Investigating Cognitive Functioning in a Sample of Spinal Cord Injury Inpatients, in Relation to the Cognitive Demands of their Specialized Rehabilitation Program: A Pilot Exploratory Study

Emma-Louise Catherine Newbery (née Gray)

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ACSENT Laboratory

Department of Psychology

University of Cape Town

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Supervisor: Dr Leigh Schrieff

Co-Supervisor: Dr Conran Joseph

COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: Signed by candidate Date: 13 September 2021

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Abbreviations

ACSENT	Applied Cognitive Science and Experimental Neuropsychology Team
AIS	American Spinal Injury Association Impairment Scale
ASSIST V3.1	Alcohol, Smoking and Substance Involvement Screening Test Version 3.1
AVLT	Audio Verbal Learning Test
BPI	Brief Pain Inventory
COWAT	Controlled Oral Word Association Test
D-KEFS	Delis-Kaplan Executive Functioning System
FISQ2	Full-Scale Intelligence Quotient Two Subtests
HADS	Hospital Anxiety and Depression Scale
HIC	High Income Countries
ISCOS	International Spinal Cord Society
LMIC	Low- to Middle- Income Countries
LoC	Loss of Consciousness
MDT	Multidisciplinary Team
MVA	Motor Vehicle Accident
NTSCI	Non-Traumatic Spinal Cord Injury
PC-PTSD5	Primary Care Post-Traumatic Stress Disorder Screen for DSM-5
PRMQ	Prospective-Retrospective Memory Questionnaire
PSQI	Pittsburgh Sleep Quality Index
PTA	Post-Traumatic Amnesia
PTSD	Post-Traumatic Stress Disorder
RPA-ProMem	Royal Prince Alfred Prospective Memory Test
SA DoH	South African National Department of Health
SCI	Spinal Cord Injury
SCIM	Spinal Cord Independence Measure 3rd Edition
SES	Socioeconomic Status
TB	Tuberculosis
TBI	Traumatic Brain Injury
TSCI	Traumatic Spinal Cord Injury
UBACC	University of California, San Diego Brief Assessment of Capacity to Consent

UCL	University of California, Los Angeles
USA	United States of America
WAIS III	Wechsler Adult Intelligence Scale _ Third Edition
WASI	Wechsler Abbreviated Scale of Intelligence (First Edition)
WCRC	Western Cape Rehabilitation Centre
WHO	World Health Organisation
WHODAS 2.0	World Health Organisation Disability Assessment Schedule 2.0

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Abstract

Spinal Cord Injury (SCI) rehabilitation programs have significant and specific cognitive demands, requiring patients to acquire knowledge and new skills while adjusting to their profoundly altered physiology. Existing research from high income countries (HIC) has shown that SCI is associated with cognitive dysfunction, which is in turn linked to poorer rehabilitation outcomes and ultimately increased costs of care. The aetiology of SCI in South Africa is distinct from HICs, which implies differences in associated risks and mediators for cognitive pathology (e.g., focal traumatic injuries, HIV-associated non-traumatic injuries), which render questionable the local generalizability of existing research evidence. There are no South African studies on cognitive dysfunction related to SCI, and research in this area from other developing world countries is sparse. Therefore, this study aimed to address the evidence gap by investigating the cognitive profile of a sample of SCI rehabilitation inpatients in relation to the cognitive demands of their SCI rehabilitation programme, at a specialized public neurorehabilitation hospital in Cape Town.

This exploratory pilot study used quantitative methodology to describe the cognitive profile of a sample of new SCI rehabilitation inpatients shortly after their admission. Twenty-nine participants aged 18-65, who were predominantly male and from lower socioeconomic backgrounds were included in the study. All participants completed a battery of neuropsychological tests, where the assessment tools chosen measured cognitive domains identified as essential for engagement with a specialized SCI rehabilitation program. Participants also completed selected questionnaires screening for common psychological, behavioural and somatic comorbidities, with established links to cognitive dysfunction.

Interpretation of the cognitive test results was undertaken through comparison with internationally and locally normed results, in conjunction with an exploration of the presence of comorbidities with known risk to cognitive function.

In comparison to international data, the sample's cognitive performance was indicative of dysfunction across all domains assessed, while performance was relatively better in certain cognitive domains, relative to available South African normative data. Considering all available normative data and local trends, learning and memory, attention and certain executive functions emerged as possible areas of cognitive deficit. The potential mismatch between SCI rehabilitation programme cognitive demands and the sample's cognitive profile was evident, while their profile of comorbidities placed them at risk for cognitive dysfunction in multiple domains.

This pilot study provided evidence to suggest that, despite their distinct epidemiology and lower rates of comorbid TBI, local SCI rehabilitation inpatients are at risk of cognitive dysfunction, where cognitive domains potentially affected are integral to their specialized SCI rehabilitation programme. As a pilot study conducted in the context of a pandemic, multiple areas for further investigation with altered methodology were identified. Nonetheless it was clear that additional in-depth research in this area would benefit the SCI rehabilitation community at large. Future studies should include a well-matched control group, where COVID-19 clinical research disruptions precluded this design in the current study.

Contents

Investigating Cognitive Functioning in a Sample of Spinal Cord Injury Inpatients, in Relation to the Cognitive Demands of their Specialized Rehabilitation Program: A Pilot Exploratory Study

Spinal Cord Injury (SCI) is an often unanticipated, life changing event associated with exceptionally high costs, both to the individual and to society at large (Lee et al., 2014). It is a significant source of worldwide mortality and morbidity and is increasingly recognised as an international heath priority (Kumar et al., 2018). Significant and specific cognitive demands are intrinsic to SCI rehabilitation programmes, which require patients to acquire novel skills in health maintenance, self-care, mobility and community involvement, while adjusting to their fundamentally changed physical functioning (Davidofi et al., 1992; Hess et al., 2003; Sachdeva et al., 2018). Considering SCI rehabilitation in South Africa, there is emerging evidence for a very different local SCI epidemiological profile as compared to that of the global North, where the majority of existing research on SCI and cognition has taken place (Draulans et al., 2011; Joseph et al., 2017). Local post rehabilitation resources are also severely limited (Maart & Jelsma, 2014), making a successful inpatient SCI rehabilitation outcome all the more critical. Therefore, authentic South African neuropsychological investigation of SCI rehabilitation and cognition, taking into account the specific cognitive demands of local specialized SCI rehabilitation programmes, is an urgent research priority.

Epidemiology of SCI

Epidemiological study of SCI is widely recognized to be extremely challenging as a result of diverse methods for reporting and classifying the disease, few national databases, likely extensive under-reporting, and exceptionally limited data from low- to middle-income countries (LMIC), amongst other methodological and reporting issues (Kumar et al., 2018; New et al., 2014; Rubiano et al., 2015). In awareness of this, the International Spinal Cord Society (ISCOS) maintains a global data repository for prevalence, incidence and survival of SCI worldwide. Their most recently published data was for traumatic SCI (TSCI[1]) incidence in 2011, which showed a global incidence rate of twenty-three per million of the population (Lee et al., 2014). While there are no reliable national SCI incidence data available for South Africa, a prospective, regional, population-based study conducted in the City of Cape Town in 2014 found the crude incidence of TSCI within the metropole to be more than three times

1 Traumatic spinal cord injury is an injury to the spinal cord caused by externally applied mechanical force, such as may occur with an impact (e.g. caused by a fall or motor vehicle accident [MVA]) or penetrating injury (e.g. gunshot or stab wound) (Ahuja et al., 2017).

the reported global incidence rate, at 75.6 per million of the population, making investigation of this local clinical population a public health priority (Joseph et al., 2015).

Pathophysiology, Symptomatology and Classification of SCI

Injury to the spinal cord may be caused by trauma (TSCI), or internal disease processes, known as non-traumatic SCI (NTSCI). As noted, the former includes penetrating injuries (as in a gunshot or stab wound), or high or low energy impact (as in a motor vehicle accident [MVA] or fall), while the latter refers to damage to the spinal cord sustained in the absence of trauma, including a wide variety of disease processes (e.g., tuberculosis of the spine [TB spine], tumours or vascular pathology) (Kumar et al., 2018; New et al., 2014). SCI results in alteration of motor, sensory and autonomic functions below the level of injury (Burns et al., 2012) and is classified according to the vertebral level of the SCI and completeness of the spinal cord damage.

Tetraplegia refers to an injury in the cervical segments of the spinal cord and may affect the sensorimotor function in all four limbs, whereas injury in the thoracic, lumbar or sacral segments of the spinal cord causes paraplegia, which may affect the trunk and/or lower limbs depending on the level of injury (Burns et al., 2012). A complete SCI (American Spinal Injury Association Impairment Scale grade A [AIS A]) refers to an absence of sensory or motor function in the sacral segments, whereas in an incomplete SCI (AIS B, C or D) some sensory or motor function is retained below the level of injury, including the sacral segments as further detailed in Table 1 (Burns et al., 2012).

Table 1

American Spinal Injury Association Impairment Scale (AIS)

AIS Grade	Degree of Neurological Impairment
A	Complete: No motor or sensory function conserved in lowest sacral segments (S4-5)
B	Incomplete (sensory): Some sensory (including S4-5) but nil motor function below the level of neurological injury.
C	Incomplete (motor): Some conservation of motor function below neurological level of injury, ≥50% of key muscles below this level only functional in a gravity eliminated plane
D	Incomplete (motor): ≥50% of key muscles below neurological level of injury functional against gravity
E	Normal neurological function (this grade is used to denote complete recovery in an individual that previously received a higher AIS grade)

In addition to sensorimotor symptoms, SCI may result in alterations in urinary and bowel, reproductive, respiratory, cardiovascular and autonomic functions (ISCOS, 2012), while common comorbidities include pain (Siddall & Loeser, 2001), sleep disorders (Giannoccaro et al., 2013) and mood disturbance (Craig et al., 2015). The level and completeness of injury is one of the single most predictive factors of survival and morbidity after injury (ISCOS, 2012).

Following medical stabilization and/or surgery in an acute setting, a patient with newly acquired SCI may transfer to a specialized rehabilitation setting to improve sensorimotor function within physiological limits and to learn essential new skills related to their condition. In addition to this, a primary goal of SCI rehabilitation is to decrease the likelihood of costly and potentially fatal secondary morbidity through optimizing patients' medical management and ensuring that they acquire the requisite knowledge and skills, not only to maintain their mental and social wellbeing, but also their physical health, by mitigating the risks related to their altered neurological status (ISCOS, 2012; Sezer et al., 2015). Such morbidity risks include pressure ulcers and sepsis, issues related to genitourinary, cardiovascular, respiratory, gastrointestinal and musculoskeletal systems, metabolic and psychological problems (ISCOS, 2012). Cognitive skills, like problem-solving,

may be crucial to enable carryover of newly acquired health maintenance skills in the community (Elliott et al., 2006).

While the devastating physical sequelae of SCI are easily identified and understandable as a straight forward consequence of lower motor neuron pathology, there is growing evidence that SCI may also be associated with cognitive dysfunction of multifactorial origin.

SCI and Cognitive Dysfunction

Mechanisms of SCI Associated Cognitive Dysfunction

The wide variation in potential cause and consequence of SCI described above corresponds in turn to a wide variety of potential mechanisms for associated cognitive dysfunction (of both pre and comorbid aetiology) potentially affecting a range of cognitive domains. These include premorbid substance use, concomitantly sustained traumatic brain injury), changes in cardiovascular control and thus brain oxygenation, psychological and somatic secondary sequelae, and potential alterations to brain structure itself.

Premorbid Substance Use. The link between substance use and neuropsychological sequelae is well documented (Cadet & Bisagno, 2016; Stavro et al., 2012), while many studies have demonstrated the high prevalence of substance involvement in SCI aetiology, especially TSCI such as assault and MVA (e.g. Crutcher et al., 2014; Eldridge et al., 2019; Lenehan et al., 2012). Furthermore, multiple studies have found a significantly higher incidence of premorbid substance abuse amongst SCI survivors than the general population (Craig et al., 2015; Kolakowsky-Hayner et al., 1999). Therefore, presence of premorbid cognitive dysfunction as a result of premorbid substance use is an important consideration when investigating SCI associated cognitive dysfunction.

Concomitant Traumatic Brain Injury (TBI). As detailed in a recent review by Sachdeva et al. (2018), the presence of cognitive impairment in individuals with SCI and concomitantly sustained TBI is well documented. Pandrich and Demetriades (2020) found the prevalence of TBI concomitant to TSCI to be 32.5%, rising to 40% for cervical SCI in particular, while Tolonen et al. (2007) previously noted that concomitant TBI with SCI is frequently under-diagnosed. Certain TSCI mechanisms are more likely to result in a blow or significant force transmission to the head than others. Budisin et al. (2016) found that MVAs and falls were the TSCI causes most likely to be associated with concomitant TBI, as compared to the lower risk from lower velocity or more focal TSCI causes.

Autonomic Changes and Medication Side Effects. The effects of SCI on motor and sensory function below the level of injury and consequent possibility for catastrophic fall-out in physical function are well known. However, the effects on autonomic functions and side effects of medication may be less immediately obvious, while their potential impact on cognitive function could be similarly severe. Sachdeva et al. (2018) summarise evidence for the cognitive consequences of decentralized cardiovascular control, including systemic hypotension, hypertension and cerebral hypoperfusion. Four out of the five recent (2010-2017) studies reviewed by Sachdeva et al. (2018) found a correlation between compromised haemodynamics in individuals with SCI and cognitive outcomes on a range of tests measuring basic cognitive and executive functions. The same review considered evidence for the cognitive consequences of sleep-disordered breathing and associated oxygen desaturation, which was found to be a frequent consequence of higher-level SCI (Sachdeva et al., 2018). Sajkov et al. (1998) demonstrated an association between significant oxygen desaturation and impaired attention, concentration, memory and learning, while Schembri et al. (2017) found that attention, information processing and immediate recall were adversely affected in SCI patients with more severe sleep apnoea. The side effects of medications used to treat common SCI comorbidities such as sleep disturbance, pain and spasticity can also be considered in terms of their potential impact on cognition. In this regard, recent preliminary findings from Shem et al. (2018) found that SCI patients newly started on Gabapentin for neuropathic pain showed a deterioration in attention, executive function and memory performance.

Psychological and Somatic Sequelae of SCI. Nine studies investigating the association between common psychological and somatic SCI comorbidities and cognitive dysfunction were included in Sachdeva et al.'s (2018) recent review. Of these, six demonstrated correlations between pain, mood disturbance and/or fatigue, and cognitive dysfunction across various domains. Post-traumatic stress disorder (PTSD) may also be particularly pertinent to consider in relation to TSCI, where Kirshblum (2016) notes an increased risk for PTSD in this SCI group and Qureshi et al.’s (2011) review found that presence and severity of PTSD was positively associated with cognitive impairment in trauma-exposed individuals, with attention as especially vulnerable.

SCI-Associated Alterations in Brain Structure. There is a new and growing body of evidence from both animal and human studies that SCI can result in degeneration of brain structures and connections in the absence of concomitant TBI. A recent review by Y. Li et al. (2020) argues that SCI should be understood as a degenerative brain disease rather than a single neuro-traumatic injury. Y. Li et al.'s (2020) review cited multiple neuroimaging studies

(including functional and static magnetic resonance imaging), which identified evidence of reduced grey matter volume and cortical reorganization across animal and human subjects. These structural changes corresponded to sensorimotor cortex, as expected, as well as to more distant regions including anterior cingulate, medial prefrontal and cerebellar cortex (Y. Li et al., 2020). A recent study by Seif et al. (2018) found progressive brain atrophy evidenced by ventricular enlargement and increased cerebrospinal fluid volume in a cohort of SCI individuals without concomitant TBI, tracked over a two-year period. Further human studies investigating cortical and subcortical connectivity have found network alterations, which correlate with processing speed impairments (Lazzaro et al., 2013) as well as alterations to networks implicit in higher cognitive functioning (X. Li et al., 2019).

The role of SCI-associated chronic brain inflammation has also been investigated as a potential mechanism for cognitive dysfunction. Reviews by F. Li et al. (2020) and Y. Li et al. (2020) both discuss multiple rodent studies (e.g., Felix et al., 2012; Wu et al., 2014), which found that chronic neuroinflammation induced by experimental SCI led to brain degeneration with associated cognitive decline. Y. Li et al.'s (2020) review cites numerous further animal studies from the lab of Wu et al., which found that chronic neuroinflammation induced by SCI resulted in altered neurogenesis. The limitations for extrapolating these organic animal model findings to cognitive functioning in human subjects is acknowledged, as is the need for further investigation into the nature of the SCI associated brain structural changes in general (Y. Li et al., 2020).

In light of the significant cognitive demands of SCI rehabilitation programs, it is important to consider these diverse findings of SCI-associated cognitive dysfunction in relation to SCI rehabilitation outcomes, including the potential functional impact of cognitive deficits in the post discharge setting, where support may be particularly limited.

Cognitive Dysfunction and SCI Rehabilitation

A body of literature investigates the direct link between adverse SCI rehabilitation outcomes and comorbid cognitive dysfunction. An early review by Davidofi et al. (1992) suggested a significant link between cognitive deficits assessed during inpatient rehabilitation and rates of hospital readmission. Further, Elliott et al.'s (2006) study in the United States of America (USA) found that reduced social problem-solving ability, as assessed during inpatient rehabilitation, was directly linked with increased risk of potentially fatal pressure ulcer formation post discharge. Further, a more recent Australian study by Craig et al. (2016), found that there was a direct correlation between cognitive dysfunction assessed in

SCI rehabilitation inpatients and negative mood states or mental illness in the same group post discharge. While there do not appear to be any formal studies on cognitive rehabilitation for SCI patients, a 2018 case report demonstrated that a virtual reality intervention showed promise in improving cogntive function in an individual with an incomplete cervical SCI and cognitive dysfunction (Maresca et al, 2018). Much existing research on SCI and cogntive dysfunction concludes that in order to be effective, specialized SCI rehabilitation programs should take into account the possibility of cognitive dysfunction of multifactorial origin and be guided by the cognitive profile of program participants (Craig et al, 2016; Davidofi et al., 1992; Elliot et al, 2006; F. Li et al., 2020; Sachdeva et al., 2018).

However, despite this recommendation for cognizance of cognition in SCI rehabilitation, there do not appear to be any published studies which explicitly examine the specific cognitive requirements of a SCI rehabilitation programmes. Given the acquisition and varied application of specific novel skills that is required of SCI rehabilitation program participants, it follows that careful consideration of the cognitive underpinnings of these programmes should guide any assessment of cognition in this population.

SCI and Cognitive Dysfunction in South Africa

The vast majority of research on SCI and cognition is undertaken in high income countries (HIC). In their review on global neurotrauma research challenges and opportunities, Rubiano et al. (2015) discuss that evidence or practice guidelines generated in the relatively resource-rich healthcare settings of HICs cannot be assumed to apply to resource poor health settings in LMICs, and that epidemiological data, which is crucial for understanding SCI in these lower income settings, is particularly sparse (Rubiano et al., 2015). Although South Africa has recently been reclassified as an upper middle income country, its Gini coefficient, indicating levels of socioeconomic inequality, is still one the highest in the world (World Bank, 2019). Therefore, the challenges identified by Rubiano et al. (2015) are especially relevant when one considers the profile of cognitive dysfunction amongst South African SCI patients in the public rehabilitation setting, relative to patients in the evidence generating HICs. Thus, it is pertinent to discuss the South African situation in terms of neuropsychological research, the cognitive implications of local SCI aetiologies, the effects of socio-economic standing, and the circumstances of local public SCI rehabilitation.

South African Neuropsychological Research with Adults. The challenges of conducting neuropsychological research in the South African setting are multiple and well recognized (Lucas, 2013; Shuttleworth-Edwards et al., 2013). One of the greatest difficulties

lies in interpreting results from the available neurocognitive assessment tools, as these are generally formulated in HICs, making the existing normative data unsuitable for the socioeconomically, educationally, linguistically and culturally diverse local setting (Lucas, 2013).

There do not appear to be any existing South African studies investigating SCI-linked cognitive dysfunction. Local neuropsychological research into other adult neurorehabilitation populations is also limited, however there is a growing body of research into the neuropsychological profile of HIV positive South African adults (e.g. Gouse et al., 2018; Witten et al., 2015). In recognition of the difficulties related to the use of internationally normed tools, these HIV-related studies tend to make use of a well-matched healthy control group to enable comparative interpretation of the neuropsychological results. Such use of a healthy control group that is well matched in key demographic variables is widely regarded as the optimal study design when locally valid normative data are not available (Shuttleworth-Edwards et al., 2013) and would be preferable for research into the neuropsychological profile of the South African SCI population, especially in a public health setting.

Local SCI Aetiology and Symptomatology: Implications for Cognitive Function

Despite the lack of South African studies specifically examining SCI-linked cognitive dysfunction, there is fledgling research into the unique aetiology of SCI in South Africa, as compared to worldwide data. As such, it is important to consider the unique South African aetiologies of both TSCI and NTSCI in terms of their impact on SCI injury profile and potential for association with comorbidities that have established links to cognitive dysfunction.

Traumatic SCI. The majority of existing research on TSCI and cognitive dysfunction has been conducted in HICs, where MVA and falls are the main causes of injury (Lee et al., 2014). In contrast, aetiological data on TSCI in Cape Town shows that MVA is not the leading cause, but rather that approximately 60 percent of TSCI are as a result of assault (Joseph et al., 2015), with local rates of SCI due to gunshot previously reported as being the highest in the world (Lee et al., 2014). The implications of the mechanism and psychosocial context of these higher levels of TSCI caused by interpersonal violence in general and gunshot in particular warrants further consideration.

Kirshblum (2016) discusses the unique disease profile of violent TSCI, including higher risk of substance use and PTSD, both identified previously as potentially associated with cognitive dysfunction, as compared to TSCI from unintentional causes. Although there

is no SCI-specific substance use incidence data available for South Africa, a review of trauma centre admissions in the Cape Town metropole found a significant relationship between substance use by patients admitted for injuries due to assault, as compared to non-violent causes of injury, where substance use was over three times more likely to be associated with the former than the latter (Schuurman et al., 2015). Further, a paper looking specifically at gunshot SCI in Cape Town found a distinct injury profile in terms of level and completeness (lower level of injury, more likely to be complete), a younger age range of patients, higher levels of medical complications and longer length of hospital stay, as compared to other causes of TSCI (Joseph, 2017).

Non-Traumatic SCI. While both global and national epidemiological data for NTSCI is poor (Joseph et al., 2017; New et al., 2014), available evidence again points to a difference in aetiology and disease profile between the HICs and lower income settings. Where the former sees a higher proportion of NTSCI due to degenerative changes and tumours, the latter is more likely to be related to infection and TB, both often associated with HIV (Draulans et al., 2011; Joseph et al., 2017; New et al., 2014). For example, Shetty et al.'s (2016) review on TB spine noted that TB is the leading HIV-associated opportunistic disease in LMICs, while HIV positive patients with TB are up to twenty times more likely to have skeletal lesions than TB patients without HIV. Godlwana et al. (2008) found that 28% of TB spine cases seen at a Kwa-Zulu Natal Hospital in the period 2005-2006 had HIV. Although high, it is noted that 28% may be a very conservative incidence, as the paper does not specify whether there was the possibility of undiagnosed or undisclosed HIV within the study population (Godlwana et al., 2008). The association between HIV and cognitive dysfunction is well documented and ranges from the more severe HIV dementia to less severe HIV-associated neurocognitive disorder, which itself has further subdivisions of severity (Sanmarti et al., 2015; Woods et al., 2009). Modi et al., (2018) mentions HIV as the leading cause of preventable and treatable neurocognitive illness worldwide. The cognitive profile of HIV-associated neurocognitive disorder is wide ranging and diverse with research identifying the potential for varying degrees of deficit across a broad spectrum of cognitive functions including attention, executive functions, processing, learning and memory, visuoperception and speech and language (Sanmarti et al., 2015; Woods et al., 2009).

