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# BMJ Open Quality of life among individuals with rugby-related spinal cord injuries in South Africa: a descriptive cross-sectional study

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## ABSTRACT

**Objectives** Rugby-related spinal cord injuries (SCIs) 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 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 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 WHO 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 SD of the WHOQOL-BREF was 15.1±2.3 arbitrary units. 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 subdomains (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 on the modifiable factors associated with QoL.

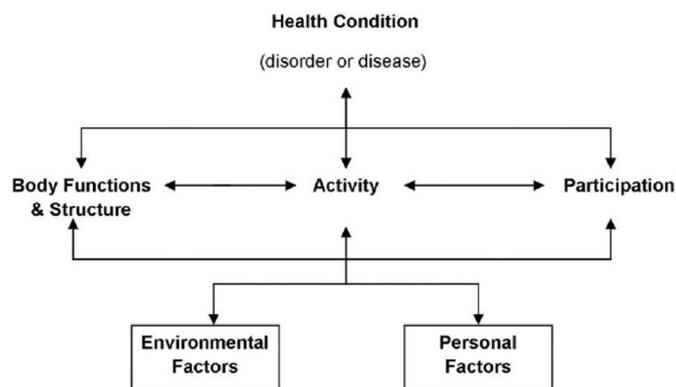
## INTRODUCTION

Sport plays a role in the aetiology of spinal cord injury (SCI) in various countries.<sup>1</sup> Rugby union, specifically, is a popular team

## 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 quality of life (QoL) in rugby players who sustain spinal cord injury (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.

sport, characterised by frequent exposure to physical contact and high-impact collisions.<sup>2</sup> Compared with other sports, rugby has been identified as one of the individual sports with highest risk for SCI.<sup>3</sup> Though the actual risk is low, serious and potentially disabling injuries are associated with the sport.<sup>4</sup> 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.<sup>5</sup> The CBPJPF is a non-profit organisation that provides support for rugby players who have sustained a catastrophic injury.<sup>5</sup> Although catastrophic injuries such as SCIs are rare, the outcome remains a life-altering event for the player and their family.<sup>4</sup> In South Africa, the overall annual incidence rate for permanent



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

outcome SCIs between 2008 and 2014 were reported as 1.8 injuries per 100 000 players (95% CI 0.3 to 3.4).<sup>6</sup>

The consequences of such an injury can be assessed by the WHO's International Classification of Functioning, Disability and Health (ICF).<sup>7</sup> The ICF contains three components of human functioning: (1) body functions and structures (physiological, psychological and anatomical functions), (2) activity (execution of tasks) and (3) 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.<sup>7</sup>

A concept not incorporated in the ICF is quality of life (QoL).<sup>8</sup> 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 conceptual 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.<sup>8</sup> 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.<sup>8,9</sup> Measuring QoL after SCI is important, as the purpose of SCI rehabilitation includes functional recovery and independence, community reintegration and ongoing enhancement of QoL.<sup>10</sup> QoL has been found to be diminished following SCI and may be affected by personal factors, such as sociodemographic and psychological factors, or cultural factors such as race and ethnicity.<sup>11-13</sup> 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.<sup>11,14</sup> Specifically, paid employment and time since injury has previously emerged as important cross-cultural predictors of

QoL after SCI.<sup>15</sup> Additionally, participation in home, social and leisure activities have been shown to have a positive effect on QoL.<sup>15,16</sup>

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.<sup>17</sup> Qualitative studies of the experiences of people who have suffered an 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.<sup>18,19</sup> International sporting federations have an obligation to protect the health of their athletes.<sup>20</sup> As is evident from the various injury prevention programmes in rugby,<sup>5</sup> 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 SCI, 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.<sup>5</sup> 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 of 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 1 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.<sup>21</sup> 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.<sup>22</sup>

### Patient and public involvement

The research objectives and study design of this study was formulated in consultation with a person with an SCI, who is also the CEO of QuadPara 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 email, post or discussed via telephone, depending on their preference.

