, management and outcome as complex problems, which requires an understanding of related contexts.

Interventions need to be context-based, and these contexts must be supplied by context-rich and relevant research.

Conclusion

This thesis identified contextual factors surrounding the SCI injury itself, but also, importantly, within the management of such injury. These contextual factors may affect the effectiveness of injury prevention interventions and the outcome of the injury. Therefore, they should be considered when implementing injury prevention and management options in general and by BokSmart specifically. The findings show that certain regions and lower SES communities require tailored injury prevention and management interventions, that is context specific. Additionally, this thesis also provided insight into the long-term effects of the injury, which indicated that the healthcare needs and QoL of lower SES players once injured, are important interventions points.

Although rugby-related SCIs are rare, all rugby stakeholders must remain cognisant of the far-reaching consequences of such an injury and as such, prevention of these injuries should remain a priority. The responsibility of player welfare should not stop at injury prevention, and every effort should be made to improve the quality and efficiency of the immediate medical management of these injuries, as well as the long-term health, welfare and QoL of these players once injured.

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Appendices

Appendix 1

Supplemental file: Chapter 4

Methods

Participants

From the 90 interviews of the broader study, stratified purposive sampling was used to select interviews for inclusion in this study. All SCI cases that occurred post-BokSmart (2009-2015), were automatically included due to the low number of players in this group (n=16). Thereafter, participants that sustained SCIs in the pre-BokSmart period (1968-2008), were grouped according to the nine respective provinces in South Africa. Within each of these provinces, participants were divided into low SES (LSES), medium SES (MSES) and high SES (HSES) groups. SES was determined by means of an asset indicator approach (composite score from the presence of assets such as electricity, indoor flushing toilet, indoor running water, television, satellite dish, computer, internet, motor vehicle, refrigerator, microwave, washing machine, radio and method of cooking) (Bradshaw & Steyn, 2001). Asset information was obtained from questionnaires completed by all participants in the broader study.

Sampling was conducted with the aim to find a proportionate representation of each province and SES group. Sampling continued until data saturation was reached and finally included thirty-two (n=32) participants from the pre-BokSmart period (1968-2008). Overall, a sufficient spread of all SES groups was obtained (Low: 19; Medium: 6; High: 23). However, some provinces had very low numbers in the broader sample. Thus, it was not possible to achieve a SES spread within these specific provinces.

Of the ninety participants included in the broader study, eighty-nine participants (n=89) had sustained a cervical level SCI, while one participant had sustained a thoracic level SCI. Level of injury was not considered as a stratification factor.

Data collection

Interview guide:

1. Can you describe what happened immediately after the injury?
 2. Who assisted you and in what way?
 3. How do you feel about the management you received?
 4. Were there any factors that you felt negatively affected or restricted your initial care or management?
 5. Are there any factors that you feel helped, or that made your management good or easier?
- Probes / recursive questions:
 - Detail orientated probes – to fill in the blank spaces in a response:
 - When? Who? Where? What? How?
 - Elaboration probes:
 - Why do you say that? / Why do you think that is? / Can you tell me more?

References

Bradshaw, D., & Steyn, K. (2001). *Poverty and chronic diseases in South Africa - Technical report - MRC.*

Appendix 2

Supplemental file: Chapter 4

Table 1. Sample characteristics (n=48).

	Number / range	%
Year of injury	1968 - 2015	
Injured Pre-or Post BokSmart		
<i>Pre-BokSmart</i>	32	67
<i>Post-BokSmart</i>	16	33
Age when injured	15 - 37	
Current age	18 - 68	
Level of play		
<i>School</i>	12	25
<i>Club</i>	34	71
<i>Correctional services</i>	2	4
Functional outcome		
<i>Wheelchair-using quadriplegia</i>	46	96
<i>Ambulant quadriplegia</i>	2	4

Appendix 3

Supplemental file: Chapter 6

Methods

Participants

From the 90 interviews of the broader study, stratified purposive sampling was used to select interviews for inclusion in this study. Participants were divided into low SES, medium SES and high SES groups. SES was determined by means of an asset indicator approach (composite score from the presence of assets such as electricity, indoor flushing toilet, indoor running water, television, satellite dish, computer, internet, motor vehicle, refrigerator, microwave, washing machine, radio and method of cooking) (Bradshaw & Steyn, 2001). Asset information was obtained from questionnaires completed by all participants in the broader study. Sampling was conducted with the aim to find a proportionate representation of each SES group. Sampling continued until data saturation was reached and finally included thirty-one (n=31) participants.