To gain a full understanding of the South African SCI rehabilitation setting, this unique combination of comorbidities and associated additional risks or potential protectors for cognitive dysfunction in the SCI population should be considered in relation to the rehabilitation services in South Africa.

Rehabilitation in South Africa

A South African national rehabilitation strategy framework was formulated in 2016, which identified rehabilitation as a national health priority, which is crucial for translating service users' medical treatment into productive community reintegration (South African National Department of Health [SA DoH], 2016). However, although it mandated the provision of "integrated, comprehensive, appropriate disability and rehabilitation services"(SA DoH, 2016, p.12), it identified numerous serious and wide-ranging challenges to this ideal within the South African public health system. Challenges of relevance to this research were lack of integration with priority health programs, notably HIV/AIDS, health professionals' poor knowledge of the multifaceted challenges faced by service users (which may be understood to include knowledge of potential cognitive dysfunction), and lack of authentic local research into factors affecting rehabilitation efficacy (SA DoH, 2016).

Further, in contrast to HIC, where community follow-up programs are often well established, Maart and Jelsma (2014) found that home-based care needs were particularly poorly met in South Africa. This lack of community support, in addition to the broader health system challenges described, implies that successful rehabilitation, including independent management of complex new health needs, in order to avoid potentially devastating secondary complications, is especially important for individuals with newly acquired SCI in South Africa.

Rationale, Aims and Objectives

The link between cognitive dysfunction and SCI, with its implications for adverse health outcomes and significant health system burden, has been established in high income settings. However, the literature reviewed above has revealed that the unique epidemiology and aetiology of SCI in South Africa renders the local generalizability of global studies on SCI and cognitive dysfunction questionable, while the very limited availability of local post rehabilitation resources implies that a successful inpatient rehabilitation outcome is critical. Thus, it is clear that research investigating the cognitive profile of South African SCI rehabilitation inpatients, as guided by the cognitive demands of the local public SCI rehabilitation setting, is urgently required. It is in this relative void of locally applicable evidence, against the backdrop of critical public health resource challenges, that the current study is situated.

To this end, the study had the following specific aims:

1) To investigate the profile of cognitive strengths and weaknesses in a sample of SCI inpatients at a specialized public rehabilitation hospital in the Western Cape.
2) To compare the cognitive profiles of these patients to the cognitive requirements of their specialized SCI rehabilitation programs.

The following objectives delineate the process for achieving the stated aims:

Objectives for Aim One

i) To establish the cognitive performance of the SCI group sample in relation to international norms.
ii) To establish the cognitive performance of the SCI group sample in relation to the limited available normative data from South Africa
iii) To establish the presence and extent of comorbidities known to affect cognitive function in the same group.

Objectives for Aim Two

i) To establish the cognitive requirements of the study setting's specialized SCI rehabilitation program using the Occupational Therapy process of activity analysis, with expert consultation.

ii) To establish the relationship between the relative cognitive strengths and weaknesses of the SCI group and the cognitive demands of their specialized rehabilitation program.

A Note on the Impact of the COVID-19 Pandemic

The original research protocol proposed the use of a well-matched comparative control group to enable interpretation of the cognitive profile, thus avoiding the pitfalls of comparison with international normative data. However, at the onset of the COVID-19 lockdown, while SCI data collection was complete, insufficient control data had been collected to enable between group comparisons.

With no certainty about the likely period of disruption in data collection, and the potential for the psychosocial impact of the pandemic to compromise the validity of any new control data collected, it was necessary to explore alternative means to conclude the research without further data collection, as this study was conducted for degree-seeking purposes. The limitations resulting from the amended design meant that the research was undertaken as a pilot study.

Method

Design and Setting

The current pilot study was exploratory with a cross-sectional design and quantitative methodology (Bowling, 2014; Terre Blanche et al, 2014). It was set at Western Cape Rehabilitation Centre (WCRC), a government funded physical rehabilitation hospital in Cape Town, which is the larger of only two specialized public rehabilitation hospitals in South Africa. WCRC is situated in Mitchells Plain, a low socioeconomic status (SES) suburb in the Cape Metropole. It is a 240 bed unit and serves patients from the surrounding communities as well as from its larger catchment area, which includes the Northern Cape, Western Cape, and Eastern Cape provinces. WCRC offers specialist intensive inpatient rehabilitation through a multidisciplinary team (MDT) approach, comprising physiotherapists, occupational therapists, speech therapists, psychologist, social workers, dietician, doctors and nurses (WCRC, 2020). In addition to SCI, survivors of stroke, TBI, amputations and other acquired neurological conditions are also eligible for referral to WCRC (WCRC, 2020). An outpatient department also offers various clinics for past patients and others requiring disability specific services (WCRC, 2020).

Neuropsychological assessments, demographic and functional ability questionnaires, and a comorbidity screening battery were completed with a group of recently admitted SCI rehabilitation inpatients. The tests in the neuropsychological screening battery were selected to target the cognitive skills required by the SCI rehabilitation programme in a process described further in the *Materials* section below.

Sample

The final sample comprised 29 SCI rehabilitation inpatients (30 assessments completed, or which 29 were useable).

Inclusion Criteria

All patients aged 18-65 who were admitted to WCRC for rehabilitation following newly acquired SCI over a four-month data collection period (November 2019- March 2020) were eligible for participation.

Exclusion Criteria

In order to utilize an adult cognitive assessment battery (as opposed to child, adolescent or geriatric), patients under the age of 18 or over 65 were excluded. Patients who had already received SCI rehabilitation, excluding therapy received in an acute setting while awaiting WCRC admission, were also excluded from the study. For logistical reasons related to availability of suitably trained translators and test materials, patients unable to understand English or Afrikaans with sufficient proficiency to complete a neuropsychology test battery and associated tests were also excluded. Language proficiency for those participants whose mother-tongue was not one of the assessment languages was determined through their self-evaluation of fluency in English or Afrikaans, as well as through the formal informed consent procedures. These procedures were conducted in English or Afrikaans and made use of a capacity assessment tool that determined participants' ability to comprehend the purpose, procedures, risk and benefits of participating in the study (assessment process described further in in *Materials*). Further exclusion criteria included patients unable to provide informed consent, as well as those who had undergone formal neuropsychology testing in the preceding 12 months.

Procedure

Cognitive Battery Test Selection

In order to derive a cognitive assessment battery appropriate to the study context and objectives, the selection of cognitive elements for evaluation was guided by an analysis of the cognitive skills that are required to engage with the content of WCRC's SCI rehabilitation program. This analysis was led by the principles of Activity Analysis. Activity Analysis is an occupational therapy process, which entails a comprehensive analysis of all steps of a given task in its performance setting in order to determine the cognitive, physical and psychosocial skills required to complete it (Duncan, 2011). A team of three occupational therapists (the author included), with extensive experience of working with patients with SCI, completed the activity analysis of the SCI rehabilitation programme, , with a specific focus on the cognitive component skills required. Further consensus on the key cognitive demands was obtained through sharing the analysis of cognitive elements with an expert neuropsychologist, and 22 postgraduate psychology students who were completing Research or Neuropsychology Honours and Masters degrees. The broad SCI programme activity areas and tasks with corresponding cognitive component demands are tabulated in Appendix A.

Recruitment

The bed manager at WCRC informed the researcher of new SCI admissions meeting the specified inclusion criteria on a weekly basis. Potential participants were approached for informed consent within the first month of their admission. The recruitment process and timing was established in a planning meeting with the centre management and therapy middle managers, representing the different rehabilitation departments in the hospital (occupational therapy, physiotherapy, speech therapy, social work and psychology). At the request of the social work middle-manager, the patients' allocated social workers forewarned eligible patients that they would be approached by an independent researcher within their first weeks at the centre, but did not give any detail about the research.

Data Collection Procedures

Recruitment and informed consent procedures were completed outside of therapy time. The 'University of California San Diego Brief Assessment of Capacity to Consent' (UBACC) (Jeste et al., 2007) was used to establish capacity for informed consent (further information on the UBACC given under *Materials)*. The consenting patient's MDT was informed of the scheduled assessment a week in advance in order to plan rehabilitation sessions accordingly. Data collection took place in a quiet and private room on the WCRC premises and was completed by the researcher in a single session of two to three hours, including a 10- to 20-minute refreshment break. At the end of the session, participants were able to ask questions regarding the assessment process; where clinical or personal questions arose, the patients were advised to discuss these further with their MDT. A brief summary of assessment results (in the form of broad performance ranges) was given to their treating social worker; this was requested by WCRC for patient records and to enable further investigation by the MDT if they so decided. The extremely limited clinical utility of the results, both due to their collection using a standardized research, rather than a clinical approach, as well as the limited utility of international norms within the local setting were discussed in the aforementioned planning meeting with clinical managers, and clearly stated on the provided summary.

Materials

The tests chosen have all originally been published in English, however, where available, authenticated Afrikaans translations of the relevant materials were utilized. Where unavailable, test translation was commissioned through the University of Stellenbosch

Language Laboratory in Cape Town, who use an established authentication process of translation and back translation[2].

The University of California, San Diego Brief Assessment of Capacity to Consent (UBACC). The UBACC (Jeste et al., 2007) was used to determine capacity to provide consent as well as an additional check for participants' self-evaluated English or Afrikaans fluency. It is a 10-item questionnaire, which assesses participants' comprehension of the research protocol and their decision-making capacity related to study participation. It was designed for use in health research and has proven psychometric properties in this regard (Jeste et al., 2007). It has recently been used in a South African genomics research study, where Campbell et al. (2017) used the tool in conjunction with an iterative learning process to enhance understanding for informed consent in an adult sample from a low SES background. Campbell et al.'s (2017) process was used as follows: participants complete the UBACC (Appendix B) immediately after an explanation of the study (as per Appendix C). Where incorrect answers are provided, the researcher immediately returns to the relevant component of the study explanation, corrects the potential participant's misinterpretation, and repeats the important information, rephrasing if needed. The incorrectly answered UBACC items are then re-administered. This process is repeated a maximum of 4 times, or until a score of at least 14.5, indicative of capacity to consent (Jeste et al., 2007), is achieved. Participants who score below this cut-off were deemed unable to provide consent, and were excluded from the study. As was the case in Campbell et al.'s (2017) use of the tool, question 10: 'who will pay for your medical care if you are injured as a direct result of participating in this study?', was not relevant for the current study, with its minimal risk of injury to participants, therefore a more relevant question was substituted: 'Who at WCRC will receive information on your assessment results?'. As a measure of comprehension for information given in either English or Afrikaans, a cut-off score of 14.5 was also used as an additional confirmation of participants' self-evaluated proficiency in either language. An Afrikaans translation of this tool was commissioned for the purposes of this study.

Demographic Questionnaire. A demographic questionnaire (Appendix D) included SCI specific aetiological information, with categories in line with the ISCOS core data sets (Biering-Sørensen et al., 2011). Supplementary medical information, including current medication and comorbidities, was also collected for all participants. Categorical socioeconomic information including household income, level of education, employment and

[2] Commissioned translations available on request, copyright restrictions allowing

material and financial resources (through an asset index enabling categorisation as low, medium and high asset ownership) was based upon the methods espoused by Myer et al. (2008) and subsequently used by Schrieff et al. (2015).

Cognitive Assessment Battery. Assessment tools with established psychometric validity and minimum hand function/fine motor requirements were selected in order to avoid disadvantaging patients with reduced hand function, as expected in tetraplegia. As far as possible, the tests had established use in SCI and local research. Where necessary, appropriate evidence-based minor adaptations were made to reduce motor requirements and enhance cultural sensitivity; these are detailed in the description of the relevant tools below. Two subjective measures were included to enrich the descriptive data and enable consideration of participants' insight into their objectively measured cognitive function. The motor free requirements, and need for testing of specific domains of particular relevance to the rehabilitation program (e.g., prospective memory) meant that it was not possible to select a pre-normed assessment battery, which may have enabled more robust data interpretation in the absence of a control group.. The following tools made up the cognitive assessment battery.

Wechsler Abbreviated Scale of Intelligence (first edition) (WASI) –Vocabulary, Matrix Reasoning and Similarities Subtests. The WASI (Wechsler, 1999) is a general intelligence measure that is suitable for clinical and research use and is designed for ages 6-90 years. It has been used in research with patients with SCI (Chiaravalloti et al., 2018; Jegede et al., 2010), and in South African research with both English and Afrikaans adolescents of low SES (Ferrett et al., 2010). The Vocabulary subtest (targeting verbal comprehension and crystalised intelligence) and Matrix reasoning subtest (targeting the executive function of visual conceptual reasoning) can be interpreted separately, or together as the Full-Scale Intelligence Quotient 2 (FISQ-2), which provides an estimate of cognitive intelligence. The Similarities subtest was chosen for its potential to measure the executive function of abstract reasoning. An Afrikaans translation of these tests was available for use, where for the Vocabulary and Similarities subtests, minor linguistic changes as developed by Ferrett (2011) were used to enhance cultural sensitivity and allow consistency between the English and Afrikaans versions of the tool. Examples include replacing *alligator* with *crocodile/krokodil* in the Vocabulary subtest and reversing the presentation of Similarities item 12 (changed to *plate-bowl / bord-bakkie* instead of *bakkie-bord / bowl-plate*) in order to reduce ambiguity with the Afrikaans word 'bakkie', which can also mean truck. The first edition WASI was selected rather than later versions, in order to make use of Ferrett's (2011)

adaptations and translations. Aside from the adaptations detailed above, tests administration was conducted according to the test manual.

Wechsler Adult Intelligence Scale – Third Edition (WAIS III): Forwards and Backwards Digit Span and Symbol Search Subtests. The WAIS III (Wechsler, 1997) is designed for use with ages 6-90 years. The earlier third edition of this test, rather than the WAIS IV, was selected in order to utilize an Afrikaans translation that was available in the UCT Psychology department. The Forwards and Backwards Digit Span subtests require the patient to repeat sequences of numbers of increasing length either as read by the examiner (forward), or in reverse order (backwards). The subtests can either be reported as a combined value for both tests, or separate scores for the longest forward and backward span, reflecting performance in attention and working memory respectively. Administration of the digit span subtests was conducted according to the test manual, where both summary and separate scores were reported. The Symbol Search subtest assesses processing speed and requires patients to scan through a symbol set as quickly as possible in order to identify whether a target is present. In order to avoid disadvantaging patients with reduced dexterity, the Symbol Search was administered verbally, rather than the standard administration that requires participants to tick a yes/no box. These subtests have been used with the SCI population (Jegede et al., 2010) as well as in South African research in multiple languages with low SES adult populations (Gouse et al., 2013; Hoare et al., 2012). All of the WAIS III subtests have undergone extensive testing to demonstrate strong internal consistency, reliability and construct validity (Wechsler, 1997).

Auditory Verbal Learning Test – World Health Organisation - University of California, Los Angeles Version (AVLT WHO-UCLA version). The WHO-UCLA version of the AVLT is suitable for ages 16 and above and is a list learning task that assesses verbal learning and memory (Maj et al., 1993). A list of 15 words is read out to a participant over five learning trials, where the number of words recalled after each trial is recorded. After the fifth trial, a different word list is presented (distractor task), whereafter the participant is required to recollect the initial target words immediately, and again after a 20 minute delay. Thereafter a recognition task is verbally administered, wherein participants are presented a new list of 30 words (including the original 15 words and 15 new words) and are required to identify the target words. The measure can be used to generate a number of different scores, and in the current study, scores of the total number of words in each of trial 5, immediate recall, delayed recall and recognition were used., The WHO-UCLA AVLT uses a word list that has been adapted to enhance validity in culturally diverse settings, with proven reliability

and validity in a wide variety of cultural and clinical settings (Maj et al., 1993). Similar list learning tasks have been used in SCI research (Gontkovsky, 2012), while the WHO-UCLA AVLT version that was used in the current study, including Afrikaans translation and minor semantic modifications, has been used in South African research with English and Afrikaans adolescents in both advantaged and disadvataged educational settings (Ferrett, et al., 2014). Test administration was conducted with the same procedures and instructions used by Ferrett (2011), as described in Strauss et al. (2006). Ferrett's (2011) Afrikaans translation of the tool was available for use in the current study.

The Delis-Kaplan Executive Functioning System (D-KEFS) Colour -Word Interference Subtests. The D-KEFS is an executive function battery that has been developed for use for ages 8-89 (Delis et al., 2004). This subtest is administered verbally and features a list of colour names printed in a discordantant ink colour, where the participant is required to inhibit their automatic verbal response by naming the ink colour, rather than reading the colour name (assessing the executive function of inhibition). In a subsequent task with a new stimulus, participants are required to follow a rule that determines whether they should name the ink colour or read the colour name (assessingcognitive flexibility). Participants are scored in terms of number errors and time taken to complete the task. The test manual details evidence for high reliability and both convergent and discriminant validity (Delis et al., 2004). It has been used in patients with SCI (Chiaravalloti et al., 2018) and with children in a low SES South African setting (Mattson et al., 2010). A similar colour-word intereference task (Stroop colour-word test) has been used in research with local adults of low SES (Hoare, 2012). Administration was conducted according to the test manual. An Afrikaans translation of the D-KEFS Colour-Word subtest was commissioned for the purposes of this study.

The Controlled Oral Word Association Test (COWAT). The COWAT is a verbal fluency task assessing both semantic and phonemic fluency (Strauss et al., 2006) and is suitable for ages 7-95. It targets the executive function of generativity by requiring participants to provide as many examples of words in a given category as they are able to in one minute, wherethe raw score is the number of correct responses generated for each category. The semantic category of Animals was used as per Strauss et al. (2006), while the phonemic categories used (B, L, S) have been validated in the South African setting for English and Afrikaans, in a study with adolescents of both advantaged and disadvantaged education (Ferrett et al., 2014). Similar verbal fluency tasks have established use in SCI research (Chiaravalloti et al., 2018). The test was administered according to the instructions

and procedures detailed in Strauss et al.(2006), which is the same form used by Ferrett (2011) and Ferrett et al. (2014). Once again Ferrett's (2011) Afrikaans translation was used.

The Royal Prince Alfred Prospective Memory Test (RPA-ProMem) Form 2: Test Items 1 and 2. The RPA-ProMem measures prospective memory performance through time- and event-based tasks (Radford et al., 2011). The full test includes two shorter term and two long term prospective memory tasks, where the long-term tasks require a response from the participant in the hours and days after the assessment session (completed by telephone voice message and standard post respectively). Only the first two (short term) tasks were used, as practical to administer in the single data collection session. Form 2 of the test was selected, as the short-term prospective memory items in this version are motor free, requiring only verbal responses from the participant. The measure has established reliability and validity (Rabin et al., 2014; Radford et al., 2011) and has been used in neurological rehabilitation research (Radford et al., 2012). Similar time- and event-based tasks have been used to assess prospective memory with adults in the South African public health setting (Hoare et al., 2012). Administration was conducted according to Radford et al. (2011). An Afrikaans translation of this tool was commissioned for the purposes of this study.

The World Health Organisation Disability Assessment Schedule 2.0 (WHODAS 2.0) – Domain 1: Cognition. Domain 1 of the WHODAS 2.0 captures a participant's subjective evaluation of their difficulty within six aspects of 'understanding and communicating', through a Likert scale-rated questionnaire (Üstün et al, 2010). The WHODAS 2.0 has established cross cultural validity and reliability (Üstün et al, 2010) and has been used with adults in low SES settings in South Africa in multiple language translations (Baron et al., 2017) as well as with SCI populations (De Wolf et al., 2012). Administration was conducted according to the test manual. An Afrikaans translation of this tool was commissioned for the purposes of this study.

Prospective-Retrospective Memory Questionnaire (PRMQ). The PRMQ is another Likert scale instrument assessing participants' subjective experience of cognitive function and targets both prospective and retrospective memory (Smith et al., 2000). It has been used in South African research with adults from a low SES setting (Hoare et al., 2012) and has widely established reliability and validity in a variety of clinical settings (e.g., Gondo et al., 2010; Mefoh et al., 2017; Smith et al., 2000). Administration was conducted according to Smith et al. (2000). An Afrikaans translation of this tool was commissioned for the purposes of this study.

Supplementary Screening Instruments. The supplementary screening instruments were chosen to screen for presence of common SCI comorbidities with established links to cognitive dysfunction. A specialized SCI functional ability screening tool was also administered in order to enrich the description of the sample. All of the instruments selected could be interviewer- or self-administered; however, in order to enhance consistency as well as accommodate participants with reduced writing ability and/or literacy, all measures were administered verbally, while the participant was allowed to read the questions along with the examiner if desired. As far as possible, instruments with established use in neurological rehabilitation and South African research were chosen.

Pittsburgh Sleep Quality Index (PSQI). This questionnaire measures subjectively experienced sleep quality and disturbance over a one-month period on a 21-point scale, with scores above five indicating poor sleep (Buysse et al., 1988). Suitable for use with an adult population, the PSQI has high internal consistency and shows good sensitivity and specificity when compared to laboratory measures, indicating good construct validity (Buysse et al., 1988; Carpenter & Andrykowski, 1998). It has been used in SCI studies (Thøfner et al., 2018) and in low SES urban South African settings with adults (Lipinska & Thomas, 2017). The sleep efficiency component score was excluded from participants' final score calculation, as this is based upon time of going to bed, rather than time of falling asleep. In the inpatient SCI setting, where patients may require assistance to get into bed, bed time is frequently determined by nursing availability, rather than patients' desire to sleep, thus this score was excluded as it may not be a valid representation of sleep efficiency in this clinical sample. An Afrikaans translation of the PSQI was obtained through the Mapi Research Trust.

Hospital Anxiety and Depression Scale (HADS). The HADS is a mood disorder screening questionnaire for ages 18 and above that is designed for use in both hospital and community medical settings (Snaith, 2003). Participants are required to answer 14 multiple choice questions (half screening for depression, half anxiety), where responses are weighted on a Likert scale, which generates a separate score out of 21 for each of anxiety and depression. A score of 7 or below is considered to be within normal range, while a score of 8 and above is suggestive of a state of anxiety or depression, with higher scores indicating greater certainty (Snaith, 2003). Despite the culturally complex construct of mood, acceptable sensitivity and specificity has been demonstrated in a number of studies in Sub Saharan Africa (Sweetland et al., 2014). It has been used with adults in the South African public health context (Wouters et al., 2012) and has demonstrated reliability and validity in SCI research (Sakakibara et al., 2009). An Afrikaans translation of the HADS was obtained

through the Mapi Research Trust following purchase of the English version of the tool from GL Assessments.

***Brief Pain Inventory (BPI*).** The BPI is a questionnaire and rating scale that screens for pain presence, severity and functional interference over the preceding 24-hours in individuals aged 18-64 (Cleeland, 2009). In order to maintain validity for wheelchair users in a medium-term inpatient setting, item 9C, rating interference in 'walking ability', was replaced with 'ability to get around' (as per Bryce et al., 2007) and item 9D: interference with 'Normal Work', was discarded (as per Atkinson et al., 2011). The tool has been validated in a wide variety of international contexts (Atkinson et al., 2011; Cleeland, 2009), has been used with adults in multilingual South African public health studies (Parker et al., 2016) and is valid and reliable for use with SCI patients (Raichle et al., 2006). An Afrikaans translation of the BPI was obtained through the UCT Physiotherapy Department.