### Dependent variable

QoL was assessed using the abbreviated version of the WHO Quality of Life questionnaire (WHOQOL-BREF). The WHOQOL-BREF is a cross-culturally valid questionnaire that consists of 26 items within four QoL domains: physical health, psychological health, social relationships and environment.<sup>22 23</sup> 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.<sup>24 25</sup> The frequency distribution of the four 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 three items, whereas those for the other domains are based on 6–8 items, thus affecting the alpha value.<sup>25</sup> The WHOQOL-BREF was also shown to correlate in appropriate domains with other QoL measures such as the 36-Item Short Form Health Survey (SF-36) ( $r_s=0.33-0.78$ ).<sup>24</sup>

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.<sup>22</sup> 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.<sup>26</sup> The overall score ranges from 4 to 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.<sup>22</sup> 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 socioeconomic 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.<sup>27</sup> The asset indicator scores were used to divide the sample into low, middle and high socioeconomic groups based on percentile cut-off points.<sup>27</sup>

#### 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-controlled wheelchairs), low quadriplegia (C5-C8, using hand-controlled 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.<sup>28</sup> 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 multicentre studies.<sup>28</sup>

The inclusion of participation in disability studies is important, but the subjective nature of participation can cause challenges with measurement.<sup>29 30</sup> The Craig Handicap Assessment and Reporting technique (CHART) is one of the most widely used measure of participation in research.<sup>31</sup> However, CHART is classified as an activity-focused, objective measure of participation (outsider's perspective) and is based on the International

Classification of Impairment, Disability and Handicap (ICIDH) framework, which is an outdated version of the ICF.<sup>32</sup> 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.<sup>32</sup> Issues of choice and control, importance, belonging and satisfaction have been included in recent definitions of participation.<sup>33 34</sup> 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.<sup>30</sup> Based on these criticisms of existing objective participation measures, a relatively new concept and measure of participation was used.<sup>30</sup> *Participation enfranchisement* assesses the subjective experience of participation and is a reflection of the meaning that individual's attach to participation across life domains.<sup>35</sup> Enfranchisement is defined as active engagement, choice and control, access and opportunity, fulfilling responsibilities, having an impact and supporting others and social connection.<sup>35</sup> 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.<sup>35</sup> Enfranchisement can also reflect personal factors, such as cultural background and SES, as well as environmental factors, such as varying opportunities between rural and urban communities.<sup>35</sup> Heinemann *et al*<sup>35</sup> developed the Community Participation Indicators (CPIs), which consists of separate components to measure participation enfranchisement. *Importance of participation*, which consists of 13 items (eg, 'I do important things with my life'), and *control over participation*, which consists of 14 items (eg, '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 participation* and *control over participation*, respectively).<sup>35</sup> Residual principle components analyses have suggested that the two item sets are one dimensional. The two enfranchisement measures share 44% of their variance.<sup>35</sup> The CPI has previously been used to measure participation in a SCI population.<sup>36</sup>

### Statistics

Descriptive statistics for sociodemographic 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 QoL, 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.<sup>15</sup> 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,

**Table 1** Sociodemographic and lesion-related variables of participants (n=90)

Quantitative variables	Mean	SD	Min	Max
<b>Age</b>				
Current age	40	11	18	68
Years since injury	8	10	1	48
Age when injured	22	6	14	40
	<b>Median</b>	<b>Min</b>	<b>Max</b>	
Number of health concerns	4	1	10	
Categorical variables	N	%		
<b>Race</b>				
African	15	17		
Mixed ancestry	28	31		
Caucasian	47	52		
<b>Marital status</b>				
Unmarried	62	69		
Married	21	23		
Divorced	6	7		
Separated	1	1		
<b>Province</b>				
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		
<b>Level of injury</b>				
High quadriplegia: (C3-C4)	7	8		
Low quadriplegia: (C5- C8)	71	79		
Paraplegia	1	1		
Ambulant quadriplegia	11	12		
<b>Completeness of injury</b>				
Complete	37	41		
Incomplete	53	59		
<b>Current employment</b>				
Unemployed	37	41		
Employed	43	48		
Student	8	9		
Correctional services	2	2		
<b>Education</b>				
Primary level	7	8		
Secondary (high school not completed)	30	33		
Secondary (high school completed)	23	26		
Tertiary level	30	33		