Of the ninety participants included in the broader study, eighty-nine participants (n=89) had sustained a cervical level SCI, while one participant had sustained a thoracic level SCI. Level of injury was not considered as a stratification factor.

Data collection

Interview guide:

1. *Which factors do believe determines a person with a spinal cord injury's QOL? / What are the essential things to have good quality of life?*
 1. Are you healthy or unhealthy? Why?
 2. Are you happy with your health?
 3. Are you happy with the healthcare you are receiving?
 4. Do you use private or public healthcare or both? Why?
 5. What do you need to stay healthy and how do you go about doing this?
 6. Do you have any problems or difficulties when you need healthcare?
 7. Is there anything that helps you to get the healthcare you need?

8. Is there anything that stops or limits you from getting the healthcare you need?

If needed:

1. Are you happy with the healthcare that you receive?
2. Tell me about the rehabilitation you had after the injury?
3. Do you still have rehabilitation now?

- Probes / recursive questions:

Detail orientated probes – to fill in the blank spaces in a response:

- When? Who? Where? What? How?

Elaboration probes:

- Why do you say that? / Why do you think that is? / Can you tell me more?

References

Bradshaw, D., & Steyn, K. (2001). *Poverty and chronic diseases in South Africa - Technical report - MRC.*

Appendix 4

Questionnaires

Demographic Questionnaire

Participant number: _____

Instructions:

1. Please complete entire questionnaire in block letters.
2. Where applicable, please indicate your choice with a 'X'

A. PERSONAL DETAILS

Surname			
Name			
Date of Birth	Year	Month	Day
Marital status	Married	Unmarried	Divorced
	Other:		
Where do you currently live?	Suburb / Town:	District Municipality:	Province:
Race	African	Mixed Ancestry	Caucasian
	Other	Prefers not to answer	

B. INJURY-RELATED DETAILS

Date of injury			
Age at time of injury			
Age group played in at time of injury			
Exact location where injury occurred (Field, Town and Province)			
Mechanism of injury	Scrum	Tackle	Ruck
Injury occurred during:	Match	Practice	Other
ISCSCI classification / diagnosis of level of injury at discharge			
Sensory level at discharge			
Motor level at discharge			
Complete at discharge	Incomplete at discharge		

C. HEALTH INFORMATION

1. Do you suffer from any of the following symptoms / conditions?	
Pneumonia or chest infection	
Pressure sores	
Urinary tract infection	
Bowel problems	
Blood clots	

Blood pressure problems (specify)	
Nerve pain	
Shoulder pain	
Neck pain	
Back pain	
Hip, knee and ankle pain	
Elbow and wrist pain	
Contractures	
Spasticity	
Depression / Anxiety/ Low mood (specify)	
Other (specify)	
How often do you exercise in a typical week?	
I don't do any exercise	
Once	
Twice	
Three times	
Four times	
Five times	
Six times	
Every day	

D. SOCIO-ECONOMIC DETAILS

What is the highest level of schooling/education that you have completed?	
Pre-primary /no formal education	
Gr. 1-3	
Gr. 4-7	
Gr. 8-11	
Gr. 12	
Gr. 10 or above with Diploma/Certificate	
Gr. 12 with Diploma/Certificate (short course less than 2 years)	
Tertiary education: non-degree /diploma (minimum of 2 years)	
Tertiary education: degree	
Other (specify)	
How would you best describe your level of productive activity at the time of your injury ?	
Paid employment: Permanent	
Paid employment: Casual	
Self employed	
Non-paid work helping in family business or volunteer/ charity work	
Work around the home such as cleaning, cooking, gardening or maintenance	
School or study	
Unemployed	
Other (specify):	
What was your gross monthly income at the time of your injury ?	