The Primary Care Post-Traumatic Stress Disorder Screen for DSM-5 (PC-PTSD5). The PC-PTSD5 comprises an opening question screening for experience of a traumatic event, with the subsequent five yes/no questions administered to screen for PTSD, in participants who confirm past experience of trauma through the opening question (Prins et al., 2015). It has proven reliability and validity in research and clinical settings (Prins et al., 2015) and has been used in South African public health (Pingo & Seedat, 2009) as well as international SCI research settings (Warren et al., 2016). An Afrikaans translation of this tool was commissioned for the purposes of this study.

The Alcohol Smoking and Substance Involvement Screening Test Version 3.1 (ASSIST V3.1). The ASSIST V3.1 is suitable for ages 18-60 and screens for substance use, enabling classification into three levels of risk (Humeniuk et al., 2010). Further testing has validated the tool for use in the geriatric population (Khan et al., 2012), although, at 59 years, the oldest study participant still fitted within the tool's originally prescribed age range. Reliability and validity have been established through extensive testing across international settings (Humeniuk et al., 2010). The tool has been used in South African clinical research with an urban adult population (Sorsdahl et al., 2012) as well as international SCI research (Clark et al., 2017). An Afrikaans version of this tool was available from the UCT Psychology Department.

The Spinal Cord Independence Measure 3rd Edition (SCIM). The SCIM is a SCI specific functional outcome measure that measures functional ability in self-care, respiration and sphincter management and mobility, generating an overall ability rating on a scale of total dependence (score of 0) to total independence (score of 100) (Catz et al., 1997). It has

well-established reliability and validity (Catz et al., 1997) and has been recommended for use in South African SCI rehabilitation settings (Joseph et al., 2016). An Afrikaans translation of this tool was obtained through the University of the Western Cape Physiotherapy Department.

Scoring and Data Analysis

Data analysis was undertaken using SPSS version 27.0, where the first stage involved generation of comprehensive descriptive statistics, including measures of central tendency (mean) and variance (range, standard deviation) for demographic variables (including etiological, medical and sociodemographic characteristics), psychosocial and physiological comorbidities (as captured by the screening instruments), and the SCIM. This enabled characterisation of the sample, in line with the exploratory descriptive study aims.

Aim One

Cognitive Measures

Deriving z-scores: International Norms. In pursuit of objective one, scaled scores were derived from neuropsychological raw score results using the conversion tables in the respective test manuals for the following tests: WAIS III Symbol Search, WASI Vocab, Matrix reasoning and Similarities, D-KEFS Inhibition (total time and total errors) and D-KEFS Inhibition/Switching (total time and total errors). The manualised norms for all three of these tests use a large demographically representative sample of the USA population (Delis et al, 2004; Wechsler, 1997; Wechsler, 1997), where for the current study, participants' scores were calculated in relation to the relevant age category. In order for all tests to be comparable on the same metric, these scaled scores were converted to z-scores (mean 0, standard deviation 1). For WAIS III digit span forwards and backwards, z-scores were calculated using the raw score norm tables in the manual, as the manualized scaled score conversion charts are only available for total digit span.

For the AVLT delayed recall trial and COWAT Semantic Fluency (Animals category only), z-scores were calculated using the international normative data tables available in Strauss et al. (2006) and Mitrushina et al., (2005). Z-score calculation and further analysis was not undertaken for the phonemic fluency category, as appropriate normative data was not available for the letters used (these letters were initially selected as validated in the local setting for English and Afrikaans, as described in *Materials*). Z-scores were calculated for the

PRMQ using norms from Crawford et al. (2003). *Table 2* shows the demographic details of the normative samples used for the AVLT, COWAT and PRMQ z-score calculations.

Table 2

Demographic Data for International Norm Studies

Test	*N*	Country	Sex (female:male)	Age in years; M(SD)	Education in years; M(SD)	Ax Language
AVLT[a]	300	USA	180 : 120	38	10.7	Spanish
COWAT[b] (Animals)	735	Canada	310 : 425	67 (19.8)	12.1 (3.2)	English
PRMQ[c]	551	UK	344 : 207	63 (15.59)	13.22 (3.38)	English

NOTES:
M = Mean; SD = Standard Deviation; Ax = Assessment; AVLT = Auditory Verbal Learning Test WHO-UCL version; COWAT = Controlled Oral Word Association Test, Semantic fluency – Animals category; PRMQ = Prospective Retrospective Memory Questionnaire

a. Pontón et al. (1996) - norms stratified by gender, age and education (categories)
b. Tombaugh et al. (1999) – norms stratified by age and education (categories)
c. Crawford et al. (2003) - unstratified norms

Deriving z-scores: Local Norms. In pursuit of objective two, the raw scores were again used to calculate a new set of z-scores, this time using norms generated in South Africa, rather than internationally derived norms. For the AVLT and WASI Similarities and Matrix reasoning tasks, the norms tables from Ferret et al. (2014) and Ferrett (2011) were used respectively. Both of these studies used the same participant group as English or Afrikaans speakers recruited from public schools in the greater Cape Town area. Participants with less than 4 years of schooling, home language other than English or Afrikaans, history of repeating more than one grade, diagnosis of learning disability, central nervous system disorder, psychiatric disorder, head injury with loss of consciousness of more than ten minutes, signs or history of Foetal Alcohol Syndrome or any abnormalities picked up via relevant clinical investigations were excluded.

Ferret et al.'s (2014) AVLT norms are stratified by quality of education (advantaged vs disadvantaged), however as this data was not collected for participants in the present study, the norms based on individuals from disadvantaged educational backgrounds were used for all participants. These were chosen over the advantaged education norms, as the majority of patients served by WCRC are from socially disadvantaged backgrounds (WCRC, 2020), as explored further in relation to the demographic profile presented in *Results* and

interpreted in *Discussion*. The Matrix reasoning and Similarities norms (Ferrett, 2011) are stratified by language, race and quality of education, however again, aside from language, these data were not collected for the current sample. In the absence of data on race, the mixed-race category was used for all participants and again the norms based on disadvantaged education for each language (English or Afrikaans test administration) were used for z-score calculations for these tests. The potential interpretive implications of the categories chosen are explored further in the *Discussion*.

For WAIS Digit Span and Symbol Search and COWAT Animals, local regression-based norms were used to calculate the z-scores (Gouse et al., 2018; Gouse et al., 2021). Where available, regression-based norms produce more statistically robust results than the discrete categories used in traditional norms tables, or a control-derived approach (Gouse et al., 2021). An Excel calculation sheet developed by the authors to automatise the regression models (Gouse et al., 2021) was used for the final calculations. Gouse et al. (2021) only provide regression equations for a combined Digit Span score; therefore, it was only possible to calculate a z-score for this variable, rather than separate Forward and Backward Digit Span scores, as per the international norms.

The control group members for Gouse et al.'s (2021) study were recruited from peri urban primary health clinics in the Cape Metropole. Inclusion criteria were an age of 18 years or older, English- or isiXhosa-speaking and able to consent for neuropsychological assessment. Potential participants were excluded if they had a history of coma or previous head injury (with loss of consciousness of more than 30 minutes or requiring hospitalisation), history of psychiatric disorder, positive screen for significant depressive symptoms, alcohol use disorder or positive urine toxicology screen for cannabis and diagnosis of diabetes mellitus or a central nervous system disorder. In addition to sex and age, the regression calculations required specification of number of years of education. However, unfortunately, the demographics questionnaire used in the present study recorded educational level categorically (see Appendix D). Thus, for these calculations, a value of ten years was chosen for regression calculations for all participants in category four (incomplete high school – 18 participants) as the middle year of the high school grades eight to twelve. For the single participant with incomplete primary school education, actual years of schooling (5 years) was incidentally recorded on the assessment form in addition to the incomplete primary school education category, thus a value of 5 years was used for this participant.

The demographic particulars for the respective studies used for local normative purposes are presented in *Table 3* below:

Table 3

Demographic Data for Local Normative Studies

Norm Group	*N*	Sex (female:male)	Age in years; M(SD)	Education in years; M(SD)	Mother Tongue
Gouse et al. (2021)[a]	114	58(51%) : 56(49%)	35.44 (11.95)	10.54 (1.43)	Xho: 112 Zul: 1 Sot: 1
Ferrett (2011)[b]	286	154(53.8%) : 132(46.2%)	13.82 (1.21)	6.83 (1.31)	Afr: 44.1% Eng: 55.9%
Ferret et al. (2014)[c]	215	54.4% : 45.6%	13.91 (1.23)	6.96 (1.27)	Afr: 43.3% Eng: 56.7%

NOTES:
N= number of participants in study; M = Mean; SD = Standard Deviation; Xho = isiXhosa, Zul= isiZulu, Sot = seSotho, Eng = English, Afr = Afrikaans

a. WAIS III Digit Span and Symbol Search and COWAT Regression-based norms with regression equation capturing age, education and sex
b. WASI Matrix Reasoning and Similarities norms stratified by language, education quality and race
c. MAVLT norms stratified by quality of education

Descriptive Statistics for Cognitive Measures. Descriptive statistics, including measures of variance (standard deviation, range) and central tendency (mean) were calculated for both sets of normative data. Following this, the frequency and percentage of participants scoring one or more standard deviations below the mean for each test was determined for both the local and internationally normed data set.

For the objective prospective memory measure (RPA ProMem form 2) and subjective cognitive measure (WHODAS 2.0, domain 1), normative data were not available. For both of these measures the descriptive statistics were generated based on the raw score values.

Further Analyses for Cognitive Measures. Investigation of the relevant statistical assumptions revealed that non parametric statistical tests were indicated for correlational analyses and paired difference tests. The Kendall's Tau-b correlational analysis was selected as the most appropriate non parametric test for small sample bivariate correlational analyses (Field, 2009). The analyses were completed using the internationally derived z-scores, except in the case of the RPA ProMem and WHODAS 2.0 results, where raw scores were used in the absence of z-scores.

A comparison of performance between the two items of the RPA ProMem (success in carrying out a time-based versus an event-based task) was conducted through a Wilcoxon signed rank test.

Comorbidity Screening Tools

Descriptive Statistics. In pursuit of objective three, descriptive statistics for the various comorbidity screening tools were calculated in the same manner as for the cognitive tests, based on the screening measure raw scores.

Correlations. The cognitive test scores and comorbidity scores for selected measures were run as described above.

Aim Two

Areas of relative cognitive strength and weakness for both international and local norms were tabulated against the SCI rehabilitation program key cognitive domains identified through the activity analysis process (described under *Procedure*).

Ethical considerations

Permissions

Ethical approval was obtained through the UCT Department of Psychology Research Ethics Committee (reference number PSY2019-021, Appendix E), as well as the UCT Faculty of Health Sciences Human Research Ethics Committee (reference number 360/2019, Appendix F). Permission to conduct research in a public hospital setting was obtained through the Western Cape Department of Health (project number WC_201908_022, Appendix G).

Informed Consent and Confidentiality

The study protocol, including purpose, procedure and potential risks and benefits was explained to each participant in their preferred language of English or Afrikaans. Aside from the summary document provided to the social worker, as required by WCRC, all data collection materials were treated with strict confidentiality. As described in *Materials*, capacity to provide informed consent was determined through the use of the UBACC (Jeste et al., 2007), together with the iterative process described by Campbell et al., (2017). Written informed consent with participant signature was obtained, however for those participants with

insufficient hand function to sign, a fingerprint was taken. While provision was made in the study protocol for procedures in the case of an illiterate participant, these were not required.

Data Storage

The data was captured in a de-identified electronic database, with numerical descriptors used in the place of names and nil potentially identifying data recorded. The computer used for this purpose was password protected and not network linked. The code for the numerical descriptors was stored on a hard drive kept separately from the computer. Paper copies of the results for both groups were stored under lock and key in the UCT Psychology Department and will be destroyed after five years.

Potential Risks

Vulnerable groups. As individuals with SCI, the research participants represent a potentially vulnerable group of persons with disabilities. All data collection and recruitment was undertaken by the researcher, whose experience as an occupational therapist and specialized SCI care-worker, including two years of employment at WCRC, meant that she was well placed to interact sensitively with participants in cognizance of their potential vulnerability.

Debriefing and referrals. Each patient at WCRC has access to a social worker and psychologist who were able to further investigate, treat or make onwards referrals for any symptoms of mood disorder, substance abuse or PTSD, which may have been uncovered by the comorbidity screening tools. The assessment process had the potential to make participants newly aware of cognitive deficits, which may be a distressing experience. This risk of increased psychological stress was mitigated through timely feedback to the participants' MDT through their social worker, who was best placed to support them and enhance their potential to derive benefit from this increased insight. In addition, debriefing was offered at the completion of each data collection session, with time allowed for patients to ask questions if required.

Managing physical discomfort. In order to minimize fatigue in the testing process, the patient's MDT was informed of the assessment date well in advance, allowing coordination with therapy bookings, which ensured that participants had sufficient rest before and after sessions. In addition, participants were given a 10- to 20-minute break during the assessment session, with light refreshment provided, and were able to ask for additional rest breaks if required, although no participants requested this.

Financial burden. The participants did not incur any financial burden as a result of participation.

Potential Benefits

The current staffing levels at WCRC (1 psychologist for 160 inpatients) means that it is logistically impossible for the level of cognitive screening used in the study to be carried out in the course of treatment as usual. Thus, the very guarded summary of test results provided to the patient's therapy team had the potential to benefit them, through prompting further investigation of potential cognitive or comorbid issues and incorporation into rehabilitation planning. Many participating patients spontaneously reported that they enjoyed the experience of participating, as a stimulating change in the normal rehabilitation centre routine.

A general feedback presentation session for staff of WCRC is planned, with opportunity for further discussion on potential applications of the research results within their setting.

Results

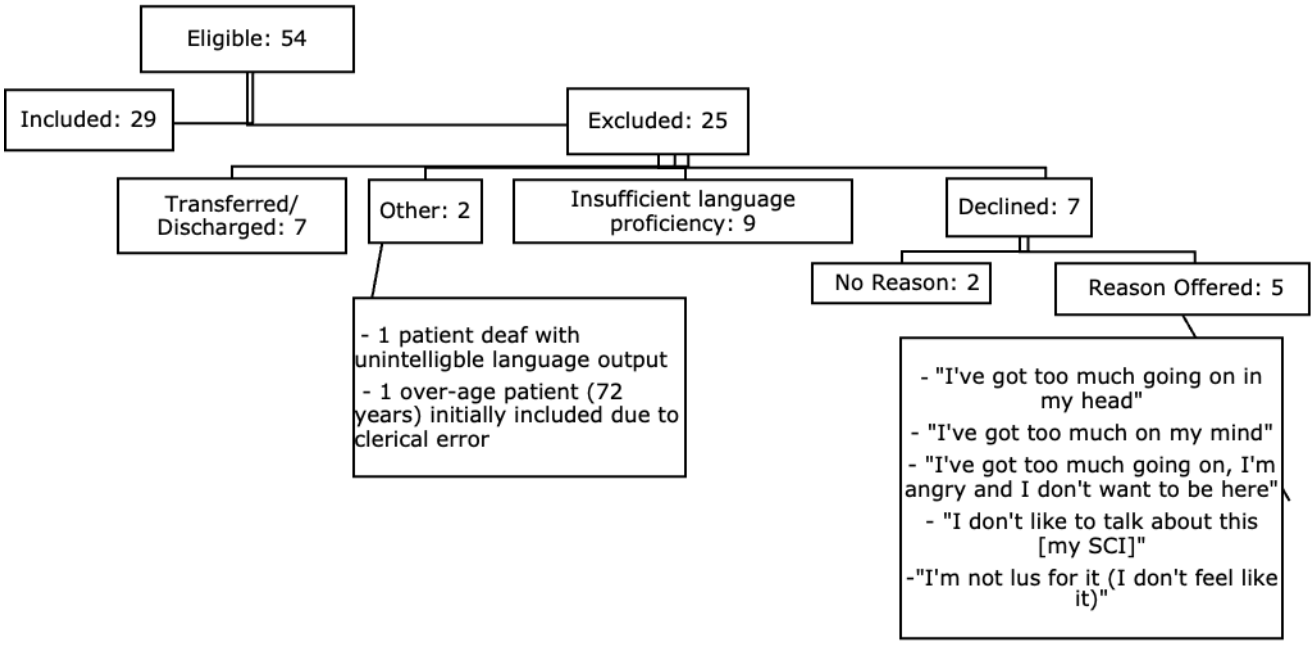
Participant Characteristics

Participant Recruitment and Sample Size

Through the recruitment process described in the previous chapter, 54 potentially eligible participants were identified in the specified data collection period. *Figure 1*. depicts the flow of these potential participants, where 25 were excluded as follows: seven patients were transferred to a different hospital or discharged before they could be invited; one patient was deaf, with unintelligible speech, thus the informed consent process could not be completed; one patient consented and was initially included due to a clerical error, but was later found to be over age; nine patients were excluded as having insufficient proficiency in English or Afrikaans, finally seven participants declined to participate after receiving an explanation of the research. Reasons offered (not solicited) for the decision to decline are also captured in *Figure 1*. Of the potential participants excluded, five (20%) were female and 20 (80%) were male. The final sample size was 29 inpatient participants.

Figure 1

Participant Flow



Demographic Characteristics of Participants

As captured in *Table 4*, the majority of the sample was male with a mean age of 33 years. Almost three quarters (21/29; 72%) were assessed in English rather than Afrikaans. While participants' mother-tongue languages included English, Afrikaans, isiXhosa and Sesotho, all had sufficient English or Afrikaans proficiency for the testing procedures, as per criteria defined in the *Method* section.

Table 4

Sample Demographic Characteristics (N = 29)

Variable	Mean (SD)	Range	Frequency	Percentage
Age (years) M (range; SD)	33.45 (11.51)	18-57		
Sex				
Male : Female			25 : 4	86% : 14%
Home Language				
English or fully Bilingual			8	28%
Afrikaans			8	28%
IsiXhosa			12	41%
Sesotho			1	3.5%
Assessment Language				
Afrikaans			8	28%
English			21	72%

NOTES:
M = Mean; SD = Standard Deviation

Sociodemographic Characteristics of Participants.

As per *Table 5*, years of education, annual household income and pre-SCI employment were captured categorically while an asset index of 17 items provided nominal socioeconomic data. Most participants (16/29; 55%) had an annual household income of R25 000 – R100 000. All participants had some formal schooling, where the majority of participants (18/29; 62%) had an incomplete high school education. More than three quarters (22/29; 77%) of participants were in some form of paid employment immediately before their admission, with the majority in either skilled, semi-skilled, or unskilled manual labour. The mean asset index score of the sample fell within 'medium' range at approximately 11, with the majority (25/29; 87%) falling in either the medium or high range.

Table 5

Sample Characteristics: Measures of Socioeconomic Status (N = 29)

Variable	Frequency	Percentage
Annual Household Income		
R 0 – R5000	0	0%
R 5001 – R 25 000	7	24%
R 25 000 – R 100 000	16	55%
R 100 001+	6	21%
Education		
0 years (nil formal education)		
1 – 6 years (less than primary education)	1	3.5%
7 years (primary education)	1	3.5%
8 – 11 years (some secondary education)	18	62%
12 years (secondary education)	6	21%
13 + years (tertiary education)	3	10%
Pre SCI Employment (Hollingstead categories)		
1: Higher executives/major professionals	0	0%
2: Medium sized business managers /lesser professionals	0	0%
3: Admin personnel/managers/minor professionals/small business owners	0	0%
4: Clerical/sales/small business	1	3%
5: Skilled manual (usually with training)	8	28%
6: Semi-skilled	8	28%
7: Unskilled	6	21%
8: Homemaker	1	3%
9: Student / unemployed	5	17%
Asset Index		
Category (low : medium : high)	4 : 13 : 12	14% : 45% : 42%

Medical History and Physical SCI-Related Characteristics

Table 6 shows that the mean days since SCI was 93.29 for the full sample. Of note here is that the mean time since injury for the NTSCI patients was markedly higher at 147 days as compared to 79.26 days for the TSCI group. On average, participants had spent almost a month in the rehabilitation setting before their assessment, where their mean SCIM score, indicating functional performance level, was just under 50/100, where 0 indicates complete functional dependence and 100 complete independence across the combined domains of *self-care, respiration and sphincter management* and *mobility*.

The majority of SCIs (23/29; 79%) were traumatic in origin. Nearly two thirds (18/29; 62%) of these TSCIs in the full sample were caused by assault (with most of these being through gunshot or stab wounds), followed by MVAs and then falls. More than two thirds (21/29; 72%) of all injuries resulted in varying degrees of paraplegia and just over half (15/29; 52%) of all injuries were classified as complete (AIS A).

Three participants out of the total sample (N=29) self-reported that they had a premorbid history of head injury with loss of consciousness, however, there was no medical confirmation thereof. Two participants had a diagnosis of TBI concomitant to their SCI recorded in their medical file. Five additional patients reported symptoms indicative of a possible concomitant TBI, although this was not recorded in their medical file (i.e., loss of consciousness [LoC] and/or a period of post traumatic amnesia [PTA] with or without known blow to the head at time of SCI). Of these possible unconfirmed TBI cases (n=5), three participants reported known head injury and LoC or PTA, and a further two reported LoC or PTA at time of SCI, but uncertainty about whether they sustained a blow to the head. Approximately 20% (6/29) of the sample was diagnosed HIV positive and on antiretroviral treatment, with the prevalence of HIV much higher in the NTSCI group (3/6; 50%) as compared to just over 10% (3/23) of the TSCI group.

Table 6

SCI Aetiology and Characteristics, Medical Information and Functional Status (N = 29)

Variable	Mean (SD)	Range	Frequency	Percentage[a]
Time since SCI (days)	93.28 (44.82)	32-236		
Time in rehabilitation setting (days)	28.41 (8.78)	13-50		
SCIM score[b]	49.03 (18.18)	14 – 81		
SCI cause				
TSCI : NTSCI			23 : 6	79% : 21%
TSCI – Assault			18	62%
(gunshot : stab : general assault)			(9 : 8 : 1)	(31% : 28% : 3%)
TSCI – MVA			3	10%
TSCI – Fall			2	7%
NTSCI – TB Spine			5	17%
NTSCI – Vascular			1	3%
SCI classification				
AIS; A : B : C : D			15 : 1 : 3 : 10	52% : 3% : 10% : 35%
Tetraplegia			8	28%
(complete : incomplete)			(4 : 4)	(14% : 14%)
Paraplegia			21	72%
(complete : incomplete)			(11 : 10)	(38% : 34%)
Medical pre and co- morbidities				
Premorbid history of HI with LoC			3	10%
TBI – diagnosed concomitant SCI			2	7%
TBI – possible concomitant SCI[c]			5	17%
HIV -ve : HIV+ : unknown			22 : 6 : 1	76% : 21% : 3%
HIV+ (TSCI : NTSCI)			(3 : 3)	
Hypertension, Diabetes			5, 1	17%, 3%

NOTES:
SD = Standard deviation; SCIM = Spinal Cord Independence Measure Third Edition; TSCI = Traumatic spinal cord injury; NTSCI = non traumatic spinal cord injury; MVA = Motor vehicle accident; AIS = American Spinal Injury Association Impairment Scale; HI = Head Injury (without confirmed TBI); LoC = loss of consciousness; TBI = Traumatic brain injury; HIV -ve = HIV negative; HIV+ = confirmed HIV positive; unknown = HIV status unknown

a. Percentage of total sample
b. Total score out of 100 across domains of *self-care*, *respiration and sphincter management* and *mobility*, where 0 = complete functional dependence and 100 = complete independence
c. Possible concomitant TBI includes verbal report of LoC or PTA at time of SCI either with or without known blow to head but nil diagnosis of concomitant TBI in medical file

Aim One, Objective One: Cognitive Function in Relation to International Norms

Cognitive Domain Subtest Results

Table 7 shows the descriptive statistics for the cognitive tests scored using the international normative data as described in *Method*. For all objective measures, the mean subtest scores were at least one full standard deviation below the international mean. However, the large range in scores, where a few higher scores may skew the results, means that it is useful to consider the percentage of the sample with scores falling one or more standard deviations below the mean, as an additional indicator of the severity and extent of cognitive dysfunction in the sample relative to international normative data. With the exception of working memory, all of the tests saw well over half of the sample performing at least one standard deviation or more below the international mean. Performance in the abstract reasoning task (Similarities) was particularly poor, with 97% of the sample scoring at least one standard deviation below the international mean. While the participants' subjective rating of their retrospective and prospective memory was below the international mean, it remained within one standard deviation.