Continued

**Table 1** Continued

Categorical variables	N	%
<b>Income*</b>		
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
<b>Asset indicator score (SES)</b>		
Low SES	32	36
Medium SES	17	19
High SES	41	46
<b>Type of residence</b>		
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
Town house	2	2
Correctional services	2	2
<b>Transport</b>		
Has own transport	48	53
Relies on others/paid transport	32	36
Relies on care facility transport	10	11
<b>Type of healthcare</b>		
Public healthcare	42	47
Private healthcare	37	41
Both	11	12
<b>Exercise*</b>		
None	39	43
1–4 times/week	17	19
More than five times/week	33	37
Missing data	1	1

\*Variable with missing data.  
SES, socioeconomic status.

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.<sup>37</sup> A p value

of  $\leq 0.05$  was considered statistically significant for all independent variables. During analysis, listwise exclusion of cases with missing values was applied.<sup>37</sup> 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 and 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 of the participants were unmarried (69%). The mean time since injury was 18 years, with a minimum time of 1 year.

The study population included 11 (n=11) SCIs who presented with permanent neurological deficits but who could walk (ambulant quadriplegia), either with assistance, crutches or ankle-foot prostheses. One-way analysis of variance 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 per cent 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 SD of the WHOQOL-BREF was 15.1±2.3 arbitrary units (AU). The domain scores ranged from 14.6 AU 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 to 0.12), very low income (B: -1.65; 95% CI -2.70 to -0.60) and low income (B: -1.45; 95% CI -2.60 to -0.30) were

**Table 2** Quality of life (QoL), level of independence and participation scores

	Mean	Median	SD	Minimum	Maximum	IQR
<b>QoL</b>						
Total QoL (out of 20)*	15.1	14.8	2.3	7.9	19.8	3.3
Missing data: n=3						
<b>Physical domain*</b>						
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						
<b>Psychological domain*</b>						
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						
<b>Social domain*</b>						
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						
<b>Environmental domain*</b>						
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						
<b>Participation*</b>						
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						
<b>Level of independence</b>						
SCIM	34.8	24.0	23.2	3.0	97.0	23.0

\*Variable with missing data.

CPI, Community Participation Indicator; SCIM, Spinal Cord Independence Measure ; WHOQOL-5, 5-item World Health Organisation Quality of Life questionnaire

most strongly associated with overall QoL (table 4). This model explained 50% of the variance in QoL ( $F=18.2$ ,  $p<0.001$ ). For the physical health domain, participation: control (B: 0.07; 95% CI 0.03 to 0.10), very low income (B: -2.47; 95% CI -3.89 to -1.04), low income (B: -2.25; 95% CI -3.79 to -0.71) and number of health concerns (B: -0.34; 95% CI -0.59 to -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 to 0.12) and participation: importance (B: 0.05; 95% CI -0.00 to -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 to 0.13) and participation: importance (B: 0.07; 95% CI 0.00 to 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 to 0.11) and the use of private healthcare (B: 2.66; 95% CI 1.36 to 3.86), or both private and public healthcare (B: 2.61; 95% CI 0.94 to 4.37) compared with public healthcare only were positively associated with increased environmental QoL. Uncompleted secondary level schooling (B: -2.47; 95% CI -4.61 to -0.33) and completed secondary level schooling (B: -3.02; 95% CI -5.34 to -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 ( $r_s=0.376$ ,  $p<0.001$ ), number of health concerns ( $r_s=0.306$ ,  $p=0.004$ ) and exercise frequency ( $r_s=0.321$ ,  $p=0.002$ ).