R0		
R1-R1 000		
R1 001-R2 500		
R2 501-R4 500		
R4 501- R8 000		
R8 001-R12 000		
R12 001-R16 000		
R16 001-R20 000		
More than R20 000		
Prefers not to answer or does not know		
How would you best describe your current level of productive activity?		
Paid employment: Permanent		
Paid employment: Casual		
Self employed		
Non-paid work helping in family business or volunteer/ charity work		
Work around the home such as cleaning, cooking, gardening or maintenance		
School or study		
Unemployed		
Other (specify):		
Do you currently have any income?	Yes	No
What is currently your main source of income? You may choose more than one option.		
Disability grant		
Unemployment benefits		
Monthly salary: Full		
Monthly salary: Part time		
Family or Spouse		
Child support grant		
Charity organisation – please specify		
Sporadic wages (odd jobs)		
7. What is your current gross monthly income?		
<i>Prefers not to answer</i>		
<i>Don't know</i>		
R1-R1 000		
R1 001-R2 500		
R2 501-R4 500		
R4 501- R8 000		
R8 001-R12 000		
R12 001-R16 000		
R16 001-R20 000		
More than R20 000		
How would you best describe your current residence?		

Nursing care facility / Cheshire home / assisted living	
Cheshire home: independent living	
Private House	
Block of flats	
Wendy house /flat /room in back yard	
Townhouse, cluster, semi-detached	
Room, flatlet attached to a house	
Retirement village / old age home	
Informal dwelling / shack	
Other (specify):	

NB If you are living in a care facility /Cheshire home, please answer the following questions according to the residence your family / spouse lives in:

How many rooms do you have in your house (excluding bathroom)?						
How many people are living at home including you?						
Is there enough space for you to move around within your home?		Yes		No		
				Please elaborate:		
Where do you wash yourself?	Bath	Shower	Both bath and shower	Neither	Basin /tub	Other (specify)
Do you have a toilet inside or outside?		Inside			Outside	
Do you have an indoor flush toilet?		Yes			No	
Do you have electricity in your house?		Yes			No	
Do you have indoor running water?		Yes			No Approximately how far is it to the nearest tap (in meters or kilometres)?	
Do you have a television?		Yes			No	
Do you have a satellite dish?		Yes			No	
Do you have a DVD machine?		Yes			No	
Do you have a washing machine?		Yes			No	
Do you have a refrigerator?		Yes			No	
Do you have a microwave?		Yes			No	
Do you have a motor vehicle?		Yes			No	
Do you have access to a telephone?		Yes				No
		Inside your home				
		Neighbour's phone				

Cell phone
Public phone within 50m
None of the above

Do you have a radio/ HiFi?	Yes	No
Do you have internet access?	Yes	No
Do you have a computer?	Yes	No
Do you an electric/gas stove?	Yes	No
Do you have a paraffin stove?	Yes	No
What is the distance to the nearest healthcare facility (in meters or kilometers)?	What is the distance to the nearest grocery / food shop (in meters or kilometres)?	
What type of transport to you mostly rely on?	Please tick	
Public Taxi (Minibus)		
Bus		
Private Taxi		
Train		
Private car		
Patient transport van		
Other:		

Do you make use of:	Public healthcare	Private healthcare	Both
Are you on medical aid?	Yes		No
	Name of medical aid and plan:		
	Monthly contribution:		

The World Health Organisation's WHOQOL-BREF

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	$(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18$ <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/>	a. =	b:	c:
28. Domain 2	$Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)$ <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/>	a. =	b:	c:
29. Domain 3	$Q20 + Q21 + Q22$ <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/>	a. =	b:	c:
30. Domain 4	$Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25$ <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/> + <input type="checkbox"/>	a. =	b:	c:

* See Procedures Manual, pages 13-15

Spinal Cord Independence Measure



LOEWENSTEIN HOSPITAL REHABILITATION CENTER

Affiliated with the Sackler Faculty of Medicine, Tel-Aviv University

Department IV, Medical Director: Dr. Amiram Catz Tel: 972-9-7709090 Fax: 972-9-7709986 e-mail: amiramc@clalit.org.il

Patient Name: _____ ID: _____ Examiner Name: _____
(Enter the score for each function in the adjacent square, below the date. The form may be used for up to 6 examinations.)