In sum, the results suggest that the overall cognitive performance of the participant group is well below international levels across all domains. Further consideration of these results in relation to local trends is required in order to comment on the variation between domain scores.

Table 7

Cognitive Battery: Z-scores Derived from International Norms (N = 29)

Domain & Subtest	Mean	Range	SD	% *N* >1 SD below int M	% *N* >2SD below int M
Attention / Concentration					
Digit span fwd[a]	-1.34	-3 – 0	0.74	69%	31%
Processing speed					
Symbol Search[a]	-1.34	-2.33 – 0	0.68	79%	28%
Audio verbal learning and memory					
Trial 5[b]	-1.07	-4.27 – 1.08	1.42	55%	38%
Immediate Recall[b]	-1.34	-3.59 – 0.84	1.21	66%	38%
Delayed Recall[b]	-1.58	-3.85 – 0.67	1.24	76%	52%
Subjective Memory					
Prospective: PRMQ ProMem[c]	-0.61	-2.48 – 2.81	1.31	11%	4%
Executive Functions					
Working memory: Digit span bwd[a]	-1.01	-2.33 – 0.66	0.66	48%	10%
Visual conceptual reasoning:					
Matrix reasoning[d]	-1.26	-3 – 0.67	1.20	62%	28%
Abstract reasoning: Similarities[d]	-1.80	-3 – -0.33	0.77	97%	48%
Inhibition:					
Inhibition – time[e]	-1.62	-3 – 0.67	1.08	72%	52%
Inhibition errors[e]	-1.59	-3 – 0.33	0.96	79%	34%
Cognitive flexibility:					
Switching – time[e]	-1.37	-3 – 0.33	1.24	55%	31%
Switching errors[e]	-1.26	-3 – 0.67	1.20	62%	38%
Generativity: Animals[f]	-1.60	-3 – 0.33	0.91	69%	31%

NOTES:
int = international; M = Mean; SD = Standard Deviation; fwd = forward; bwd = backwards; switching = inhibition/switching subtest

a. Wechsler Adult Intelligence Scale edition 3 (WAIS III)
b. Auditory – Verbal Learning Test WHO-UCL version (AVLT)
c. Prospective Retrospective Memory Questionnaire (PMRQ) – prospective memory score
d. Wechsler Abbreviated Scale of Intelligence (WASI)
e. Delis-Kaplan Executive Function Scale (D-KEFS)
f. Controlled Oral Word Association Test (COWAT), Semantic fluency (Animals category)

General Intellectual Function Measures

Internationally normed measures of general intellectual functioning are given in *Table 8*. While performance across the tests was again significantly poorer than the international norm, the verbally loaded WASI *Vocabulary* and *Similarities* tasks yielded the worst results with well over 80% of the sample at least one standard deviation below the normative mean.

Table 8

General Intellectual Function (International norms) (N=29)

WASI Subtest	Mean	Range	SD	% *N* >1 SD below int M	% *N* >2SD below int M
Vocabulary	-1.75	-3 – 0.33	0.85	86%	45%
Matrix Reasoning	-1.26	-3 – 0.67	1.20	62%	28%
Similarities	-1.80	-3 – -0.33	0.77	97%	48%
FISQ-II	77	55 – 102	13.33	76%	28%

NOTES:
All scores are z-scores (M =0, SD = 1), except for the FISQ-II which is an IQ Score (M = 100, SD = 15)
WASI = Wechsler Abbreviated Scale of Intelligence; SD = Standard Deviation; int M = International Mean; FISQ-II = WASI Full Scale IQ 2 Sub tests

Aim One, Objective Two: Cognitive Function in Relation to Available Local Norms

Cognitive Domain Subtest Results

Descriptive statistics for the cognitive tests for which local norms are available are grouped according to cognitive domain and presented in *Table 9*. The mean scores of the current sample were within one standard deviation of the respective normative means for all subtests, although the mean AVLT immediate and delayed recall subtests (measuring verbal learning and memory) approach one standard deviation below the mean and fall within Low Average range (Guilmette et al., 2020). For these two AVLT subtests, almost half of the SCI group scored one standard deviation or more below Ferret et al.'s (2014) normative mean. While the sample mean easily fell within one standard deviation for both the visual conceptual reasoning and generativity tasks, it is worth noting that the large range of scores means that approximately one third of the sample scored one standard deviation or more below the normative mean in these subtests, and that the visual conceptual reasoning group mean score still falls within low average range (Guilmette et al., 2020).

In sum the locally normed results suggest markedly better overall performance of the SCI population in comparison to internationally normed scores. Mean performance in the

audio verbal learning and memory and conceptual visual reasoning tasks seem to be relatively lower than performance in the other domains, however further interpretation of these scores is required. The was generally a broader range in scores in the locally as compared to internationally normed results.

Table 9

Cognitive Battery: Z-scores Derived from Local Norms (N = 29)

Domain & Subtest	Mean	Range	SD	% *N* >1 SD below local M	% *N* >2SD below local M
Attention / Working memory					
Combined digit span[a]	-0.01	-2.70 – 1.48	1.12	17%	3%
Processing speed					
Symbol Search[a]	0.22	-1.52 – 2.61	1.19	14%	0%
Audio verbal learning and memory					
Trial 5[b]	-0.55	-3.51 – 1.06	1.29	28%	10%
Immediate Recall[b]	-0.75	-3.33 – 1.42	1.13	41%	17%
Delayed Recall[b]	-0.81	-2.95 – 1.49	1.05	45%	17%
Executive Functions					
Memory retrieval:					
Recognition[b]	0.05	-3.37 – 0.85	1.01	14%	3%
Visual reasoning:					
Matrix reasoning[c]	-0.43	-2.13 – 2.09	1.15	38%	3%
Abstract reasoning:					
Similarities[c]	-0.28	-2.04 – 1.05	0.88	21%	3%
Generativity: Animals[d]	-0.11	-2.69 – 2.23	1.50	31%	21%

NOTES:
M = Mean; SD = Standard Deviation; fwd = forward; bwd = backwards; switching = inhibition/switching subtest

a. Wechsler Adult Intelligence Scale version 3 (WAIS III) – Norms from Gouse et al. (2021); norms were only available for the combined score, rather than separate forwards and backwards digit span.
b. Auditory – Verbal Learning Test WHO-UCL version (AVLT) – Norms from Ferrett et al. (2014)
c. Wechsler Abbreviated Scale of Intelligence (WASI) – Norms from Ferrett (2011)
d. Controlled Oral Word Association Test (COWAT), Semantic fluency – Norms from Gouse et al. (2021)

Aim One: Results from Cognitive Tests without Normative Data

Normative data for the selected subtests from the RPA-ProMem (Radford et al., 2011) and WHODAS 2.0 (Üstün, 2010) are not available. Raw score results from these tests, are presented in *Tables 10* and *11* along with description of pertinent correlational analyses (*Table 15* in Appendix H) and significance tests.

Prospective Memory

Table 10 presents descriptive statistics for the raw scores of the objective measure of prospective memory function (RPA ProMem), where it can be seen that more than half of the sample failed outright on the time-based task, while in contrast, more than half achieved a perfect score on the event-based task. A Wilcoxon Signed-Rank test indicated that scores on the event-based task (mean rank = 8.38) were significantly higher (p = 0.003) than scores on the time-based task (mean rank = 5.50), Z = -2/84, where higher scores indicate better performance.

Correlation between the objective (RPA ProMem) and subjective (PRMQ) prospective memory scores can be seen in *Table 15* (*Appendix H)*, which shows that there was no significant association between either of the objective scores and the subjective score.

Table 10

RPA ProMem Prospective Memory Raw Scores (N=29)

Variable; M (range; SD)	Mean	Range	SD	% fail	% partial points	% perfect score
RPA ProMem						
Time based	1.14	0 – 3	1.43	59%	7%	34%
Event based	2	0 – 3	1.25	17%	24%	57%
Total	3.14	0 – 6	2.29	17%	52%	31%

NOTES:
RPA ProMem = Royal Prince Alfred Prospective Memory Test – Form 2; M = Mean; SD = Standard Deviation

Insight

The WHODAS 2.0 was used to determine participants' subjective rating of their cognitive performance in the domains of concentration, procedural learning and problem-solving (as captured by the questions detailed in the notes of *Table 11*). Responses are

captured on a Likert scale of 1 (no difficulty) to 5 (extreme difficulty), where mean scores for all questions were approximately 2, corresponding with the description of 'mild difficulty'.

Kendall's Tau-b correlational analyses are again presented in *Table 15* (Appendix H), where the association between the WHODAS 2.0 scores and corresponding objective measure results can be read as an indication of the participants' insight into their cognitive abilities. Here self-rated difficulty in 'concentrating on doing something for ten minutes' was compared with the attention/concentration test scores and 'analysing and finding solutions to problems in day-to-day life' to the various executive function measures related to problem-solving. An appropriate objective measure score was not available for this comparison for procedural learning. There was no significant correlation between the respective subjective and objective scores, however there were significant positive correlations between the subjective scores themselves and also with the PRMQ subjective prospective memory measure discussed above.

Table 11

WHODAS 2.0 Results (Subjective cognitive performance) (N=29)

				Moderate to extreme difficulty[a]	
Variable	Mean	Range	SD	Frequency	Percentage
WHODAS 2.0					
Concentration[b]	1.59	1 – 3	0.78	5	17%
Problem Solving[c]	2.03	1 – 5	1.05	9	31%
Procedural Learning[d]	2.31	1 – 5	1.37	12	41%

NOTES:
WHODAS 2.0 = World Health Organisation Disability Assessment Scale, Domain 1

a. Denotes participants rating their subjective functioning in the respective domains at 3 (moderate difficulty), 4 (severe difficulty) or 5 (extreme difficulty or cannot do)
b. Self-rated difficulty in 'concentrating on doing something for ten minutes'
c. Self-rated difficulty in 'analysing and finding solutions to problems in day-to-day life'
d. Self-rated difficulty in 'learning a new task, for example, learning how to get to a new place'

Aim One, Objective Three: Presence of Comorbidities Known to Affect Cognitive Function

Mood. The results of the comorbidity screening instruments are given in *Table 12*. For the HADS anxiety and depression scores, a cut off of 8 or higher was taken as falling within possible mood disorder range, in line with existing research using the tool in an SCI population (Le & Dorstyn,2016). More than half of the sample fell within this range for both

the anxiety and depression scales (62% and 52% respectively), with the mean score of the full sample also within possible anxiety range. More than half of the sample (16/29; 55%) screened positive for potential PTSD.

Sleep Quality. Despite the removal of one of the PSQI items (and thus a potential three points, as detailed in *Method),* more than two thirds of participants still scored above five, indicating symptoms, sleeping habits and sleeping patterns congruent with 'poor sleep'. In addition, it is notable that the mean score of the full sample also still fell within the 'poor sleep' range

Substance Use. The results of the ASSIST 3.1 showed that the majority of participants (23/29; 79%) had used alcohol and close to half had used cannabis in the preceding three months. Use of cocaine, amphetamines (tik), inhalants, sedatives, hallucinogens and opioids were also screened for and while four participants had a history of using cocaine or tik, use of the other substances within the past three months did not feature.

Pain. Through the BPI, two thirds of participants (19/29; 66%) indicated presence of pain 'other than everyday kinds of pain' (Cleeland, 2009), making them eligible to complete the full screening tool. Of these (*n*=19), almost 70% (or 45% of the full sample) rated their average pain severity as 5/10 or greater, with more than a quarter experiencing average pain of 7/10 or greater, where a rating of 10 indicates 'Pain as bad as you can imagine' on the 10-point Likert scale.

Table 12

Psychological and Somatic Comorbidities (N=29)

Variable	*N*	Mean	Range	SD	Frequency	Percentage
HADS[a]	29					
Anxiety score	29	8.27	0 – 20	4.82	18	62%
Depression score	29	7.31	1 – 15	3.57	15	52%
PSQI	29					
Total score[b]	29	7.86	1 – 19	3.86	20	69%
PC-PTSD5	29					
In potential PTSD range	16				16	55%
ASSIST 3.1 [c]	29					
Alcohol	28	5.86	0 – 23	5.35	23	79%
Cannabis	17	6	0 – 19	6.11	13	45%
Cocaine	4	8.25	0 – 21	8.96	3	10%
Amphetamines	4	11.75	8 – 19	4.99	4	14%
BPI [d]	29					
Screened in	19				19	66%
Average pain	19	4.94	0 – 9	2.12		
Avg pain >5/10					13	68%
Avg pain >7/10					5	26%
Pain medication used					17	89%

NOTES:

a. *N* = participants completing test item; SD = Standard Deviation; HADS = Hospital Anxiety and Depression Scale, PSQI = Pittsburgh Sleep Quality Inventory, PC-PTSD = Primary Care PTSD Screen for DSM5, ASSIST 3.1 = Alcohol Smoking and Substance Involvement Screening Test, BPI = Brief Pain Inventory; Avg = averageFrequency and percentage for HADS denote participants scoring within anxiety and depression range respectively (8 and above)

b. Note that these scores have been adjusted due to nonutility of the sleep efficiency question in this clinical setting, therefore this represents a score out of 18, rather than the original version of 21 (see *Method*); Frequency and percentage indicate participants within 'poor sleep' range (score > 5 as per original scoring criteria)

c. All participants answer screening questions on which substances they have ever used, substance specific questions are only asked for those participants who indicate they have ever used each substance). Frequency and percentage indicate participants who have used the substance within previous 3 months

d. All participants answer initial question screening for pain presence, but only those indicating experiencing more than 'occasional everyday pain …(such as minor headaches, sprains, and toothaches)' answer full questionnaire (i.e. 'screened-in'). Pain severity is rated on a 10 point Likert scale where 0 = 'No Pain' and 10 = 'Pain as bad as you can imagine'.

Correlational Analyses

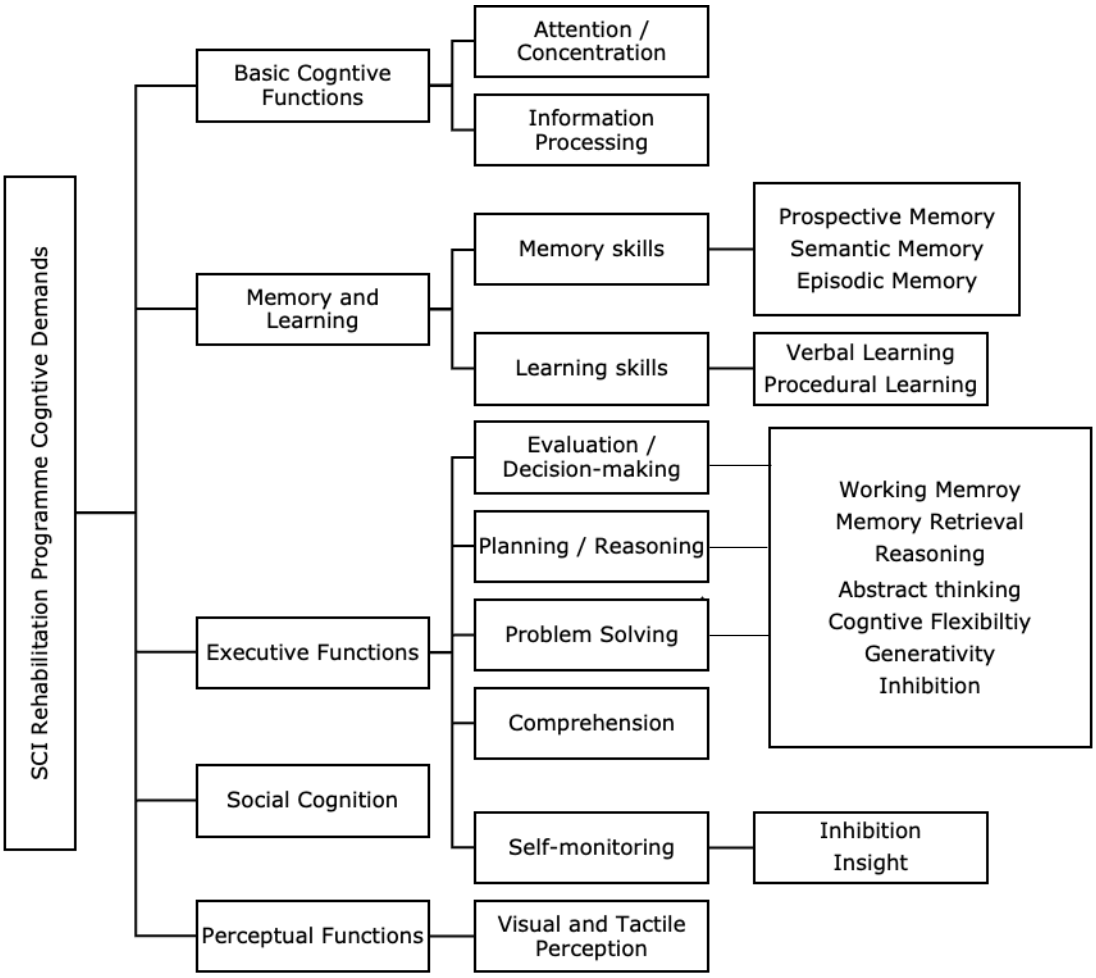
The results of Kendall's tau-b correlational analyses exploring the relationship between certain comorbidities and cognitive performance are presented in *Tables 16 and 17 (*Appendix H*)*, with significant scores highlighted in red. The BPI correlations are reported separately as only a portion of the sample (n = 19) screened in to complete this tool. *Table 16* shows positive correlations at the 0.05 level of significance between anxiety and depression, anxiety and subjective prospective memory, anxiety and the time score on the Inhibition task; depression and objectively measured prospective memory (time-based); poor sleep and working memory and poor sleep and the error score on the cognitive flexibility task. The stronger positive correlation between anxiety and subjectively evaluated procedural memory was highly significant at $p < 0.01$. There were no significant associations between the average pain scores and the various cognitive and comorbidity scores for the sample subset completing the BPI (*Table 17*).

Aim Two, Objective One: SCI Rehabilitation Programme Cognitive Requirements

Following the activity analysis and consultation process described in the *Method* section, Appendix A captures the study setting's specialized SCI rehabilitation programme in terms of the three broad areas of 'acquiring specific knowledge and skills related to the new physiological condition', 'acquiring specific skills related to new functional capacity' and 'general demands of the rehabilitation setting'. In this appendix, the tasks relevant to these areas are detailed alongside the cognitive abilities required to engage with them. Based on this, the overall cognitive demands of the study setting's specialized rehabilitation programme are captured in *Figure 2*. As per the *Method* section, as far as possible, these cognitive demands were used to guide test selection for the cognitive battery. Considering the cognitive domains included in *Figure 2*, it may be noted that certain executive functioning processes, such as generativity and cognitive flexibility, were not explicitly identified in the initial programme analysis (Appendix A), but were relevant to include in the final battery. To explain this discrepancy, it is noted that assessment of more complex executive function skills (e.g., problem solving) may be best achieved through targeting the neurocognitive processes underlying these skills (i.e., cognitive flexibility, generativity and working memory) (Suchy, 2009).

Figure 2

SCI Rehabilitation Programme Cognitive Demands



Aim Two, Objective Two: Comparison of Cognitive Profile and SCI Rehabilitation Programme

Finally, discussion of the relationship between the cognitive profile of the SCI group and the cognitive demands of their specialized rehabilitation programme will consider the relative cognitive strengths and weaknesses identified through cognitive testing, in relation to the relevant cognitive domains, as captured in *Table 13* below. The domain names used in this table refer to the results of the tests used to investigate these domains and match with the tests and domain descriptions in *Tables 7* and *9*. The descriptive ranges given in the table are in line with the American Association of Clinical Neuropsychologists'recommendations (Guilmette et al., 2020). Here it can be seen that while the sample performed at a Below Average level for most of the domains relative to international norms, they performed in Average range relative to local norms for most domains, where these norms were available.

Discussion of this objective in the next section will also draw upon the prospective memory and insight related data presented in relation to aim one, as well as further interpretation of the differences between the locally and internationally normed results.

Table 13

Comparison of Cognitive Profile and SCI Programme Skills for Tests with Normative Data

Extracted Domain	International norms		Local norms	
	Mean description	>50% *N* below 1 SD	Mean description	>%25 *N* below 1 SD
*Attention / Concentration**	Below Average	Yes		
Processing speed	Below Average	Yes	Average	No
Learning and memory[a]	Below Average	Yes	Low average	Yes (45%)
Executive Functions:				
*Working memory**	Low average	Yes		
*Memory retrieval**			Average	No
Inhibition[b]*	Below Average	Yes		
Problem Solving:				
Visual reasoning	Below Average	Yes	Low Average	Yes (38%)
Abstract reasoning	Exceptionally Low	Yes	Average	No
Generativity	Below Average	Yes	Average	Yes (31%)
Cognitive flexibility[b]*	Below Average	Yes		

NOTES:
SD = Standard Deviation; norm descriptor ranges according to American Association of Clinical Neuropsychologists guidelines (Guilmette et al., 2020); * denotes tests where either local or international norms were unavailable.

a. Based on AVLT delayed score
b. Both D-KEFS scores in these subtests fell within this range

Discussion

The link between cognitive dysfunction and SCI, and the associated need for cognizance of neuropsychological function in SCI rehabilitation, has been established in high income settings. However, the applicability of this evidence to the local SCI rehabilitation milieu, where injury profile and rehabilitation resources are distinct from HICs, is uncertain. Thus, it is hoped that this pilot study may shed light on the neuropsychological profile of South African SCI inpatients from a local public rehabilitation centre, and enable preliminary consideration of its implications for planning and implementing specialized SCI rehabilitation programmes in local public health settings.

To this end, this study had the following aims:

1) To investigate the profile of cognitive strengths and weaknesses in a sample of SCI inpatients at a specialized public rehabilitation hospital in the Western Cape.
2) To compare the cognitive profiles of these patients to the cognitive requirements of their specialized SCI rehabilitation programmes.

In pursuit of these aims, cognitive performance data was collected using a neuropsychological test battery that was formulated in cognizance of the cognitive demands of the study setting's SCI rehabilitation programme. Questionnaires screening for common psychological and somatic comorbidities associated with SCI, that have established links to cognitive dysfunction, were also administered. In the absence of matched controls with which to compare the performance of the SCI sample, this discussion shall seek limited interpretation of the SCI group results in relation to available international and local normative data. This will inform a consideration of the relationship between the cognitive profile of the group and the cognitive demands of their rehabilitation programme. The information gained from the comorbidity screening tools, as potential proxy measures for areas of cognitive risk, may further enrich understanding of the sample's cognitive risk profile and could reveal future avenues for intervention.

Sample Characteristics

SCI-related Characteristics

Joseph et al.'s (2015) study documenting TSCI incidence and aetiology in the Cape Metropole's public hospital system is currently the only multicentre 21st century epidemiological study on SCI in South Africa. While it is important to note the differences between that study's clinical population and the current study's sample, in terms of stage of injury management (acute vs inpatient rehabilitation setting, respectively), aetiology

(exclusively TSCI vs TSCI and NTSCI, respectively), and age range (where Joseph et al. [2015] include patients up to the age of 80), it is nonetheless useful as a basic local benchmark. The age and sex distribution of the full sample in the current study was consistent with that of Joseph et al.'s (2015) study sample and international trends (Lee et al., 2014), as predominantly male and in their early- to mid-30s. The present study's main cause of injury, as assault (62% of the sample), with the significant majority caused by focal stab or gunshot wounds, was also consistent with the Joseph et al.'s (2015) study (59.3% SCI caused by assault). Considering only the TSCI group, the proportion of violent aetiologies in the current study's sample is even higher (where 78% of all TSCI were of violent origin).