**Table 3** Bivariate analysis: association between dependent and independent variables (analysis of variance and Spearman's correlation)

	Total QoL	Physical QoL	Psychological QoL*	Social QoL*	Environmental QoL
Quantitative variables					
CPI: control	$r=0.657$ ; $p<0.001$	$r=0.492$ ; $p<0.001$	$r_s=0.654$ ; $p<0.001$	$r_s=0.541$ ; $p<0.001^*$	$r=0.441$ ; $p<0.001$
CPI: importance	$r=0.518$ ; $p<0.001$	$r=0.259$ ; $p=0.02$	$r_s=0.558$ ; $p<0.001$	$r_s=0.535$ ; $p<0.001^*$	$r=0.360$ ; $p=0.001$
SCIM	$r=0.292$ ; $p=0.01$	$r=0.281$ ; $p=0.01$	$r_s=0.185$ ; $p=0.08$	x	x
Number of health concerns	$r=-0.239$ ; $p=0.03$	$r=-0.380$ ; $p<0.001$	$r_s=-0.248$ ; $p=0.02$	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

$r$ =Pearson's correlation coefficient.

$r_s$ =Spearman's correlation coefficient.

\*Psychological and Social domains not normally distributed.

ANOVA, analysis of variance; CPI, Community Participation Indicator; QoL, quality of life; SCIM, Spinal Cord Independence Measure; SES, socioeconomic status.

## 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.<sup>38</sup> The current sample had higher QoL scores compared with the only WHOQOL-BREF score data that could be found for a South African SCI population.<sup>15</sup> This sample scored higher, in all four domains, than a comparable study in a Taiwanese SCI population.<sup>26</sup> Except for the environmental domain, this sample also scored higher than an Australian study sample.<sup>16</sup> Instead, these QoL scores were similar to those reported for healthy adults.<sup>39</sup> These comparisons are limited to studies that used 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

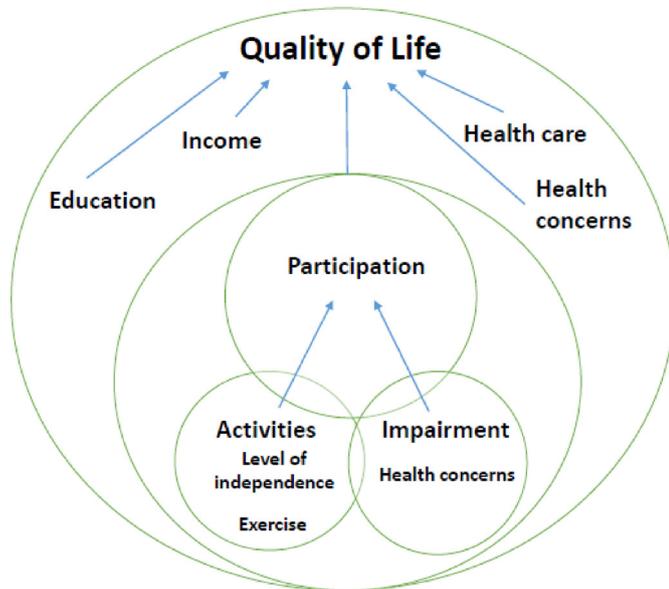
significantly associated with the various QoL domains. Previous research has indicated that participation in home, work, social and community activities was highly related to QoL.<sup>16 40</sup> Importantly, participation was the only ICF component that was significantly associated with *all* QoL domains in this study. Similarly, the Taiwanese study found participation to be consistently associated with all domains of the WHOQOL-BREF.<sup>26</sup> 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.<sup>41 42</sup> Additionally, reviews have proposed that sports and recreational activities improve self-confidence and performance of activities of daily life in people with SCI.<sup>43</sup> Compared with non-active persons with disabilities, those who engage in organised sports have decreased depression and anxiety and increased opportunities for employment.<sup>44</sup> 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