SCIM-SPINAL CORD INDEPENDENCE MEASURE

Version III, Sept 14, 2002
EXam 1 2 3 4 5 6

Self-Care

DATE / / / / / /

1. **Feeding** (cutting, opening containers, pouring, bringing food to mouth, holding cup with fluid)
 0. Needs parenteral, gastrostomy, or fully assisted oral feeding
 1. Needs partial assistance for eating and/or drinking, or for wearing adaptive devices
 2. Eats independently; needs adaptive devices or assistance only for cutting food and/or pouring and/or opening containers
 3. Eats and drinks independently; does not require assistance or adaptive devices
2. **Bathing** (soaping, washing, drying body and head, manipulating water tap). **A-upper body; B-lower body**
 - A. 0. Requires total assistance
 1. Requires partial assistance
 2. Washes independently with adaptive devices or in a specific setting (e.g., bars, chair)
 3. Washes independently; does not require adaptive devices or specific setting (not customary for healthy people) (adss)
 - B. 0. Requires total assistance
 1. Requires partial assistance
 2. Washes independently with adaptive devices or in a specific setting (adss)
 3. Washes independently; does not require adaptive devices (adss) or specific setting
3. **Dressing** (clothes, shoes, permanent orthoses: dressing, wearing, undressing). **A-upper body; B-lower body**
 - A. 0. Requires total assistance
 1. Requires partial assistance with clothes without buttons, zippers or laces (cwobzl)
 2. Independent with cwobzl; requires adaptive devices and/or specific settings (adss)
 3. Independent with cwobzl; does not require adss; needs assistance or adss only for bzl
 4. Dresses (any cloth) independently; does not require adaptive devices or specific setting
 - B. 0. Requires total assistance
 1. Requires partial assistance with clothes without buttons, zippers or laces (cwobzl)
 2. Independent with cwobzl; requires adaptive devices and/or specific settings (adss)
 3. Independent with cwobzl without adss; needs assistance or adss only for bzl
 4. Dresses (any cloth) independently; does not require adaptive devices or specific setting
4. **Grooming** (washing hands and face, brushing teeth, combing hair, shaving, applying makeup)
 0. Requires total assistance
 1. Requires partial assistance
 2. Grooms independently with adaptive devices
 3. Grooms independently without adaptive devices

SUBTOTAL (0-20)

Respiration and Sphincter Management

5. **Respiration**
 0. Requires tracheal tube (TT) and permanent or intermittent assisted ventilation (IAV)
 2. Breathes independently with TT; requires oxygen, much assistance in coughing or TT management
 4. Breathes independently with TT; requires little assistance in coughing or TT management
 6. Breathes independently without TT; requires oxygen, much assistance in coughing, a mask (e.g., peep) or IAV (bipap)
 8. Breathes independently without TT; requires little assistance or stimulation for coughing
 10. Breathes independently without assistance or device
6. **Sphincter Management - Bladder**
 0. Indwelling catheter
 3. Residual urine volume (RUV) > 100cc; no regular catheterization or assisted intermittent catheterization
 6. RUV < 100cc or intermittent self-catheterization; needs assistance for applying drainage instrument
 9. Intermittent self-catheterization; uses external drainage instrument; does not need assistance for applying
 11. Intermittent self-catheterization; continent between catheterizations; does not use external drainage instrument
 13. RUV < 100cc; needs only external urine drainage; no assistance is required for drainage
 15. RUV < 100cc; continent; does not use external drainage instrument
7. **Sphincter Management - Bowel**
 0. Irregular timing or very low frequency (less than once in 3 days) of bowel movements
 5. Regular timing, but requires assistance (e.g., for applying suppository); rare accidents (less than twice a month)
 8. Regular bowel movements, without assistance; rare accidents (less than twice a month)
 10. Regular bowel movements, without assistance; no accidents
8. **Use of Toilet** (perineal hygiene, adjustment of clothes before/after, use of napkins or diapers).
 0. Requires total assistance
 1. Requires partial assistance; does not clean self
 2. Requires partial assistance; cleans self independently
 4. Uses toilet independently in all tasks but needs adaptive devices or special setting (e.g., bars)
 5. Uses toilet independently; does not require adaptive devices or special setting