In participants with NTSCI, the vast majority of cases in the present studywere caused by TB spine, as compared to other causes (5:1). This is comparable with other studies on NTSCI in sub Saharan Africa (Draulans et al., 2011), and again represents an aetiological distinction to HIC data, where degenerative changes and tumours predominate (New et al., 2014). Three of the five TB spine cases in the current study's sample were associated with comorbid HIV, again consistent with developing world literature, which identifies common co occurrence of these two diseases (Shetty et al., 2016).

In summary, the aetiological profile of SCIin the current study, while fairly consistent with existing data on SCI in South Africa and other LMIC settings (Draulans et al., 2011; Joseph et al., 2015) is distinct to that described in HIC settings, where the vast majority of research on SCI and cognitive function has taken place (Sachdeva et al., 2018). Considering comorbid medical diagnoses potentially associated with cognitive dysfunction, more than half of the participants with TB spine had a comorbid HIV diagnosis. In contrast, the incidence of comorbid TBI for TSCI participants appears much lower as compared to international studies (Pandrich & Demetriades, 2020), even when possible undiagnosed cases of TBI in the current study's sample are included (Bombardier et al., 2016; Sharma et al., 2014).

Socioeconomic Characteristics

The majority of the sample had a medium to high asset index score and level of premorbid unemployment (17% in the 'student/unemployed' category) which is lower than the national average of 30% for the same period (Statistics South Africa, 2020), where it is notable that students are not considered 'unemployed' in SSA definitions. Annual household income for most participants fell in the R25 000-R100 000 bracket, in interpreting this it is noted that the minimum wage at the time of data collection was R20 per hour (South African

National Department of Labour, 2018), which would amount to approximately R35 000 per annum for a single earner in full time employment. Thus, while the lower level of unemployment and medium to high asset index scores might be interpreted as indicating a mean middle SES status for the sample, the potential for many participants to fall at the lower end of the R25 000- R100 000 bracket as minimum wage earners or lower, means that an average classification of low- to middle-SES is more suitable, while it is emphasized that the sample's SES is far from homogenous.

Aim One: Investigating the Cognitive Characteristics of the Sample

The first aim of the study was to characterise the cognitive profile of the inpatient sample, using international and local normative data for interpretive comparison. In addition, investigation of the prevalence of psychological and somatic comorbidities known to affect cognitive function provides a potential proxy measure for areas of cognitive risk.

Objective One: Cognitive Performance in Relation to International Norms

The history of cognitive assessment in South Africa is controversial, where tests created and normed in high income, English-speaking international contexts were inappropriately applied in the local setting, with the outcomes used to defend discriminatory apartheid policies and practices (Laher & Cockcroft, 2013). However, while the pitfalls of indiscriminate present-day use of such testing materials and normative data are well known, the availability of appropriate local testing materials and norms are severely limited (Lucas, 2013; Shuttleworth-Edwards et al., 2013). South Africa's heterogenous profile of language, cultural, socio economic and educational factors, all of which have been found to have the potential to influence cognitive testing performance (Lucas, 2013), means that development of appropriately stratified norms and testing materials is difficult, expensive and time consuming. Further, the effects of acculturation mean that frequent revision of any such research is likely to be required to maintain normative validity (Lucas, 2013). Where local normative data for selected tests or batteries have been developed, research samples tend to be small and/or from fairly homogenous groups (e.g., all of the same home language and similar socioeconomic status [Gouse et al., 2018]; very small sample with tertiary education and only two of the eleven official languages [Shuttleworth-Edwards et al., 2013], and English- and Afrikaans-speaking school children [Ferrett et al., 2014]). Where large-scale normative research has been attempted (Claassen et al., 2001), extensive retrospective methodological critique has rendered the data to be of very limited normative use

(Shuttleworth-Edwards et al., 2013). Thus, while the issues with using international norms in the local setting are clear, the dearth and limitations of available local norms often results in continued reliance on the international normative data.

In an attempt to mitigate the pitfalls of test score interpretation using international norms, most South African neuropsychological research studies use a well-matched control group to interpret cognitive test scores (Shuttleworth-Edwards et al., 2013). Where this is no longer possible for the current study, a critical but guarded interpretation of the sample's internationally normed cognitive test scores will be attempted, drawing upon research that has identified local trends in relation to international normative data use, an approach described by Lucas (2013), in her commentary on the challenges of local test adaptation and norming.

Established Trends in Local, Relative to International, Neuropsychological Test Performance. In addition to language, sociocultural and economic factors (Lucas, 2013), quality of education is widely regarded as a crucial determinant of performance in neuropsychological testing (Cockcroft et al., 2015; Shuttleworth-Edwards et al., 2013). Where internationally normed performance ranges for intelligence measures seem to be largely valid for South Africans with a 'privileged' education, cognitive test scores tend to be significantly lower across most domains for individuals with a background of poorly resourced schooling (Laher & Cockcroft, 2013; Shuttleworth-Edwards et al., 2013). Shuttleworth-Edwards et al. (2013) note that IQ scores as measured on the WAIS III could be as much as 20 points lower amongst participants with a background of disadvantaged as compared to advantaged education, meaning that the population mean would fall within the international 'Below Average' (Guilmette et al., 2020) range for this group. While verbal intelligence subtests have been found to be especially prone to cultural bias and educational disadvantage, performance-related IQ tasks are also likely to be affected (Cockcroft et al., 2015; Shuttleworth-Edwards et al., 2013). Considering processing speed measures, there is established evidence for lower South African performance in this domain relative to normative standards (Nell, 2000; Shuttleworth-Edwards et al., 2013), which has been linked to differences in educational approaches in disadvantaged local as compared to Western settings (Cockcroft et al., 2015). However, slower processing speed in local groups with a background of disadvantaged education is not a uniform finding. A study involving over 100 South African university students of disadvantaged educational backgrounds, predominantly from rural, low SES settings, found their processing speed performance to be equivalent to

international normative standards, with the effects of acculturation postulated as being influential to this relatively better than expected performance (Cockcroft et al., 2015).

Shuttleworth-Edwards et al. (2013) notes that tests of verbal attention and concentration are also less likely to be affected by education quality. Further, tests of working memory with basic numerical or verbal concepts have been found to be relatively less influenced by both education quality and socio-economic factors (Cockcroft, et al., 2015; Engel et al., 2008; Shuttleworth-Edwards et al., 2013). Interestingly, although also an executive functioning measure, there is some evidence that perceptual reasoning, as targeted in the Wechsler Matrix Reasoning subtests, is also less prone to the effects of cultural bias for low SES South Africans with a background of disadvantaged education (Cockcroft et al., 2015).

Finally, before discussing these trends in relation to the cognitive profile of the sample in the current study, it is important to note that historically, and persistent today, educational resource allocation is not uniform across previously disadvantaged groups (Shuttleworth-Edwards et al., 2013). This means that, along with other historic and dynamic demographic factors, individuals from disadvantaged socioeconomic backgrounds are not a homogenous group with a correspondingly homogenous neuropsychological profile. In addition, individuals may be able to access more advantaged education despite their lower socioeconomic status (Shuttleworth-Edwards et al., 2013). Thus, although the trend is for generally lowered scores across previously disadvantaged groups, the extent of this lowering is variable between and within these groups (Bethlehem, et al., 2003; Claassen et al., 2001; Shuttleworth-Edwards et al., 2013). It is particularly pertinent to remain mindful of this potential heterogeneity in relation to the expected cognitive performance of the current study's sample. As such, the sample's heterogenous language profile and demonstrated variance in socioeconomic indicators (albeit within the low- to middle-SES range), means that their experience of educational disadvantage, and its potential effects on neuropsychological test performance, is unlikely to have been uniform. In addition, a portion of the sample was tested in their second language, and while measures to ensure sufficient second language proficiency for neuropsychological testing were in place, the potential additional disadvantage of nonmother tongue testing, especially in linguistically loaded tasks (Cockcroft et al., 2015), must be acknowledged. Taken together, these factors mean that any interpretation of the sample's cognitive scores must be made cautiously.

Internationally Normed Cognitive Profile Interpretation. The mean subtest scores for all objectively measured domains in the current study's sample were one standard

deviation or more below the international mean. Although there was a broad range in scores across the objective measures, even the upper limit outliers fell within one standard deviation of the mean, while the sample's mean IQ of 77 places them in 'Below Average' range (Guilmette et al., 2020). Thus, although far from homogenous, the overall performance of the sample, both in mean and distribution was clearly far below international levels. This globally lowered performance is congruent with the broad trends identified and discussed in the preceding section.

Performance in the audio-verbal learning task and certain executive function measures, especially in linguistically loaded tasks (e.g., abstract reasoning), was particularly low, while working memory performance was relatively better than performance on the attention task. Here it is noted that attention is integral to learning/memory and executive functioning performance (Cohen, 2014), and thus poor attention may have undermined performance in these latter two cognitive domains. In interpreting the sample's relatively poorer performance on the attention measure, as compared to the working memory measure (both based upon digit span), one might have expected poor attention to undermine working memory performance and result in correspondingly poor scores in the latter task. Considering why this does not appear to be the case, the test structure may have played a role – where the attention task (forward digit span) is presented first and thus may enable a measure of test familiarity that would provide advantage in the subsequent working memory (backwards digit span) task. The forward digit span task also appears relatively easier than the backwards span on face value, and thus participants could have applied more conscious attentional effort in the latter task, where this may not have seemed necessary in the former. Further possible reasons for this unexpected performance will be considered in relation to the sample's profile of comorbidities.

Considering performance in those domains discussed as having more mixed evidence for lowered performance in the local setting, the groups' processing speed seems particularly low in relation to the other test scores, while they fared better in visual conceptual reasoning performance than the other executive functioning tasks (with the exception of working memory).

Conclusion of International Norms Discussion. Before drawing final conclusions on the cognitive profile of the sample relative to international norms, the potential effects of the sample's demographic heterogeneity across multiple variables must again be highlighted. As such, any interpretation of the SCI sample's scores in relation both to international norms and the local neuropsychological test score trends for these norms, remains guarded.

Nonetheless, the especially poor performance in tests targeting domains of attention, verbal learning/memory, processing speed and certain executive functions, is noteworthy. Considering the possible relationships between these variables, the potential for poor attention to undermine performance in executive functioning and learning/memory tasks was noted. Comparison of these scores to more appropriately matched local norms is however required for fairer interpretation of these results.

Objective Two: Cognitive Performance in Relation to Available South African Norms

The test battery formulated for the current study has not been used in its entirety in any existing South African studies, therefore it was necessary to use several local normative data sets to cover as many of the subtests as possible. The normative studies chosen were selected for similarity both in terms of subtests employed and overlap in terms of study sample demographics and socioeconomic background.

The difficulties associated with development of appropriate local cognitive testing norms were discussed in the previous section. As such, the relatively small samples of the chosen normative studies (in comparison with the international manualised norms) as well as their differences to the current study's sample in certain demographic variables and the aforementioned potential impact of second language assessment, mean that once again, interpretation of the cognitive domain scores using these local norms is undertaken with caution. The normative data sets and derived z-scores are considered separately below.

Normative Data for Processing Speed, Generativity and Attention / Working Memory. Gouse et al.'s (2021) norms from peri urban primary health clinics in the Cape metropole were used to calculate Z-scores for tests within the domains of attention/concentration and working memory (WAIS III combined Digit Span score), processing speed (WAIS III Symbol Search) and executive function/generativity (COWAT – Animals). It is noted that while the current study's sample is fairly well matched to the normative group in terms of geographical location/public health setting, age and level of education, they differ markedly in sex and language profile. Where the language heterogeneity of the predominantly male sample of the present study has been discussed, Gouse et al.'s (2021) group has a much more homogenous language profile of almost all first language isiXhosa speakers (who were tested in English or isiXhosa according to their preference) and approximately equal numbers of male and female participants.

In contrast to the internationally derived cognitive profile, the mean performance of the current study's sample was approximately equivalent to Gouse et al.'s (2021) normative

group for all scores. In interpreting the difference between the local and internationally normed performance, the latter which was markedly lower, it is important to acknowledge the potentially confounding effects of the demographic discrepancies between the two local groups. Indeed, the variance in the locally normed scores is much broader than those normed using international data, indicating a particularly heterogenous profile of cognitive performance relative to local norms. Notwithstanding these limitations, the marked 'improvement' in the processing speed and generativity scores with local norms is notable, and suggests that performance in these areas might not be indicative of marked cognitive pathology for the present study's sample. However, it is again noted that evidence for processing speed performance in the local setting is mixed, where the aforementioned study by Cockcroft et al. (2015) saw a group of predominantly isiXhosa-speaking university students from disadvantaged educational backgrounds, who were tested in their second language, performing on par with international standards. While there are clear differences in the level of education of Cockcroft et al. (2015) and Gouse et al.'s (2021) samples, their socioeconomic and educational backgrounds are similar. Thus, it is possible that the processing speed performance of Gouse et al.'s (2021) sample is not wholly representative of the general local public health user population. As such, it cannot be assumed that the processing speed performance of the current study's sample would be within normal range relative to an uninjured but demographically matched local peer group.

Unfortunately, Gouse et al. (2021) provide only a combined digit span score regression calculation. This means that it is not possible to undertake further interpretation of the apparent discrepancy between attentional and working memory performance implied by the internationally normed results.

Normative Data for Learning / Memory and Executive Functions of Abstract and Perceptual Reasoning. The normative data from Ferrett, (2011) and Ferrett et al. (2014) are discussed together, as the 2014 paper draws upon a subset of the 2011 sample and is very closely matched on all demographic indicators. It is noted that while the norms for 'disadvantaged education' were used for all participants in the current study (as per the *Method*), their quality of education could likely have been heterogeneous, and indeed include the possibility that some participants benefited from 'advantaged' education, as previously discussed. The most notable discrepancy between the SCI sample and the normative sample is in age and thus years of schooling. The mean age of the normative sample is less than half that of the SCI sample with their educational level similarly lower, as they were adolescents who were still completing their schooling. Norms are generally stratified by age (e.g., all of

the international norms used in the current study) and often also by educational level (e.g., multiple norms provided in Strauss et al. [2006]). A higher level of education has been associated with better performance in cognitive testing when other demographic variables are equal (Lam et al., 2013). However, the educational attainment discrepancy between the current study's sample and that of Ferrett (2011) and Ferrett et al. (2014) is a direct result of their age mismatch, therefore it cannot be assumed that the more educated SCI sample should perform better as a result. Of relevance to the domains discussed in this section, there is some evidence that performance in audio verbal learning tasks is relatively similar in adolescence as compared to early to mid- adulthood (Vakil et al., 2010). However, when large data sets are considered, the precise effects of age on cognitive performance have been found to vary markedly across other cognitive domains (Hartshorne & Germine, 2015). Thus, once again, interpretation of this locally normed data must remain guarded as it is limited by the uncertain effects of demographic discrepancies between the two samples.

The SCI sample's mean scores on all measures, except the recognition scores for learning and memory (AVLT), were below those of the local normative group. Performance on the delayed recall trial of the AVLT was particularly poor, with the current study's sample mean approaching one standard deviation below the mean at -0.81 and almost half scoring at least one standard deviation below this local normative mean. This is in contrast to their scores for prompted memory retrieval (AVLT recognition), which were approximately equivalent to Ferrett et al.'s (2014) group ($z = 0.02$). The SCI sample's relatively better scores in memory retrieval aided by prompting, may indicate that their poor memory performance was due to difficulties with memory retrieval (an executive function) rather than memory encoding.

While the SCI sample's performance on the two executive functioning measures (WASI Matrix Reasoning and Similarities, measuring visual conceptual reasoning and abstract reasoning respectively) was relatively better than in memory and learning, it was still slightly below average relative to the adolescent norm group. Here, it is important to again consider the possible effects of second language testing for a portion of the SCI sample. As such scores for the linguistically loaded abstract reasoning task should be interpreted with particular caution, as potentially vulnerable to the effects of second language testing (Cockcroft et al., 2015).

Conclusion to Objectives One and Two: Characterisation of the Cognitive Profile

Before cautious formulation of the sample's cognitive profile in relation to the norms presented above, the results of the tests for cognitive domains without normative data should be considered. These include the prospective memory measure and the subjective measures of cognitive function, where lack of correlation between the respective subjective and objective measures is considered as an indication of participants' level of insight into their cognitive functioning.

Prospective Memory (RPA ProMem). Prospective memory (remembering to carry-out intentions) was identified as a particularly important cognitive skill for the SCI rehabilitation programme. However, the assessment tool targeting this domain relied on a control group comparison for interpretation of results, as comprehensive normative data are not yet available. This comparison was of course not possible. Thus, interpretation in the adapted research design is limited to a comparison of time as compared to event-based prospective memory performance, as well as considering the relationship between perceived and actual prospective memory performance (captured by the objective [RPA ProMem] and subjective [PRMQ] prospective memory scores respectively).

Time vs Event-based Prospective Memory Performance. The majority of participants failed outright in the time-based task, while more than half of participants passed perfectly in the event-based task, and almost a quarter seemed to benefit at least somewhat from the prompt of the alarm (i.e., scoring partial points). The Wilcoxon rank analysis confirms that participants' performance was significantly better in the event than the time-based task, a trend that is congruent with previous South African research on prospective memory in a local adult population (Hoare et al., 2012). This implies that participants' performance on prospective memory tasks is much better with external prompting (i.e., an alarm), than when relying solely on internal processes (i.e., independently remembering to check the clock). The potential clinical application of this finding will be discussed further in relation to Aim Two.

Objective vs Subjective Prospective Memory. The sample's subjective scores were within one standard deviation of the international norm, and the proportion of the sample scoring one or more standard deviations below was small (11%), indicating that most of the sample rated their prospective memory as fairly 'normal'. However, there were no significant correlations between any of the objective prospective memory performance raw scores and the subjective score. This lack of subjective/objective correlation implies that participant's self-rating of their prospective memory performance was not consistent with their actual

performance on the test. One may interpret this lack of association as indicating that participants have reduced insight into their level of prospective memory functioning, a finding that would be congruent with the aforementioned South African study, which also used the PRMQ (Hoare et al., 2012). However, such an interpretation should be made cautiously, as artificial assessment situations, such as set-up by the RPA ProMem, are very different to real-life situations, where personal motivation and varied external behavioural cues may influence actual performance (Fish et al, 2010).

Insight: WHODAS 2.0 and Associated Objective Measures. The sample's mean scores for their subjective performance in concentration, procedural learning and problem-solving of approximately 2 ('mild difficulty' [Üstün et al., 2010]), indicates that the sample did not feel that they had marked cognitive difficulties in these areas. In order to examine participants' level of insight into their cognitive abilities, the correlation between their WHODAS 2.0 scores and the relevant objective measures are examined, with self-rated difficulty in 'concentrating on doing something for ten minutes' compared with the attention/concentration test scores and 'analysing and finding solutions to problems in day-to-day life' compared to the various executive function measures related to problem-solving. The learning-related WHODAS 2.0 item can be understood to target procedural learning, rather than audio verbal learning, and thus correlation with an appropriate objective measure was not available.

While there was a moderate positive correlation between the subjective scores themselves (and also with the PRMQ subjective measure discussed above), there was again no association between the subjective and objective cognitive test scores. This indicates that while participants were consistent in their subjective ratings of their performance across domains (i.e., they generally rated their performance across different cognitive domains as equally good or poor), their self-rated cognitive performance does not seem to be consistent with their objectively measured performance in these areas. This lack of correlation between subjective and objective measures may again be cautiously interpreted as indicating that participants had limited insight into their cognitive ability in these domains. The sample's relatively poor performance in multiple executive functioning measures might also support this, as self-monitoring forms part executive functioning (Suchy, 2009).

Overall Interpretation of Cognitive Profile

Following the interpretation of both the internationally and locally normed scores and those scores for which normative data are not available, the following cautious overall formulation of the cognitive profile of the sample is offered:

Cognitive domains suggestive of relative weakness for the sample include attention/concentration, audio verbal learning and memory, and certain executive functions such as memory retrieval, inhibition and problem-solving skills related to visual conceptual reasoning and cognitive flexibility. It is noted that any attentional issues would be likely to impact on performance in executive function and memory tasks (Cohen, 2014). It is possible that participants have reduced insight into their cognitive abilities and their prospective memory performance appears to improve with external aids. Working memory appears to be relatively preserved, while processing speed performance appears age-appropriate relative to the local regression-based norms used (Gouse et al., 2021), but very poor in relation to international data. Inconsistencies in the evidence for local processing speed performance in low SES populations were noted and thus overall interpretation of the SCI sample's processing speed ability remains inconclusive.

Considering this cautious cognitive profile formulation in relation to the international evidence for cognitive profiles in SCI, it is interesting to note that international findings of deficits in verbal learning (Chiaravalloti et al., 2018; Dowler et al., 1995; Hess et al., 2003) and various executive functions (Cohen et al., 2017; Dowler et al., 1995) are consistent with the findings for the current study's sample. However, there also appear to be some areas of possible difference with international trends, where many SCI studies cite reduced processing speed as an area of significant deficit (Chiaravalloti et al., 2018; Cohen et al., 2017; Dowler et al., 1995; Hess et al., 2003) while noting that attention appears relatively spared (Chiaravalloti et al., 2018; Hess et al., 2003). In interpreting these differences, it is important to note the heterogeneity of the current study's sample, which includes a portion of participants with HIV and participants with possible TBI, for whom attentional problems are frequently reported (Azouvi et al.,, 2017; Woods et al., 2009). However one might also expect poor levels of processing speed among individuals with a history of TBI and/or HIV, and yet processing speed seemed to be relatively intact in the sample.

Further, individuals with possible TBI were excluded in Hess et al., (2003) and Chiaravalloti et al. (2018), the latter who also excluded participants with a history of comorbid substance abuse and PTSD. In addition, in relation to processing speed, the potential effect of differing time since injury is noted, where Chiaravalloti et al. (2018);

Cohen et al. (2017) and Dowler et al. (1995) recruited community dwelling participants with chronic SCI (i.e., a much longer time since injury than the current sample). One mechanism for reduced processing speed in the absence of TBI is postulated to be accelerated aging (i.e., a neurodegenerative process) (Chiaravalloti et al., 2018), thus given their much shorter time since injury, this may not yet have proceeded to the extent that it affects cognitive function in the current study's more acute sample.

Objective Three: Presence and Extent of Comorbidities Known to Affect Cognitive Function

Psychological and somatic sequelae of SCI, as well as risky premorbid behaviours (such as substance use), were discussed in the *Introduction* as potential mechanisms for cognitive dysfunction in SCI. In line with the exploratory research design, assessment included screening for these variables. This discussion makes no attempt to infer causality, where the subjectivity of the screening measures and heterogeneity of the sample in terms of epidemiological factors, time since injury, duration of comorbid symptoms and medication side effects, amongst a multitude of other confounding variables, render this impossible, and indeed incongruent with the exploratory research aims. Rather, an understanding of the potential prevalence of these pre- and comorbidities may indicate areas of present or future risk for cognitive dysfunction or suggest avenues for future research and intervention design.

Mood: Anxiety, Depression and PTSD (HADS and PC-PTSD). The association between adverse mood states and cognitive dysfunction is well documented: anxiety has been linked with impaired attentional control, including associations with impaired inhibition and working memory (Moran, 2016), while depression has been associated with deficits across domains of executive function, memory and attention (Rock et al., 2014; Snyder, 2013). Qureshi et al.'s (2011) review found that PTSD was associated with cognitive dysfunction across a range of domains, with the most consistent evidence being for a negative impact on attentional processes.