**Table 4** Multiple regression models for quality of life (QoL)

Model	R	R <sup>2</sup>	Adjusted R <sup>2</sup>	Independent variables	Unstandardised coefficients B	95% CI		P values
						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>							
Psychological domain	0.63	0.40	0.38	Health concerns	-0.34	-0.59	-0.09	0.01
				Participation: control	0.08	0.04	0.12	<0.001
Social domain	0.57	0.32	0.30	Participation: importance	0.05	-0.00	0.10	0.05
				Participation: control	0.08	0.03	0.13	0.002
Environmental domain	0.71	0.51	0.47	Participation: importance	0.07	0.00	0.13	0.04
				Participation: control	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>							

who identify as athletes are more likely to maintain, or find the need to maintain, sporting behaviour over the long term.<sup>45</sup> Qualitative research has examined the experiences of people who have suffered a SCI through playing sport.<sup>18 19 46 47</sup> These studies have revealed that individuals with strong athletic identity before the SCI can have adaptation difficulties after their injury.<sup>19</sup> However, athletic identity has also been reported as factor that can promote recovery and is considered as a means to enhance long-term adjustment to disability.<sup>48</sup> This may be explained by

research that has shown athletic identity to be a predictor of sport participation among individuals with acquired physical disabilities.<sup>49</sup> Sports participation has also been associated with improved QoL.<sup>42</sup> Certain barriers may impede exercise or sporting behaviour, such as cost, level of disability, health complications, lack of facilities, difficulties with transport and accessibility.<sup>50</sup> 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.<sup>49</sup> This requires an in-depth individualised



**Figure 2** Factors associated with QoL based on the ICF-CR framework (based on Ravenek *et al*<sup>8</sup>). QoL, quality of life.

assessment to understand the specific participation components that are perceived as important to the individual.<sup>51</sup>

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.<sup>52 53</sup> 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 rehospitalisations. Furthermore, health concerns in SCI population might create greater barriers to employment, thereby affecting both income and participation in general.<sup>54</sup> In contrast, level of injury was not associated with QoL in any of the final models. This finding is also consistent with other literature that showed that impairments do not affect QoL directly but rather via their impact on activities and participation.<sup>15 16</sup> In the present study, activity (ie, 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.<sup>55</sup> An improvement of these skills is likely to have a substantial impact on level of independence.<sup>55</sup> 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.<sup>56 57</sup> 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.<sup>56</sup> The findings of a South African household survey confirmed that poor, uninsured, black Africans and rural groups still have inequitable access to healthcare.<sup>58</sup> 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.<sup>59</sup> Disability further impedes accessibility to healthcare.<sup>56 60</sup> The associations of the type of healthcare being used 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.

Owing to difficulties in the quantification of SES in South Africa, we considered many different proxies of SES.<sup>27</sup> 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 life-time 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 with persons with higher income.<sup>61</sup> Marginalisation of people with disabilities may result in loss of productivity and opportunities to generate income, which again is linked to health and QoL.<sup>62</sup> 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 among the most important 'participation activities' for adults with disabilities and being employed is regarded as a key indicator to social integration.<sup>15 63</sup> Unfortunately, the South African Census of 2011 showed low overall absorption rates of people with disability in the labour market.<sup>64</sup> Apart from employment opportunities, lack of skills and education are also important barriers to successful employment for people with disabilities in South Africa.<sup>64</sup>

The highest level of education attained by participants showed specific associations in the environmental domain. Compared with 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.<sup>65</sup> This limits learners' opportunities for tertiary education and subsequently restricts them to low-level jobs.<sup>66</sup> Moreover, for a player injured while studying or at school, continuation of their education

postinjury can be challenging in a country with inequitable access to education and even more so for persons with disabilities.<sup>65</sup> Another possible explanation is based on the country's political past and Calman's definition of QoL as the gap between expectation and experience.<sup>9,67</sup> 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 postinjury.

## 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 acquired a disability 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 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 on 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. Furthermore, 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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