SUBTOTAL (0-40)

Mobility (room and toilet)

DATE

\ / \ / \ / \ / \ /

9. Mobility in Bed and Action to Prevent Pressure Sores

- 0. Needs assistance in all activities: turning upper body in bed, turning lower body in bed, sitting up in bed, doing push-ups in wheelchair, with or without adaptive devices, but not with electric aids
- 2. Performs one of the activities without assistance
- 4. Performs two or three of the activities without assistance
- 6. Performs all the bed mobility and pressure release activities independently

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10. Transfers: bed-wheelchair (locking wheelchair, lifting footrests, removing and adjusting arm rests, transferring, lifting feet).

- 0. Requires total assistance
- 1. Needs partial assistance and/or supervision, and/or adaptive devices (e.g., sliding board)
- 2. Independent (or does not require wheelchair)

--	--	--	--	--	--

11. Transfers: wheelchair-toilet-tub (if uses toilet wheelchair: transfers to and from; if uses regular wheelchair: locking wheelchair, lifting footrests, removing and adjusting armrests, transferring, lifting feet)

- 0. Requires total assistance
- 1. Needs partial assistance and/or supervision, and/or adaptive devices (e.g., grab-bars)
- 2. Independent (or does not require wheelchair)

--	--	--	--	--	--

Mobility (indoors and outdoors, on even surface)

12. Mobility Indoors

- 0. Requires total assistance
- 1. Needs electric wheelchair or partial assistance to operate manual wheelchair
- 2. Moves independently in manual wheelchair
- 3. Requires supervision while walking (with or without devices)
- 4. Walks with a walking frame or crutches (swing)
- 5. Walks with crutches or two canes (reciprocal walking)
- 6. Walks with one cane
- 7. Needs leg orthosis only
- 8. Walks without walking aids

--	--	--	--	--	--

13. Mobility for Moderate Distances (10-100 meters)

- 0. Requires total assistance
- 1. Needs electric wheelchair or partial assistance to operate manual wheelchair
- 2. Moves independently in manual wheelchair
- 3. Requires supervision while walking (with or without devices)
- 4. Walks with a walking frame or crutches (swing)
- 5. Walks with crutches or two canes (reciprocal walking)
- 6. Walks with one cane
- 7. Needs leg orthosis only
- 8. Walks without walking aids

--	--	--	--	--	--

14. Mobility Outdoors (more than 100 meters)

- 0. Requires total assistance
- 1. Needs electric wheelchair or partial assistance to operate manual wheelchair
- 2. Moves independently in manual wheelchair
- 3. Requires supervision while walking (with or without devices)
- 4. Walks with a walking frame or crutches (swing)
- 5. Walks with crutches or two canes (reciprocal walking)
- 6. Walks with one cane
- 7. Needs leg orthosis only
- 8. Walks without walking aids

--	--	--	--	--	--

15. Stair Management

- 0. Unable to ascend or descend stairs
- 1. Ascends and descends at least 3 steps with support or supervision of another person
- 2. Ascends and descends at least 3 steps with support of handrail and/or crutch or cane
- 3. Ascends and descends at least 3 steps without any support or supervision

--	--	--	--	--	--

16. Transfers: wheelchair-car (approaching car, locking wheelchair, removing arm- and footrests, transferring to and from car, bringing wheelchair into and out of car)

- 0. Requires total assistance
- 1. Needs partial assistance and/or supervision and/or adaptive devices
- 2. Transfers independent; does not require adaptive devices (or does not require wheelchair)