The HADS results show that more than half (52%) of participants in the current study reported symptoms suggestive of depression, and nearly two thirds of anxiety. This is more than double the rates reported in global review publications on mood and SCI, where Le and Dorstyn, (2016) found prevalence rates of anxiety ranging from 15-32%, with study setting or time since injury not significantly affecting results, and Williams and Murray's (2015) meta-analysis of 19 studies found a mean prevalence of SCI and depression comorbidity of 22%. It is also notable that amongst those patients who offered reasons for declining to participate in

the current study, four out of five responses seem to imply feeling overwhelmed by psychological processes or the implications of their injury.

More than half of participants in the present study (55%) screened positive for possible PTSD, again higher than studies from HIC settings, where a recent study by Cao et al., (2017) found a prevalence of 24.9% in a large cohort of SCI patients in the USA and an older review by Kennedy and Duff, (2001) gives a PTSD-SCI comorbidity prevalence range of 10-40%.

The rates of mood disturbance in the current sample also appear to be much higher than in the local general population, where the only large scale, nationally representative study on the lifetime prevalence of psychiatric disorders in South Africa found prevalence of any anxiety disorder (including PTSD) at 15.8% and major depressive disorder at 9.8% (Stein et al., 2008). Here it is noted that while the current study used a simple screening tool, the in-depth diagnostic interview used by Stein et al., (2008) is likely to have generated more clinically robust results. Another South African study using a mood disorder screening tool with a group of public health users in the Western Cape (individuals seeking HIV testing), also found much lower prevalence of depression (14.2%), anxiety (5%) and PTSD (4.9%) than in the current study (Kagee et al., 2017).

As with the cognitive test interpretation, it is important to consider the potential effect of assessment in a second language, which may in itself be anxiety provoking. While the HADS is structured to target feelings occurring within the preceding week, and as such should not tap transient feelings related to the test situation, the potential for second language screening to skew the results in favour of higher anxiety scores cannot be entirely discounted.

There was a significant positive correlation between the depression and anxiety scores, which is congruent with evidence supporting high comorbidity rates for these disorders (e.g., Lamers et al., 2011). Beyond this finding, correlational analyses linking mood disturbance and cognitive function were inconclusive. This lack of demonstrated correlation is not unexpected given the heterogeneity of the sample in terms of socioeconomic factors, as well as epidemiological factors and other comorbidities with potential additional association to cognitive dysfunction. Nevertheless, the seemingly high prevalence of psychological disturbance in the sample in terms of anxiety, depression and PTSD, especially when compared to SCI studies in international settings, is an important finding. It may indicate that, along with a distinct aetiological profile, this local SCI sample has a higher prevalence of psychiatric comorbidity than is evident in existing research and importantly, that the psychological comorbidities identified are already known to have a relationship with

cognitive dysfunction. Thus, this may indicate an area of risk for cognitive dysfunction, even although the specific associations are not demonstrated in this study.

Sleep (PSQI). Sleep disturbance and poor sleep quality are associated with cognitive dysfunction across a number of different domains that were identified in the *Results* as crucial for participation in an SCI rehabilitation programme. These include attention, learning and memory, processing speed and various executive functions including inhibition and generativity (Durmer & Dinges, 2005; Kronholm et al., 2009). While it is understandable that multiple factors, such as mood, pain or disturbance in an unfamiliar shared ward environment, might affect the sleep quality of any hospital inpatient, SCI inpatients have additional challenges to their sleeping routine as their pressure sore risk means that they are routinely woken for turning in the night, while some patients may need to wake to perform intermittent catheterization. Thus, the experience of poor sleep reported by more than two thirds of the sample, although not unexpected, represents a notable cognitive risk factor, especially as a typical SCI rehabilitation admission may span months, and pressure relief and continence measures are likely to be lifelong.

Again, correlational analyses were inconclusive, a finding that is understandable both in terms of the sample's aforementioned multifaceted heterogeneity as well as variability, both within and between participants, in relation to the experience of poor sleep and its effect on cognitive functioning, a subject explored in some depth by Durmer and Dinges (2005).

The high rate of sleep disturbance for participants in the current study is consistent with international studies on sleep disturbance and SCI (Aydin et al., 2020; Giannoccaro et al., 2013), while many of the cognitive skills that have been identified as important for participation in the study setting's rehabilitation programme are proven to be vulnerable to the effects of sleep disturbance. Of particular note are the domains of attention, learning and memory and certain executive functions, which have been identified in the preceding discussions as areas of likely relative cognitive weakness in the current study's sample. Thus, while correlational analyses were inconclusive, sleep disturbance remains an important potential contributor to cognitive dysfunction in the sample.

Pain (BPI). Chronic pain is known to impact attentional processes, which in turn negatively impact executive functions such as working memory and managing attention switching or interference tasks (such as targeted in the two D-KEFS subtests used in the current study) (Moriarty et al., 2011). Two thirds of the sample 'screened-in' when completing the BPI, meaning that they were experiencing pain 'other than… everyday kinds of pain ('such as minor headaches, sprains and toothache') (Cleeland, 2009) on the day of

testing. In addition, all but two of these participants were prescribed medication for their pain, suggesting that pain experience was fairly chronic. Of those experiencing pain, two thirds rated their average pain as 5/10 or higher, with just over a quarter as 7/10 or more. These findings are consistent with global data on pain and SCI, which puts prevalence of individuals with SCI experiencing pain at 65% , with approximately a third of these rating their pain as severe (Siddall & Loeser, 2001). While it is beyond the scope of this study to investigate the possible side effects of the various pain medications taken by the study participants, the additional potential impact of these on cognitive functioning was explored in the *Introduction* (Shem et al., 2018).

Correlational analyses did not reveal any significant associations between level of pain and other comorbidities or cognitive domain scores for those who completed the screen. While the multiple confounding variables noted in the previous discussions on the limitations of the correlational analyses also apply in the case of pain, it is additionally important to note that the sample is even smaller for this data set, as only 19 participants screened in for pain and thus completed the BPI. Notwithstanding the correlational results, it is clear that as with sleep and mood disturbance, pain is also a relevant risk factor for cognitive dysfunction in the study's sample.

Substance Use (ASSIST 3.1). The ASSIST 3.1 places emphasis on individuals' substance use patterns within the preceding three months, however most participants had been in hospital without access to substances for a significant portion of this period. Therefore, the scores are of limited use as an indicator of the patterns of premorbid usage. Nevertheless, they capture both whether participants have ever used a substance, as well as indicating those who had been users in the past three months (i.e., users at time of injury). While the tool screens for ten different classes of substances, only tobacco, alcohol and cannabis were widely used in the study sample, with the scores for alcohol and cannabis reported as substances broadly acknowledged as potentially directly affecting cognitive function (Cadet & Bisagno, 2016; Stavro et al., 2012). Research on the effects of alcohol use on cognitive function generally relate to alcohol dependence, which is associated with decline across a broad range of cognitive domains, with dysfunction persistent weeks to months after cessation of use (Stavro et al., 2012). Despite being unable to identify alcohol use patterns, the high proportion of alcohol use in the sample, with 80% having used in the last three months, is notable in relation to national statistics on consumption, where prevalence of current use is only one third of the general South African adult population (Vellios & van Walbeek, 2018).

Heavy cannabis use is associated with deficits across a number of cognitive domains, with potential attention, memory and executive issues being of relevance to the current study (Cadet & Bisagno, 2016). Of interest in relation to the inpatient setting, is a finding that deficits may persist even after a month of abstinence (Bolla et al., 2002). Almost half of the study sample reported cannabis use in the preceding three months, again a much higher prevalence than the reported national usage, estimated at 4% of the general adult population (Peltzer & Phaswana-Mafuya, 2018). Although the ASSIST 3.1 likely provides a gross underestimate of use frequency, the mean cannabis score of users still fell within the tool's 'brief intervention range', implying that normal usage patterns were likely to be regular.

Notwithstanding the limitations for assessing substance use in a setting of enforced abstinence, the results of the ASSIST 3.1 revealed a much higher premorbid prevalence of alcohol and cannabis use in the study sample than in the general South African adult population. This finding is consistent with international SCI data, which reports patterns of persistently higher substance use in individuals with SCI, as compared to the general population, especially post discharge (Tate et al., 2004). While the limitations of the tool meant that the scores were of limited value in establishing usage patterns, and correlational analyses were thus not relevant, it is nonetheless clear that comorbid substance use is a cognitive risk factor of relevance to the study sample.

Objective Three: Conclusions

This section briefly presented international research findings on the cognitive domains affected by the potential pre and comorbidities of mood disturbance, poor sleep, pain and substance use. It was notable in terms of the sample's cautiously presented cognitive profile that dysfunction in the cognitive domains of attention, memory and various executive functions have been associated with all of these conditions.

Through this discussion, it became apparent that, despite the demonstrated aetiological and epidemiological differences between the study sample and the global SCI population, their profile of behavioural (substance use) and somatic (poor sleep, pain) comorbidities are similar, with psychological comorbidities of anxiety, depression and PTSD possibly more prevalent in the South African sample. While investigation of the precise mechanisms of possible cognitive dysfunction in the sample was never an objective of the study, the prevalence of these multiple comorbidities, with known links to the areas of their potential cognitive weakness , represents a multivariate risk for present or future cognitive dysfunction within the group. This risk is despite the much lower prevalence of comorbid

TBI and in addition to the other physiological and medical mechanisms discussed in the *Introduction*, which were not investigated but may be applicable (e.g., chronic hypotension, sleep apnoea, brain structural changes, medication side effects).

Aim 2: Comparing the Sample's Cognitive Profile with the Cognitive Requirements of Their Rehabilitation Programme

Cognitive Profile and Rehabilitation Programme: Synthesis of Results and Discussion

Figure 2 in the *Results* identified key cognitive skills required for optimal participation in WCRC's specialized rehabilitation programme. These cognitive demands were then tabulated against the sample's cognitive performance relative to both the international and locally normed cognitive scores (*Table 13*). Discussion of objectives one and two, above, has enabled an overall interpretation of these separately normed results and cautious formulation of a cognitive profile for the study sample. Thus, in pursuit of the second research aim, it is now possible to synthesize a revised comparative table, where the newly generated cognitive profile is compared with the cognitive demands of the SCI rehabilitation programme as captured in *Table 14*.

In order to interpret the information in *Table 14* further, it is pertinent to refer back to the original analysis of the SCI rehabilitation programme content (Appendix A), where the different rehabilitation programme activities were divided into three broader areas, each discussed separately in the next section. In this discussion it is important to note that while, in accordance with the aims of the study, only the cognitive skills related to these areas are discussed, the different rehabiliation prgoramme activities obviously also demand specific physical and psychological skills from the patients.

Table 14

Overall Comparison of Cognitive Profile and SCI Programme Skills

	Cognitive Profile[a]	
Cognitive skill	Interpretation from normed tests	Comment on tests without norms
Attention / Concentration	Suggestive of deficit	
Processing speed	Inconclusive	
Learning and memory[b]		
Audio verbal learning and memory	Suggestive of deficit (possibly retrieval rather than encoding related)	
Prospective Memory	n/a	Event-based performance significantly better than time-based
Executive Functions:		
Working memory	Suggestive of normal range	
Memory retrieval	Suggestive of deficit	
Inhibition[b]	Suggestive of deficit	
Insight (into cognitive function)	n/a	*Suggestive of possible deficit*
Problem Solving:		
Visual conceptual reasoning	*Suggestive of possible deficit*	
Abstract reasoning	Inconclusive	
Generativity	Inconclusive	
Cognitive flexibility[c]	Suggestive of deficit	

NOTES:
n/a = not applicable
a. Drawn from discussion section: ***Conclusion to objectives one and two: characterisation of the cognitive profile***
b. Based on AVLT delayed score
c. Both D-KEFS scores in this subtest fell within this range

Application of Cognitive Profile to Current Rehabilitation Programme Content and Structure

'Acquiring Specific Knowledge and Skills Related to the New Physiological Condition'. This programme area includes continence, skin and medication management as well as aspects of sexuality. Considering the relevant domains suggestive of cognitive dysfunction in the sample, attention is a gateway cognitive function required for assimilation of information for further processing in the brain (Cohen, 2014). It underlies and interacts with more complex cognitive functions like executive function and memory formation or

retrieval (Cohen, 2014) and thus arguably, underlies the ability to participate in all tasks within this SCI programme area. Further, verbal learning and memory skills could be seen to be especially important in relation to retaining the large volume of new information required for managing their new health condition. Prospective memory is crucial for successful application of this knowledge, where skin care, bladder and medication management all potentially require patients to remember to initiate particular actions at regular intervals. Finally, the potentially compromised areas of executive function related to problem solving may be important in applying the skills learned within inpatient rehabilitation to the community setting, with its potentially unexpected environmental and resource challenges.

'Acquiring Specific Skills Related to New Functional Capacity'. Although unfortunately not a cognitive domain targeted in the battery, this area of the programme is especially heavy in its procedural learning demands, where patients are required to learn skills, either to be executed by themselves or through instruction to a caregiver, which enable them to participate optimally in the practical aspects of their daily life post discharge. Again, attention and concentration are crucial basic cognitive skills to enable this learning. Executive functioning elements related to problem-solving become increasingly relevant as the patient is required to apply these skills outside of the supervised hospital environment.

'General Demands of the Rehabilitation Setting'. This SCI programme area includes those cognitive skills related to being able to participate in both the group and individual aspects of a rehabilitation programme, such as living in a shared ward environment and participating in therapy and goal-setting sessions. Considering the cognitive domains of likely deficit in the group, once again, attention and concentration are crucial basic skills required to engage with incoming information and the environment (Cohen, 2014), and thus may be understood as elemental for productive participation in therapy processes, while executive functions are crucial for goal-setting. Further, successful interpersonal interactions, likely to be necessary in group or shared ward environments, require self-regulation, which relies on both inhibition and insight (Heatherton, 2011).

Consideration of Areas of Relative Cognitive Strength. In contrast to existing evidence on SCI and cognitive dysfunction, compared to some local norms, processing speed has emerged as a potentially more preserved cognitive skill in the sample. In addition, working memory function appears largely intact. If these findings were confirmed in a much bigger control group study, these relatively preserved domains could be leveraged in the SCI rehabilitation programme. As such, if strategies to compensate for participants' reduced attention, memory and learning were implemented, their relatively preserved speed of

information processing and working memory could be harnessed to optimise their acquisition and implementation of the functional skills outlined in the paragraphs above. While in-depth exploration of such strategies represents an area for future research and is beyond the scope of this dissertation, examples may include reducing environmental distractions, cueing attention, providing written materials or encouraging note taking while learning, and employing appropriate adult education principles to enhance both semantic/episodic and procedural learning and memory retention. Similarly, participants' relative strength in event-based as compared to time-based prospective memory tasks implies that use of external strategies to cue prospective memory related tasks may be beneficial. Again, this represents a future research opportunity, but examples may include setting mobile phone alarms or reminders for tasks such as pressure relief, intermittent catheterization and medication.

Limitations

The methodological limitations of the study caused by disruption to control participant data collection as a result of the COVID-19 pandemic have been frequently mentioned. Comparison with a well-matched control group, including match for quality of education, may have mitigated the well-known limitations around using international norms in the local setting, as well as compensating for the demographic heterogeneity of the study's sample. This meant that interpretation of the cognitive profile of the sample remains guarded in general, but especially for those tests without any South African normative data, such as the D-KEFS executive function measures, as well as for the linguistically demanding subtests that may have been more vulnerable to the effects of assessment in a second language. The small size of the study sample, although arguably acceptable in a pilot design, places further limitations on the generalizability of findings.

While an argument might be made that the heterogeneity of the sample's epidemiological and comorbidity profiles was also a limitation, it should be noted that this is in fact likely to be an essential disease characteristic in the rehabilitation setting. Thus, attempts at controlling for these multitude variables would be likely to create a sample that is no longer clinically meaningful as representative of South African public sector SCI rehabilitation inpatients.

Considering the limitations of the cognitive battery and data collection procedures, the lack of suitably translated isiXhosa testing materials, interpreters and translators, and the confounding effect that this may have had on the test performance of first language isiXhosa speakers, despite the measures implemented to ensure proficiency in English or Afrikaans, is

acknowledged. This limitation also affected the composition of the sample, where potential participants without sufficient English or Afrikaans ability were excluded. In addition to language-related limitations, the test battery itself was limited by lack of suitable procedural memory or social cognition measures, or an integrated problem-solving measure, as cognitive skills identified as important in the rehabilitation setting. In addition, the use of only one measure for each of attention and working memory is a limitation in terms of potential for optimal characterisation of performance in these domains. Attention is known to be vulnerable to fluctuations in performance (Cohen, 2014), thus use of more than one measure at more than one stage of the assessment would have been preferable. While there is some evidence that the backwards span task used to delineate working memory performance may have reduced precision in identifying deficits in this domain (Zokaei et al., 2015). In addition it is noted that the verbal administration of the WAIS III Symbol Search subtest may limit the comparability of results to available norms based on standard administration, which require participants to indicate yes/no manually.

Considering the comorbidity screening instruments, the subjective nature of these self-report measures is acknowledged as potentially limiting to their clinical accuracy, with the screening of certain participants in a second language potentially compounding this limitation.

Finally, it is important to acknowledge the limitations of drawing functional conclusions from 'paper-based' neuropsychological tests. In this case, that the cognitive performance of the sample identified through neuropsychological testing, will be representative of their cognitive function in the real-world rehabilitation setting, where performance is mediated through a kaleidoscope of interacting environmental, psychosocial, interpersonal and physiological factors.

Recommendations

As a pilot study, it is pertinent to offer recommendations for the next phase of research. As such, it is clear that a larger sample with carefully matched control group and appropriate measures for inclusion of all isiXhosa speakers would enhance any future study. It is also recommended that an SCI-specific cognitive battery be formulated, with potential amendments including additional attention and working memory assessment measures as well as tests targeting social cognition, procedural learning and a more comprehensive problem-solving measure. It is noted that existing neuropsychological measures for the latter two cognitive domains tend to have significant motor requirements, thus novel test design or

validated modification of existing instruments would be required. The outcomes of a larger control-matched study with an improved cognitive assessment battery could provide a basis for formulation of suitable compensatory and rehabilitative interventions to enhance the efficacy of patients' participation in their SCI rehabilitation programme.

Considering future research avenues related to South African SCI rehabilitation and cognition, longitudinal studies of the cognitive function of individuals with SCI, spanning acute, rehabilitation and community settings, are recommended. This may further enhance planning of SCI treatment by identifying the most effective stages for cognitively heavy aspects of rehabilitative intervention. It is recommended that such research includes correlation of pertinent physiological, psychological, somatic and behavioural comorbidities, as potential areas for parallel intervention that may in turn improve cognitive function. The seemingly high prevalence of mood disturbance in the current study's sample especially warrants further investigation, as does the potential differences between TSCI and NTSCI subgroups in cognitive and comorbidity profiles. In addition, consideration for use of different research methodologies, which are suited to indepth analysis of complex comorbidities, such as the Single-Case Study for Neuropsychology (Mazzi & Savazzi, 2019), is recommended.

Finally research into the current beliefs and practices of rehabilitation clinicians in South Africa, in terms of cognitive function in patients with SCI, is warranted. Such research might give insight into clinical assumptions that may in practice either hinder or help patients' optimal participation in their SCI rehabilitation. In conjunction with the further clinical research proposed in the paragraphs above, this insight into existing clinical beliefs and practice may provide a basis for interdisciplinary professional education and ultimately enhanced SCI rehabilitation programme planning and implementation.

Conclusion

The findings of this pilot study suggest that, as with evidence from HIC settings, SCI in South Africa is associated with cognitive dysfunction and a profile of comorbidities with established links to cognitive pathology. While methodological limitations mean that the cognitive profile generated must be interpreted with caution, there appear to be some differences with international trends (i.e., reduced attention, yet possible relatively spared processing speed and working memory), while other areas suggestive of deficit (i.e., learning/memory and certain executive functions) are congruent with international research findings. The profile of somatic and behavioural comorbidities with links to cognitive

dysfunction is similar to international trends, with the possibility that the prevalence of mood disturbance is higher in the current study's sample. It is notable that many of the cognitive domains known to be affected by these comorbidities are congruent with the identified areas of possible cognitive weakness in the present study's sample. The pilot study also generated evidence in support of previous findings of a distinct aetiological and epidemiological profile of South African public SCI inpatients as compared to global trends.

Comparison of the guarded cognitive profile and the participants' specialized SCI rehabilitation programme suggested that there was potential for a mismatch between the cognitive abilities of the patients and the cognitive demands implicit in the programme's structure and content. This could have implications for the efficacy of their rehabilitation and in turn, risk for complications on discharge from the rehabilitation setting. Perhaps, following evidence from a larger, more robust study, the discrepancy between cognitive abilities and demands could be considered in the formulation and design of SCI rehabilitation programmes moving forward.

As a pilot study, multiple areas for further investigation with improved methodology were identified. Nonetheless, it is clear that awareness of the potential for cognitive dysfunction in South African SCI rehabilitation inpatients is warranted, where consideration of its implications for rehabilitation program planning and implementation in local public health settings may well benefit the patients served.

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Appendix A

Table 18

Analysis of SCI Rehabilitation Programme Cognitive Demands

Programme Area	Activity	Task Details	Cognitive Components
Acquiring specific knowledge and skills related to new physiological condition	Bladder Management (Goal = managed continence i.e., nil bypassing urine, healthy urinary system)	Understanding/ adjusting to profound physiological changes in bladder function, including understanding risks, preventative strategies and bladder emptying techniques. Self-monitoring bladder function in the absence of sensory cues Recognizing symptoms of bladder complication, remembering and implementing appropriate steps to remedy and/or problem solving how to apply this in an out of hospital situation. Remembering to drink sufficient water (initially likely to be much more than premorbid consumption), or implementing compensatory memory strategies. Remembering to implement clean techniques when managing catheter and/or problem solving how to do this in an out of hospital environment, or implementing compensatory memory strategies. Depending on bladder management system prescribed (indwelling catheter or clean intermittent catheterization) this may also include: • Remembering to empty bladder approximately every two hours, or dependent on emptying regime prescribed • Independently managing/adjusting emptying times to accommodate changes in personal daily routine/environment	Attention Concentration Information processing Memory: Prospective memory Semantic memory Episodic memory Learning: Conceptual learning Procedural learning Verbal learning Executive functions: Working memory Problem solving Organization Planning Self-monitoring Reasoning Evaluation / Decision-making Initiation Comprehension Insight

Programme Area	Activity	Task Details	Cognitive Components
Acquiring specific knowledge and skills related to new physiological condition (continued)	Bowel Management (Goal = regular/predictable emptying of bowel with well-formed stool)	Understanding / adjusting to profound physiological changes in bowel function, including understanding risks, preventative strategies and bowel management techniques. Self-monitoring bowel function in the absence of sensory cues Monitoring and adjusting diet (often a very different diet to eaten premorbid, in order to enable regular bowel function). Remembering to drink sufficient water (usually much more than consumed premorbid), or use of compensatory memory strategies Self-monitor bowel function (including frequency and stool consistency) and adjust medication/diet accordingly Independently managing/adapting timing of bowel stimulation in accordance with changes in daily routine Depending on physical abilities (level of injury) bowel management may include: • Learning technique for inserting suppositories and/or digital (manual) bowel stimulation • Instructing a caregiver in the above • Self-monitoring bowel function (including timing of medication/bowel stimulation) in order to decide when to transfer to toilet/back to bed for a bed-based bowel routine • Learning how to clean up after bowel movement or instructing a caregiver (including appropriate steps for hygiene/infection prevention)	Attention Concentration Information processing Memory: Prospective memory Semantic memory Episodic memory Learning: Verbal learning Procedural learning Conceptual learning Executive functions: Working memory Problem solving Organization Planning Self-monitoring Reasoning Evaluation / Decision-making Initiation Comprehension Inhibition (related to diet and stopping self from eating potentially problematic foods) Insight

Programme Area	Activity	Task Details	Cognitive Components
Acquiring specific knowledge and skills related to new physiological condition (continued)	Bowel Management (continued)	• Problem solving to adapt routine learnt in hospital for out of hospital environment (challenges may include inaccessible toilet facilities, sub optimal cleaning facilities, running out of medication)	
Acquiring specific knowledge and skills related to new physiological condition	Skin Management (goal = nil pressure ulcer formation)	Understanding / adjusting to profound physiological changes in skin function, including understanding risks and preventative strategies including pressure relief techniques. Self-monitoring skin integrity in the absence of sensory cues and adapting this to environmental changes that may have an effect on risk (i.e., climatic changes, different surfaces will pose different risks for pressure sore formation) Remembering to implement pressure relief strategies hourly or as prescribed (independently or instructing caregiver), or use of compensatory memory strategies Implementing a night time schedule for skin integrity (this may include waking to turn self, or ensuring that this is completed by caregiver)	Attention Concentration Visual and tactile perception Memory: Prospective memory Semantic memory Episodic memory Conceptual learning Learning: Information processing Verbal learning Procedural learning Executive functions: Problem solving / Reasoning Working memory Organization / Planning Self-monitoring Evaluation / Decision-making Initiation Comprehension Insight

Programme Area	Activity	Task Details	Cognitive Components
Acquiring specific knowledge and skills related to new physiological condition (continued)	Medication Management	Understanding reason for medication. Remembering what/when/how to take prescribed medication or use of compensatory memory strategies Ensuring uninterrupted supply of medication (this may include remembering to collect medication from clinic including problem solving for potential logistical challenges related to this)	Attention Concentration Information processing Memory: Prospective memory Semantic memory Episodic memory Executive functions: Working memory Problem solving / Reasoning Planning / Organization Decision-making Initiation Comprehension Insight
Acquiring specific knowledge and skills related to new physiological condition	Managing Sexuality	Understanding/adjusting to profound physiological changes in sexual function (as well as socioemotional changes). May include: • Discussing the above with intimate partners • Problem solving/adapting sexual performance for changes in physical function and to minimise secondary risks • Remembering/planning how to implement medical management advice	Attention Concentration Information processing Memory: Semantic memory Episodic memory Executive functions: Abstract thinking Problem solving / Reasoning Planning / Organization Self-monitoring Evaluation / Decision-making Initiation Comprehension

Programme Area	Activity	Task Details	Cognitive Components
Acquiring specific skills related to new functional capacity	Activities of Daily Living	Learning new techniques for dressing/washing/household tasks (depending on level of injury/physical function, this may include instructing a caregiver to aid or carry these tasks out) Adapting new skills/techniques to different out of hospital environments.	Attention Concentration Information Processing Learning and Memory: Procedural learning Executive functions: Problem solving / Reasoning Working memory Organization / Planning (preparing task elements) Self-monitoring Decision-making Initiation Comprehension
Acquiring specific skills related to new functional capacity	Transfers	Learning new ways to move self safely from surface to surface (either independently or through instructing a caregiver to assist). Assessing risk vs ability and adapting techniques to respond to different environmental challenges, including managing the consequences of a failed transfer.	Attention Concentration Learning: Procedural learning Executive functions: Problem solving Self-monitoring / insight Evaluation / Decision-making (matching ability level to environmental challenge) Initiation

Programme Area	Activity	Task Details	Cognitive Components
Acquiring specific skills related to new functional capacity (continued)	Assistive Devices	Learning how to use mobility (i.e., wheelchair) and other assistive devices Learning how to maintain/repair assistive devices (including problem solving for potential logistical challenges related to this) Adapting use of assistive devices according to environmental barriers	Attention Concentration Information processing Memory: Semantic memory Episodic memory Learning: Verbal learning Procedural learning Conceptual learning Executive functions: Problem solving / Reasoning Working memory Planning / Organization Self-monitoring Evaluation / Decision-making (matching ability level to environmental challenge) Initiation Comprehension

Programme Area	Activity	Task Details	Cognitive Components
General participation in a rehabilitation setting	Goal setting	Participating in a goal setting meeting: Facilitated identification of short-, medium- and long- term goals based on an understanding of injury and implications for physical function (i.e. participation goals for within both hospital and home environments)	Attention / Concentration (goal setting meetings at least 30-60 minutes, only talking) Information Processing Memory: Semantic memory Episodic memory Executive functions: Working memory Abstract reasoning Planning Self-monitoring Reasoning Evaluation / Decision-making Initiation Comprehension
General participation in a rehabilitation setting	Participating in individual therapy sessions	Working with a health professional on specific component aspects derived from goals set (as per above). This may include work in shared therapy spaces and in second/third language.	Attention / Concentration Information Processing Memory: Semantic memory Episodic memory Learning: Verbal learning Procedural learning Conceptual learning Executive functions: Working memory Self-monitoring Decision-making Initiation Comprehension

Programme Area	Activity	Task Details	Cognitive Components
General participation in a rehabilitation setting (continued)	Participating in group sessions	Participating with health professional/s and/or other patients and/or peers in various goal directed group tasks and activities.	Attention / Concentration Information Processing Executive functions: Social cognition Self-monitoring Decision-making Problem solving / Reasoning Initiation Inhibition Comprehension
General participation in a rehabilitation setting	Living in a shared ward environment	Complying with institutional rules/routines Acting on instructions from nursing staff Getting along with fellow patients including negotiating/navigating use of shared facilities	Memory: Semantic memory Episodic memory Executive functions: Social cognition Decision making Judgement Comprehension Problem solving / Reasoning Initiation Inhibition

Appendix B

University of California Brief Assessment of Capacity to Consent (UBACC)

	Trial 1 Circle	Trial 2 Circle	Trial 3 Circle	Trial 4 Circle
1. What is the purpose of the study just described to you?				
Response (2 = study investigates thinking skills/learning/cognition in people with spinal cord injury (SCI), thinking skills and SCI rehabilitation) 1 = one concept (investigate learning/cognition/thinking skills or SCI rehab) 2 = Whole concept	0 1 2	0 1 2	0 1 2	0 1 2
2. What makes you want to consider participating in this study?				
Response (to find out more about my thinking skills/cognition, to help my rehab, help improve SCI rehab) 1 = one concept 2 = 2 or 3 concepts	0 1 2	0 1 2	0 1 2	0 1 2
3. Do you believe this is mainly for research or mainly for treatment?				
Research = 2	0 2	0 2	0 2	0 2
4. Do you have to be in this study if you do not want to participate?				
No = 2 (I don't know or yes = 0)	0 2	0 2	0 2	0 2
5. If you withdraw from this study, will you still be able to receive WCRC treatment?				
Yes = 2 (I don't know or no = 0)	0 2	0 2	0 2	0 2
6. If you participate in this study, what are some of the things you will be asked to do?				
Response (thinking skills tasks/tests (e.g., memory/understanding), questionnaires/interview) 1 = one concept 2 = two concepts	0 1 2	0 1 2	0 1 2	0 1 2
7. Please describe some of the discomforts that people may experience if they participate in this study?				
Response: get tired/fatigued	0 2	0 2	0 2	0 2
8. Please describe some of the possible benefits of this study?				
Response (Information to help my therapy team plan my rehab/improve rehab for future patients) 1 = one concept 2 = two concepts	0 1 2	0 1 2	0 1 2	0 1 2
9. Is it possible that this study will not have any benefit to you?				
Yes = 2	0 2	0 2	0 2	0 2
10. If you agree to participate, who at WCRC will receive information on your assessment results?				
2 = my WCRC therapy team (OT/PT/SW/doctor/Psych/nursing)	0 2	0 2	0 2	0 2
TOTAL SCORE must achieve at least 14.5 to take part →				

Appendix C

Informed Consent Documents

CONSENT FOR PARTICIPATION IN A RESEARCH STUDY

TITLE: *Investigating the Characteristics and Deficiencies of Cognitive Function in a Sample of Spinal Cord Injury Inpatients, in Relation to the Cognitive Demands of their Specialized Rehabilitation Program: An Exploratory South African Public Health Sector Study*

Name of Participant: _____

PRINCIPAL INVESTIGATOR:

Emma-Louise Newbery (Supervised by Dr Leigh Schrieff)
Department of Psychology
Division of Neuropsychology
University of Cape Town
Rondebosch
7701
Contact number: 084 757 1574

This Informed Consent Form has two parts:

- **Information Sheet (to share information about the research with you)**
- **Certificate of Consent (for signatures if you agree to take part)**

You will be given a copy of the full Informed Consent Form

PART I: Information Sheet

Introduction
I am a Neuropsychology Masters candidate at UCT. As part of the requirements of my degree, I am doing research on cognition (the way people think) and how this relates to a spinal cord injury rehabilitation program. I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research.

There may be some words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain.

Purpose of the research
SCI is often an unexpected and life-changing event, which requires those affected to learn many new ways of doing things and looking after their bodies. Rehabilitation hospitals like WCRC assist patients to learn all of these new skills by having them participate in a specialized SCI rehabilitation program. We know that learning new skills requires good thinking (cognitive) skills, and research done overseas shows that these skills can sometimes be affected in people with SCI, but there hasn't been any research done in South Africa into cognitive skills and SCI. The reasons people have SCI in South Africa are sometimes quite different to overseas, and our health system is also quite different. Therefore, the reason I am doing this research is to understand more about the cognitive skills, and other things that may affect thinking of people who have recently sustained a SCI in South Africa. I will also look at how the thinking skills match with skills needed for the SCI rehabilitation program. If we understand the needs of people who are coming for SCI rehabilitation better, we might be able to improve the SCI rehabilitation programs in countries with similar challenges to ours, so that patients who come through these programs have a better chance of a healthy and fulfilling life after their SCI.

Type of Research Intervention
This research will require you to participate in two assessment sessions at the beginning of your time at WCRC, and the primary researcher will also need to look at your WCRC medical file.

Participant selection
We are inviting all adults (18-65 years) who are in their first two weeks of SCI rehabilitation at WCRC, for a new SCI to participate in this research.

Voluntary Participation
Your participation in this research is entirely voluntary. This means that it is your choice whether to participate or not. Regardless of your decision, all the rehabilitation services you receive at WCRC will continue unchanged. You may change your decision at any time, even if you have already begun participating. If you have any questions regarding your rights in this research, you may phone Rosalind Adams in the Psychology Department offices at +27 21 650 3417.

Procedures and Protocol
If you agree to participate in the research, the main researcher will look at the medical notes taken when you were admitted to WCRC in order to fill in a form with information related to your SCI and medical history.

Within your first two weeks at WCRC, you will have two assessment sessions with a researcher who is trained to complete neuropsychology tests. The first session will take 1-2 hours and you will complete a few tasks to measure different thinking skills (some examples are remembering, reasoning and understanding). None of these tasks will require you to use your hands, and they will be completed in a language you can

understand. The second session will take about 45 minutes and you will be asked to answer a few sets of questions (questionnaires) on some things that are known to affect people's cognitive ability (sleep, pain, mood and substance use) as well as a questionnaire on how you complete certain daily tasks.

The researcher will agree on the assessment times with all of the members of your rehabilitation team (ie. Physio, OT, social worker, nurses, doctor, speech therapist and/or psychologist) so that they cause as little disruption as possible to your rehabilitation program.

At the end of each session you will also be given feedback on your results and you will have a chance to ask any questions you would like to. A summary of the results will be given to your rehabilitation team, so that they can investigate these further if they need to, and can also give you any further support related to the results that you might feel that you need.

Risks
There are no physical risks involved in participating in this research.

It is possible that you may find the assessment sessions tiring, but you will be able to take breaks throughout the sessions as you need them. It is possible that answering the questionnaires or taking part in the cognitive assessment may make you aware of unexpected difficulties. You will have an opportunity at the end of the sessions to ask any questions that may arise, and you will be able get further support from you WCRC team, who will be aware that you are participating.

Benefits
The results of each assessment session will be made available to your therapy team, who will be able to investigate this information further. This may enrich the planning of your individual rehabilitation program.

In terms of future benefit, this research may help us to better understand the challenges faced by individuals who have a SCI and are participating in a SCI rehabilitation program. We hope that this may in turn improve the way that rehabilitation for SCI is offered in future.

Reimbursements
You will not receive any money or gifts in exchange taking part in this research.

Confidentiality
A summary of the results will be provided to your therapists, and will therefore be subject to WCRC's rules governing confidentiality. Other than these standard procedures within WCRC, the information that we collect from this research project will be kept confidential, which means that outside of WCRC, no-one but the researchers will be able to see it. No information with your name on it will leave WCRC. Any assessment results taken from the hospital for the research will have a number on it instead of your name. Only the researcher will know what your number is and we keep this in a secure electronic database, which will be deleted once the research is completed.

Sharing the Results
You will be able to ask the researcher any questions related to your assessment sessions at the end of each session. At the end of the research period, the results may be shared with other rehabilitation professionals through presentations or publications, however confidential or identifiable information will never be shared.

Right to Refuse or Withdraw
Your participation in this research is voluntary and you may stop participating at any time. Refusing to participate or withdrawing from participation will not affect your right to treatment at WCRC in any way

Who to Contact

You may ask any questions related to the research now, later or even when you have started participating in the study. You may contact any of the following:

Emma-Louise Newbery (Principal researcher): gryemm002@myuct.ac.za, 084 7571574
Leigh Schrieff (Supervisor): leigh.schrieff-elson@uct.ac.za, 021 650 3708

This proposal has been reviewed and approved by the UCT Faculty of Health Human Research Ethics Committee (UCT FHS HREC) and UCT Psychology Department Ethics Committee, which is a committee whose task it is to make sure that research participants are protected from harm. If you wish to find about more about the UCT FHS HREC, contact UCT Faculty of Health Sciences on 021 650 3002, if you wish to find out more about the UCT Psychology Ethics committee, you may contact Rosalind Adams in the
Psychology Department offices at +27 21 650 3417.

PART II: Certificate of Consent
I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research.

Print Name of Participant_____
Signature of Participant _____
Date _____
Day/month/year

If illiterate
A literate witness must sign (if possible, this person should be selected by the participant and should have no connection to the research team). Participants who are illiterate should include their thumb-print as well.

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness_____ **AND** **Thumb print of participant**
Signature of witness _____
Date _____
Day/month/year

Statement by the researcher/person taking consent
I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:
1. The admission clerking forms within their WCRC medical folder will be reviewed by the researcher to obtain specific demographic information related to their health condition.
2. They will participate in two assessment sessions within the first two weeks of their WCRC admission.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent_____

Signature of Researcher /person taking the consent_____
Date _____
Day/month/year

Appendix D

Demographic Questionnaire and Asset Index

Birth date (YYYYMMDD) __ __ __ __/ __ __/ __ __

Injury date (YYYYMMDD) __ __ __ __/ __ __/ __ __

Acute Admission (YYYYMMDD) __ __ __ __/ __ __/ __ __

Rehabilitation Admission (YYYYMMDD) __ __ __ __/ __ __/ __ __

Gender: □ Male □ Female □ Transgender and other related □ Unknown

Home Language: _____ **Assessment Language:** □ Eng □ Afr

SPINAL CORD INJURY SPECIFIC INFORMATION:

Injury Aetiology:

□ Sports □ Assault - gunshot □ Assault – other □ Transport □ Fall;

□ Birth injury or other traumatic cause

□ Congenital or genetic Specify:_____

□ Degenerative non-traumatic etiology

□ Tumor – benign □ Tumor – malignant □ Vascular etiology □ Infection

□ TB Spine □ Other non-traumatic SC dysfunction Specify: _____

□ Unspecified or Unknown

Vertebral Injury: □ No □ Yes □ Unknown

Associated Injury: □ No □ Yes □ Unknown

Spinal Surgery: □ No □ Yes □ Unknown

Ventilatory Assistance:

□ No □ Yes, < 24 hrs pd □ Yes, 24 hrs/d □ Yes, unknown number hrs/d

□ Continuous Positive Airway Pressure (CPAP) for sleep apnea □ Unknown

Neurological Data:

Date of neurological examination: _____ ASIA Score _____

Sensory Level Left_____ Right _____

Motor Level Left _____ Right_____

SUPPLEMENTARY MEDICAL INFORMATION:

Current Medication and dosage:

_____

_____

Diagnosed comorbid health conditions: _____ _____

HOUSEHOLD INCOME: (Please circle appropriate number for household income per year)

R0	1
R1 – R5 000	2
R5001 – R25 000	3
R25 000 – R100 000	4
R100 001+	5

EDUCATION: (Please circle appropriate number for highest level of education reached)

0 years (No Grades / Standards) = No formal education (never went to school)	1
1-6 years (Grades 1-6 / Sub A-Std 4) = Less than primary education (didn't complete primary school)	2
7 years (Grade 7 / Std 5) = Primary education (completed primary school)	3
8-11 years (Grades 8-11 / Stds 6-9) = Some secondary education (didn't complete high school)	4
12 years (Grade 12 / Std 10) = Secondary education (completed senior school)	5
13+ years = Tertiary education (completed university / technikon / college)	6
Don't know	7

EMPLOYMENT (Hollingstead categories): (Please circle appropriate number)

Higher executives, (e.g. major professionals, owners of large businesses)	1
Business managers of medium sized businesses, lesser professions (e.g. nurses, opticians, pharmacists, social workers, teachers)	2
Administrative personnel, managers, minor professionals, owners / proprietors of small businesses (e.g. bakery, car dealership, engraving business, plumbing business, florist, decorator, actor, reporter, travel agent)	3
Clerical and sales, technicians, small businesses (e.g. bank teller, bookkeeper, clerk, draftsperson, timekeeper, secretary)	4
Skilled manual – usually having had training (e.g. baker, barber, chef, electrician, fireman, machinist, mechanic, painter, welder, police, plumber, electrician)	5
Semi-skilled (e.g. hospital aide, painter, bartender, bus driver, cook, garage guard, checker, waiter, machine operator)	6

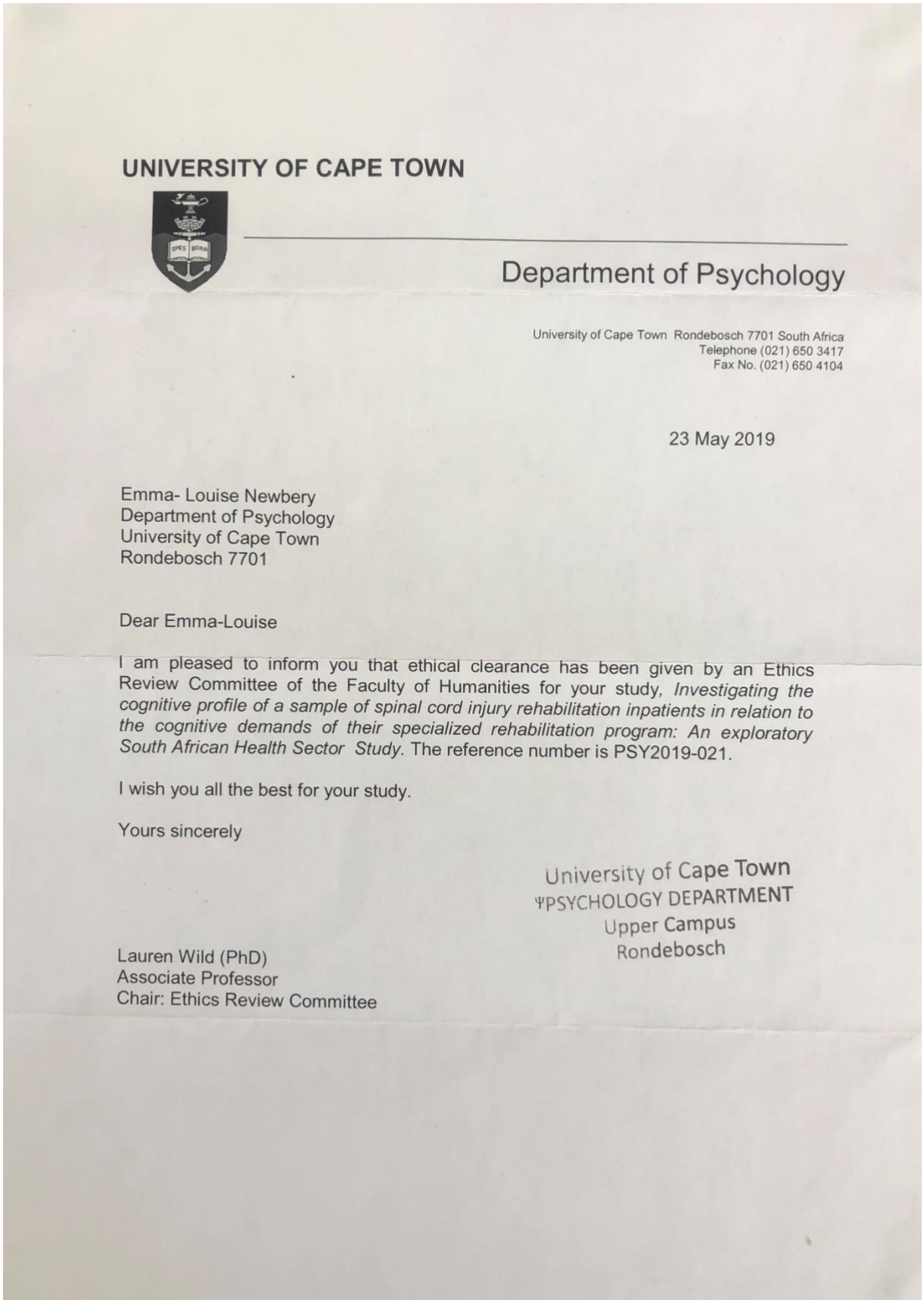
Unskilled (e.g. attendant, janitor, construction helper, unspecified labour, porter, unemployed)	7
Homemaker	8
Student, disabled, no occupation	9

MATERIAL AND FINANCIAL RESOURCES (ASSET INDEX): (Please circle appropriate number)

Which of the following items, in working order, does your household have?	**Yes**	**No**
A refrigerator or freezer	1	1
A vacuum cleaner or polisher	2	2
A television	3	3
A hi-fi or music center (radio excluded)	4	4
A microwave oven	5	5
A washing machine	6	6
A video cassette recorder or dvd player	7	7
Which of the following do you have in your home?	**Yes**	**No**
Running water	1	1
A domestic worker	2	2
At least one car	3	3
A flush toilet	4	4
A built-in kitchen sink	5	5
An electric stove or hotplate	6	6
A working telephone	7	7
Do you personally do any of the following?	**Yes**	**No**
Shop at supermarkets	1	1
Use any financial services such as a bank account, ATM card or credit card	2	2
Have an account or credit card at a retail store	3	3

Appendix E

UCT Department of Psychology Research Ethics Committee Ethical Approval



UNIVERSITY OF CAPE TOWN

Department of Psychology

University of Cape Town Rondebosch 7701 South Africa
Telephone (021) 650 3417
Fax No. (021) 650 4104

23 May 2019

Emma- Louise Newbery
Department of Psychology
University of Cape Town
Rondebosch 7701

Dear Emma-Louise

I am pleased to inform you that ethical clearance has been given by an Ethics Review Committee of the Faculty of Humanities for your study, *Investigating the cognitive profile of a sample of spinal cord injury rehabilitation inpatients in relation to the cognitive demands of their specialized rehabilitation program: An exploratory South African Health Sector Study*. The reference number is PSY2019-021.

I wish you all the best for your study.