--	--	--	--	--	--

17. Transfers: ground-wheelchair

- 0. Requires assistance
- 1. Transfers independent with or without adaptive devices (or does not require wheelchair)

--	--	--	--	--	--

SUBTOTAL (0-40)

--	--	--	--	--	--

TOTAL SCIM SCORE (0-100)

--	--	--	--	--	--

Community Participation Indicators Questionnaire

Community Participation Indicators

CaseId #

--	--	--	--

Page

Shade circles like this: ●
 Not like this: ⊗ ⊙

Please mark the choice that most closely reflects your opinion:

		<i>All the time</i>	<i>Frequently</i>	<i>Sometimes</i>	<i>Seldom</i>	<i>Almost never</i>
1. I live my life the way that I want.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. People try to put limits on me.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I participate in a variety of activities.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I am uncomfortable participating in community activities....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I spend time doing things that improve my community.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I participate in activities that I choose.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I spend time helping others.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I count as a person in society.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I have the freedom to make my own decisions.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I live my life fully.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I regularly seek out new challenges.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I have reliable access to a telephone.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. I have a say on decisions in my community.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. I have choices about the activities I do.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. I actively pursue my dreams and desires.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. I do things that are important to me.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. People have high expectations of me.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. I am able to go out and have fun.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. I contribute to society.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. I have opportunities to make new friends.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. I speak up for myself.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. People speak to me disrespectfully.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. I take responsibility for my own life.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. I have good job opportunities.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. People underestimate me.....	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Community Participation Indicators		CaseId #				

Shade circles like this: ●
 Not like this: ⊗ ⊙

Please mark the choice that most closely reflects your opinion:

	All the time	Frequently	Sometimes	Seldom	Almost never
26. I assume leadership roles in organizations.....	○	●	○	○	○
27. I am welcome in my community.....	○	●	○	○	○
28. I am treated equally.....	○	●	○	○	○
29. I have reliable access to community services.....	○	●	○	○	○
30. I do important things with my life.....	○	●	○	○	○
31. My community respects me the way that I am.....	○	●	○	○	○
32. I have influence in my community.....	○	●	○	○	○
33. I am in control of my own life.....	○	●	○	○	○
34. I am ignored.....	○	●	○	○	○
35. I feel safe participating in community activities.....	○	●	○	○	○
36. I am treated as a valued member of society.....	○	●	○	○	○
37. People see my potential.....	○	●	○	○	○
38. I have access to reliable transportation.....	○	●	○	○	○
39. I have reliable access to the Internet.....	○	●	○	○	○
40. I have control over how I spend my time.....	○	●	○	○	○
41. People listen to what I say.....	○	●	○	○	○
42. I participate in activities when I want.....	○	●	○	○	○
43. I am uncomfortable participating in public meetings.....	○	●	○	○	○
44. I am treated like a human being.....	○	●	○	○	○
45. People count on me.....	○	●	○	○	○
46. I contribute to the well-being of my community.....	○	●	○	○	○
47. I am actively involved in my community.....	○	●	○	○	○
48. It is hard for me to get information about community services.....	○	●	○	○	○

Appendix 5

Ethical approval



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
Email: ncsi.tsama@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

07 April 2016

HREC REF: 893/2015

Prof ML Lambert
Sports Science Institute
Human Biology

Dear Prof Lambert

PROJECT TITLE: LIFE AFTER THE GAME: A QUALITATIVE AND QUANTITATIVE ANALYSIS OF THE LONG-TERM EFFECTS OF ACUTE SPINAL CORD INJURIES IN SOUTH AFRICAN RUGBY UNION PLAYERS (PhD-candidate-M Badenhorst)

Thank you for your response letter to the Faculty of Health Sciences Human Research Ethics Committee dated 16 March 2016.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until 30 April 2017.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please note last sentence of point 15 of the response letter: The reviewer does not have any recommendations regarding aspects of the Framework & Strategy for Disability and Rehabilitation that need consideration in the study protocol at this stage.

Please quote the HREC REF in all your correspondence.

We acknowledge that the student M Badenhorst will also be involved in this study

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur."

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

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