Yours sincerely

University of Cape Town
PSYCHOLOGY DEPARTMENT
Upper Campus
Rondebosch

Lauren Wild (PhD)
Associate Professor
Chair: Ethics Review Committee

Appendix F

UCT Faculty of Health Sciences Human Research Ethics Committee Ethical Approval

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

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone (021) 406 6626
Email: shunita.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

02 August 2019

HREC REF: 360/2019

Dr L Schrieff-Elson
Psychology
Humanities Graduate School Building
Upper Campus

Dear Dr Schrieff-Elson

PROJECT TITLE: INVESTIGATING THE CHARACTERISTICS AND DEFICITS OF COGNITIVE FUNCTIONING IN A SAMPLE OF SPINAL CORD INJURY INPATIENTS, IN RELATION TO THE COGNITIVE DEMANDS OF THEIR SPECIALIZED REHABILITATIDN PROGRAM: AN EXPLORATORY SOUTH AFRICAN PUBLIC HEALTH SECTOR STUDY (MA CANDIDATE - MRS E-L NEWBERY)

Thank you for submitting your response to the Faculty of Health Sciences Human Research Ethics Committee.

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

Approval is granted for one year until the 30 August 2020.

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 quote the HREC REF in all your correspondence.

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, where necessary, before the research may occur.

The HREC acknowledge that the student, Emma-Louise Newbery will also be involved int this study.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines.
The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Appendix G

Western Cape Department of Health Access Approval

Western Cape Government
Health

Health Impact Assessment
Health Research sub-directorate
Health.Research@westerncape.gov.za
tel: +27 21 483 6857: fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: WC_201908_022
ENQUIRIES: Dr Sabela Petros

University of Cape Town

Anzio Road

Observatory

Cape Town

7925

For attention: Dr Leigh Schrieff-Elson, Mrs Emma-Louise Newbery

Re: **Investigating the Characteristics and Deficits of Cognitive Functioning in a Sample of Spinal Cord Injury Inpatients, in Relation to the Cognitive Demands of their Specialized Rehabilitation Program: An Exploratory South African Public Health Sector Study.**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following people to assist you with any further enquiries in accessing the following sites:

Western Cape Rehabilitation Centre	**Jonathan Vaughan**	**021 370 2313**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely

14/09/2014

DR M MOODLEY
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE:
CC

Appendix H

Additional Results Tables

Table 15

Kendall's Tau-b Correlations: Cognitive Test Scores (N=29)

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Attention (1) [i]	Correlation Coefficient	1.000	.323*	0.251	0.042	0.033	-0.043	0.014	-0.054	0.036	0.039	-0.060	0.117	-0.115	0.017	-0.104	-0.051	0.070	0.115	0.151	-0.101	-0.037
	Sig. (2-tailed)		0.029	0.084	0.771	0.816	0.769	0.923	0.712	0.801	0.786	0.682	0.424	0.426	0.907	0.472	0.756	0.662	0.418	0.347	0.516	0.809
Working Memory (2)[ii]	Correlation Coefficient	.323*	1.000	0.229	0.112	0.149	0.238	0.084	0.028	0.072	0.204	-0.003	0.136	-0.022	0.017	-0.081	0.007	-0.003	0.149	-0.035	-0.110	-0.128
	Sig. (2-tailed)	0.029		0.111	0.437	0.295	0.104	0.550	0.846	0.615	0.152	0.984	0.349	0.877	0.907	0.573	0.965	0.983	0.289	0.827	0.477	0.397
Processing Speed (3)[iii]	Correlation Coefficient	0.251	0.229	1.000	0.247	0.086	0.264	0.136	0.257	0.270	.353*	-0.038	0.212	0.178	0.240	0.198	0.205	.343*	0.018	-0.216	-.298*	-0.077
	Sig. (2-tailed)	0.084	0.111		0.082	0.542	0.067	0.324	0.069	0.054	0.012	0.788	0.139	0.207	0.094	0.163	0.197	0.028	0.894	0.168	0.050	0.605
Crystalized Intelligence (4)[iv]	Correlation Coefficient	0.042	0.112	0.247	1.000	.467**	.537**	.753**	-0.133	0.078	0.024	0.093	0.257	.327*	0.207	0.214	.355*	0.135	-0.192	-0.277	-.320*	-0.110
	Sig. (2-tailed)	0.771	0.437	0.082		0.001	0.000	0.000	0.348	0.580	0.864	0.513	0.074	0.021	0.149	0.131	0.026	0.389	0.165	0.077	0.036	0.462
Visual Reasoning (5)[v]	Correlation Coefficient	0.033	0.149	0.086	.467**	1.000	.348*	.703**	-0.171	0.122	0.071	0.084	0.011	0.088	0.104	0.243	.377*	0.040	0.104	0.096	-0.039	-0.044
	Sig. (2-tailed)	0.816	0.295	0.542	0.001		0.015	0.000	0.222	0.382	0.608	0.552	0.939	0.529	0.466	0.083	0.016	0.796	0.449	0.533	0.795	0.766
Abstract Reasoning (6)[vi]	Correlation Coefficient	-0.043	0.238	0.264	.537**	.348*	1.000	.469**	-0.241	0.066	-0.041	0.053	0.048	0.259	0.107	0.230	.465**	0.293	-0.081	-0.079	-0.196	-0.045
	Sig. (2-tailed)	0.769	0.104	0.067	0.000	0.015		0.001	0.093	0.645	0.773	0.713	0.742	0.070	0.461	0.110	0.004	0.065	0.566	0.617	0.204	0.764
Intelligence (7)[vii]	Correlation Coefficient	0.014	0.084	0.136	.753**	.703**	.469**	1.000	-0.173	0.098	0.013	0.124	0.149	0.255	0.112	0.162	.328*	0.081	-0.101	-0.117	-0.182	-0.114
	Sig. (2-tailed)	0.923	0.550	0.324	0.000	0.000	0.001		0.210	0.472	0.925	0.370	0.286	0.063	0.422	0.239	0.033	0.593	0.451	0.441	0.218	0.430
Verbal Learning/Memory Trial 5(8)[viii]	Correlation Coefficient	-0.054	0.028	0.257	-0.133	-0.171	-0.241	-0.173	1.000	.406**	.516**	0.033	0.223	-0.040	0.108	0.065	-0.132	-0.067	0.094	-0.064	-0.006	-0.142
	Sig. (2-tailed)	0.712	0.846	0.069	0.348	0.222	0.093	0.210		0.004	0.000	0.818	0.119	0.774	0.453	0.646	0.406	0.666	0.494	0.682	0.968	0.340

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Verbal Learning/Memory - immediate recall (9)[ix]	Correlation Coefficient	0.036	0.072	0.270	0.078	0.122	0.066	0.098	.406**	1.000	.628**	0.221	0.084	0.202	0.022	.382**	0.034	-0.043	0.008	-0.106	-0.114	-0.260
	Sig. (2-tailed)	0.801	0.615	0.054	0.580	0.382	0.645	0.472	0.004		0.000	0.117	0.553	0.148	0.878	0.006	0.828	0.780	0.955	0.492	0.449	0.078
Verbal Learning/Memory – delayed recall (10)[x]	Correlation Coefficient	0.039	0.204	.353*	0.024	0.071	-0.041	0.013	.516**	.628**	1.000	0.178	0.084	0.069	-0.076	0.216	-0.017	0.027	0.060	-0.213	-0.216	-0.281
	Sig. (2-tailed)	0.786	0.152	0.012	0.864	0.608	0.773	0.925	0.000	0.000		0.206	0.553	0.620	0.591	0.123	0.913	0.864	0.663	0.169	0.151	0.057
Inhibition – errors (11)[xi]	Correlation Coefficient	-0.060	-0.003	-0.038	0.093	0.084	0.053	0.124	0.033	0.221	0.178	1.000	-0.067	.329*	-0.164	0.126	-0.228	0.088	-0.140	-0.279	-0.126	-0.057
	Sig. (2-tailed)	0.682	0.984	0.788	0.513	0.552	0.713	0.370	0.818	0.117	0.206		0.643	0.020	0.254	0.377	0.154	0.574	0.312	0.076	0.410	0.705
Inhibition – time (12)[xii]	Correlation Coefficient	0.117	0.136	0.212	0.257	0.011	0.048	0.149	0.223	0.084	0.084	-0.067	1.000	0.060	.546**	0.187	0.060	0.014	-0.072	-0.212	-0.176	-0.235
	Sig. (2-tailed)	0.424	0.349	0.139	0.074	0.939	0.742	0.286	0.119	0.553	0.553	0.643		0.673	0.000	0.192	0.709	0.931	0.606	0.180	0.252	0.120
Cognitive Flexibility – errors (13)[xiii]	Correlation Coefficient	-0.115	-0.022	0.178	.327*	0.088	0.259	0.255	-0.040	0.202	0.069	.329*	0.060	1.000	0.173	0.239	0.107	0.130	-.373**	-.445**	-0.226	-0.277
	Sig. (2-tailed)	0.426	0.877	0.207	0.021	0.529	0.070	0.063	0.774	0.148	0.620	0.020	0.673		0.226	0.089	0.498	0.401	0.007	0.004	0.134	0.062
Cognitive Flexibility – time (14)[xiv]	Correlation Coefficient	0.017	0.017	0.240	0.207	0.104	0.107	0.112	0.108	0.022	-0.076	-0.164	.546**	0.173	1.000	.422**	0.297	-0.034	-0.059	-0.161	-0.105	-0.096
	Sig. (2-tailed)	0.907	0.907	0.094	0.149	0.466	0.461	0.422	0.453	0.878	0.591	0.254	0.000	0.226		0.003	0.065	0.828	0.674	0.308	0.494	0.522
Generativity (15)[xv]	Correlation Coefficient	-0.104	-0.081	0.198	0.214	0.243	0.230	0.162	0.065	.382**	0.216	0.126	0.187	0.239	.422**	1.000	.433**	0.219	-0.144	-0.138	-0.121	-0.121
	Sig. (2-tailed)	0.472	0.573	0.163	0.131	0.083	0.110	0.239	0.646	0.006	0.123	0.377	0.192	0.089	0.003		0.006	0.162	0.296	0.377	0.423	0.415
Prospective Memory – time based (16)[xvi]	Correlation Coefficient	-0.051	0.007	0.205	.355*	.377*	.465**	.328*	-0.132	0.034	-0.017	-0.228	0.060	0.107	0.297	.433**	1.000	.444*	-0.060	-0.017	-0.027	0.155
	Sig. (2-tailed)	0.756	0.965	0.197	0.026	0.016	0.004	0.033	0.406	0.828	0.913	0.154	0.709	0.498	0.065	0.006		0.011	0.696	0.922	0.873	0.352
Prospective Memory – event based (17)[vxii]	Correlation Coefficient	0.070	-0.003	.343*	0.135	0.040	0.293	0.081	-0.067	-0.043	0.027	0.088	0.014	0.130	-0.034	0.219	.444*	1.000	-0.205	-0.251	-0.302	0.066
	Sig. (2-tailed)	0.662	0.983	0.028	0.389	0.796	0.065	0.593	0.666	0.780	0.864	0.574	0.931	0.401	0.828	0.162	0.011		0.177	0.146	0.072	0.687
Subjective Prospective Memory (18)[xviii]	Correlation Coefficient	0.115	0.149	0.018	-0.192	0.104	-0.081	-0.101	0.094	0.008	0.060	-0.140	-0.072	-.373**	-0.059	-0.144	-0.060	-0.205	1.000	.453**	.376*	.304*
	Sig. (2-tailed)	0.418	0.289	0.894	0.165	0.449	0.566	0.451	0.494	0.955	0.663	0.312	0.606	0.007	0.674	0.296	0.696	0.177		0.003	0.011	0.036

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Subjective Concentration (19)[xix]	Correlation Coefficient	0.151	-0.035	-0.216	-0.277	0.096	-0.079	-0.117	-0.064	-0.106	-0.213	-0.279	-0.212	-.445**	-0.161	-0.138	-0.017	-0.251	.453**	1.000	.509**	0.217
	Sig. (2-tailed)	0.347	0.827	0.168	0.077	0.533	0.617	0.441	0.682	0.492	0.169	0.076	0.180	0.004	0.308	0.377	0.922	0.146	0.003		0.002	0.187
Subjective Problem solving (20)[xx]	Correlation Coefficient	-0.101	-0.110	-.298*	-.320*	-0.039	-0.196	-0.182	-0.006	-0.114	-0.216	-0.126	-0.176	-0.226	-0.105	-0.121	-0.027	-0.302	.376*	.509**	1.000	.594**
	Sig. (2-tailed)	0.516	0.477	0.050	0.036	0.795	0.204	0.218	0.968	0.449	0.151	0.410	0.252	0.134	0.494	0.423	0.873	0.072	0.011	0.002		0.000
Subjective Procedural Learning (21)[xxi]	Correlation Coefficient	-0.037	-0.128	-0.077	-0.110	-0.044	-0.045	-0.114	-0.142	-0.260	-0.281	-0.057	-0.235	-0.277	-0.096	-0.121	0.155	0.066	.304*	0.217	.594**	1.000
	Sig. (2-tailed)	0.809	0.397	0.605	0.462	0.766	0.764	0.430	0.340	0.078	0.057	0.705	0.120	0.062	0.522	0.415	0.352	0.687	0.036	0.187	0.000	

NOTES:
Significant correlations are highlighted in red
Sig. (2-tailed) = two tailed significance value

i. WAIS III Digit Span Forward
ii. WAIS III Digit Span Backward
iii. WAIS III Symbol Search
iv. WASI Vocabulary
v. WASI Matrix Reasoning
vi. WASI Similarities
vii. WASI FISQ 2
viii. AVLT Trial 5
ix. AVLT Immediate Recall trial
x. AVLT Delayed Recall trial
xi. D-KEFS Inhibition errors score
xii. D-KEFS Inhibition time score
xiii. D-KEFS Inhibition/Switching errors score
xiv. D-KEFS Inhibition/Switching time score
xv. COWAT Semantic Fluency -Animals category
xvi. RPA ProMem time-based task score
xvii. RPA ProMem event-based task score
xviii. PRMQ Prospective memory score
xix. WHODAS 2.0 Domain 1.1
xx. WHODAS2.0 Domain 1.3
xxi. WHODAS 2.0 Domain 1.4

All correlation calculations are based on z-scores derived from international norms, except FISQ2 (IQ score) and RPA ProMem and WHODAS 2/0 (raw scores)
**. Correlation is significant at the 0.01 level (2-tailed).; *. Correlation is significant at the 0.05 level (2-tailed).

Table 16

Kendall's Tau-b Correlations: Comorbidity to Cognitive Test Score Correlations (N=29)

		Anxiety (HADS)	Depression (HADS)	Sleep Quality (PSQI)
Attention (WAIS III Digit Span Forward)	Correlation Coefficient	-0.059	0.078	0.242
	Sig. (2-tailed)	0.684	0.587	0.092
Working Memory (WAIS III Digit Span Backward)	Correlation Coefficient	0.008	-0.083	.284*
	Sig. (2-tailed)	0.954	0.561	0.046
Processing Speed (WAIS III Symbol Search)	Correlation Coefficient	0.051	-0.204	0.008
	Sig. (2-tailed)	0.717	0.147	0.954
Visual Reasoning (WASI Matrix Reasoning)	Correlation Coefficient	-0.048	-0.096	0.209
	Sig. (2-tailed)	0.732	0.493	0.133
Abstract Reasoning (WASI Similarities)	Correlation Coefficient	-0.121	-0.267	-0.052
	Sig. (2-tailed)	0.397	0.062	0.715
Intelligence (WASI FISQ 2)	Correlation Coefficient	-0.223	-0.148	0.008
	Sig. (2-tailed)	0.103	0.280	0.955
Verbal Learning/Memory (AVLT Trial 5)	Correlation Coefficient	-0.005	-0.016	0.003
	Sig. (2-tailed)	0.970	0.909	0.985
Verbal Learning/Memory (AVLT Immediate Recall)	Correlation Coefficient	-0.093	-0.077	-0.108
	Sig. (2-tailed)	0.506	0.581	0.436
Verbal Learning/Memory (AVLT Delayed Recall)	Correlation Coefficient	0.032	-0.117	0.077
	Sig. (2-tailed)	0.819	0.402	0.582
Inhibition – errors (D-KEFS Inhibition)	Correlation Coefficient	0.070	0.041	0.092
	Sig. (2-tailed)	0.618	0.774	0.515

		Anxiety (HADS)	Depression (HADS)	Sleep Quality (PSQI)
Inhibition – time (D-KEFS Inhibition)	Correlation Coefficient	-.343*	-0.194	0.019
	Sig. (2-tailed)	0.016	0.173	0.893
Cognitive Flexibility – errors (D-KEFS Inhibition/Switching)	Correlation Coefficient	-0.224	-0.120	-.337*
	Sig. (2-tailed)	0.109	0.391	0.016
Cognitive Flexibility – time (D-KEFS Inhibition/Switching)	Correlation Coefficient	-0.213	-0.216	-0.133
	Sig. (2-tailed)	0.134	0.129	0.347
Generativity (COWAT Semantic Fluency -Animals)	Correlation Coefficient	-0.110	-0.263	-0.096
	Sig. (2-tailed)	0.434	0.061	0.493
Prospective Memory – time based (RPA ProMem)	Correlation Coefficient	0.021	-.313*	-0.065
	Sig. (2-tailed)	0.896	0.047	0.679
Prospective Memory – event based (RPA ProMem)	Correlation Coefficient	0.187	-0.150	0.093
	Sig. (2-tailed)	0.228	0.333	0.548
Subjective Prospective Memory (PRMQ)	Correlation Coefficient	.337*	0.151	0.202
	Sig. (2-tailed)	0.014	0.272	0.140
Subjective Concentration (WHODAS D1.1)	Correlation Coefficient	0.133	-0.020	0.236
	Sig. (2-tailed)	0.390	0.897	0.127
Subjective Problem solving (WHODAS D1.3)	Correlation Coefficient	0.255	0.220	0.138
	Sig. (2-tailed)	0.089	0.145	0.359
Subjective Procedural Learning (WHODAS D1.4)	Correlation Coefficient	.434**	0.212	0.067
	Sig. (2-tailed)	0.003	0.153	0.649
Anxiety (HADS)	Correlation Coefficient	1.000	.290*	0.230
	Sig. (2-tailed)		0.038	0.098
Depression (HADS)	Correlation Coefficient	.290*	1.000	-0.013
	Sig. (2-tailed)	0.038		0.924

		Anxiety (HADS)	Depression (HADS)	Sleep Quality (PSQI)
Sleep Quality (PSQI)	Correlation Coefficient	0.230	-0.013	1.000
	Sig. (2-tailed)	0.098	0.924	

NOTES:
Significant correlations are highlighted in red
Sig. (2-tailed) = two tailed significance value
HADS = Hospital Anxiety and Depression Scale; PSQI = Pittsburgh Sleep Quality Inventory; WAIS III = Wechsler Adult Intelligence Scale edition 3; WASI = Wechsler Abbreviated Scale of Intelligence; AVLT = Auditory – Verbal Learning Test WHO-UCL version; D-KEFS = Delis-Kaplan Executive Function Scale; COWAT = Controlled Oral Word Association Test Semantic fluency (Animals category); RPA ProMem = Royal Prince Alfred Prospective Memory Test – Form 2; PMRQ = Prospective Retrospective Memory Questionnaire – prospective memory score; WHODAS 2.0 = World Health Organisation Disability Assessment Scale domain 1;

All correlation calculations are based on z-scores for cognitive tests, except FISQ2 (IQ score) and RPA ProMem (raw scores).
** Correlation is significant at the 0.01 level (2-tailed).; * Correlation is significant at the 0.05 level (2-tailed).

Table 17

Kendall's Tau-b Correlations: Average Pain (N=19)

		Average Pain (BPI)
Attention (WAIS III Digit Span Forward)	Correlation Coefficient	-0.007
	Sig. (2-tailed)	0.970
Working Memory (WAIS III Digit Span Backward)	Correlation Coefficient	0.101
	Sig. (2-tailed)	0.592
Processing Speed (WAIS III Symbol Search)	Correlation Coefficient	0.129
	Sig. (2-tailed)	0.483
Visual Reasoning (WASI Matrix Reasoning)	Correlation Coefficient	-0.061
	Sig. (2-tailed)	0.740
Abstract Reasoning (WASI Similarities)	Correlation Coefficient	-0.157
	Sig. (2-tailed)	0.405
Intelligence (WASI FISQ 2)	Correlation Coefficient	-0.184
	Sig. (2-tailed)	0.305
Verbal Learning/Memory (AVLT Trial 5)	Correlation Coefficient	0.276
	Sig. (2-tailed)	0.137
Verbal Learning/Memory (AVLT Immediate Recall)	Correlation Coefficient	-0.154
	Sig. (2-tailed)	0.397
Verbal Learning/Memory (AVLT Delayed Recall)	Correlation Coefficient	0.081
	Sig. (2-tailed)	0.658
Inhibition – errors (D-KEFS Inhibition)	Correlation Coefficient	-0.284
	Sig. (2-tailed)	0.127
Inhibition – time (D-KEFS Inhibition)	Correlation Coefficient	0.157
	Sig. (2-tailed)	0.394
Cognitive Flexibility – errors (D-KEFS Inhibition/Switching)	Correlation Coefficient	-0.286
	Sig. (2-tailed)	0.120
Cognitive Flexibility – time (D-KEFS Inhibition/Switching)	Correlation Coefficient	0.097
	Sig. (2-tailed)	0.602
Generativity (COWAT Semantic Fluency -Animals)	Correlation Coefficient	-0.068
	Sig. (2-tailed)	0.712
Prospective Memory – time based (RPA ProMem)	Correlation Coefficient	-0.064
	Sig. (2-tailed)	0.763
Prospective Memory – event based (RPA ProMem)	Correlation Coefficient	0.017
	Sig. (2-tailed)	0.934
Subjective Prospective Memory (PRMQ)	Correlation Coefficient	0.060
	Sig. (2-tailed)	0.740
Subjective Concentration (WHODAS D1.1)	Correlation Coefficient	-0.102
	Sig. (2-tailed)	0.616

		Average Pain (BPI)
Subjective Problem solving (WHODAS D1.3)	Correlation Coefficient	-0.070
	Sig. (2-tailed)	0.723
Subjective Procedural Learning (WHODAS D1.4)	Correlation Coefficient	-0.082
	Sig. (2-tailed)	0.671
Anxiety (HADS)	Correlation Coefficient	0.095
	Sig. (2-tailed)	0.604
Depression (HADS)	Correlation Coefficient	0.163
	Sig. (2-tailed)	0.375
Sleep Quality (PSQI)	Correlation Coefficient	0.286
	Sig. (2-tailed)	0.120
Average Pain (BPI)	Correlation Coefficient	1.000
	Sig. (2-tailed)	

NOTES:
Sig. (2-tailed) = two tailed significance value
BPI = Beck Pain Inventory; WAIS III = Wechsler Adult Intelligence Scale edition 3; WASI = Wechsler Abbreviated Scale of Intelligence; AVLT = Auditory – Verbal Learning Test WHO-UCL version; D-KEFS = Delis-Kaplan Executive Function Scale; COWAT = Controlled Oral Word Association Test Semantic fluency (Animals category); RPA ProMem = Royal Prince Alfred Prospective Memory Test – Form 2; PMRQ = Prospective Retrospective Memory Questionnaire – prospective memory score; WHODAS 2.0 = World Health Organisation Disability Assessment Scale domain 1; HADS = Hospital Anxiety and Depression Scale; PSQI = Pittsburgh Sleep Quality Inventory;

All correlation calculations are based on z-scores for cognitive tests, except FISQ2 (IQ score) and RPA ProMem (raw scores).