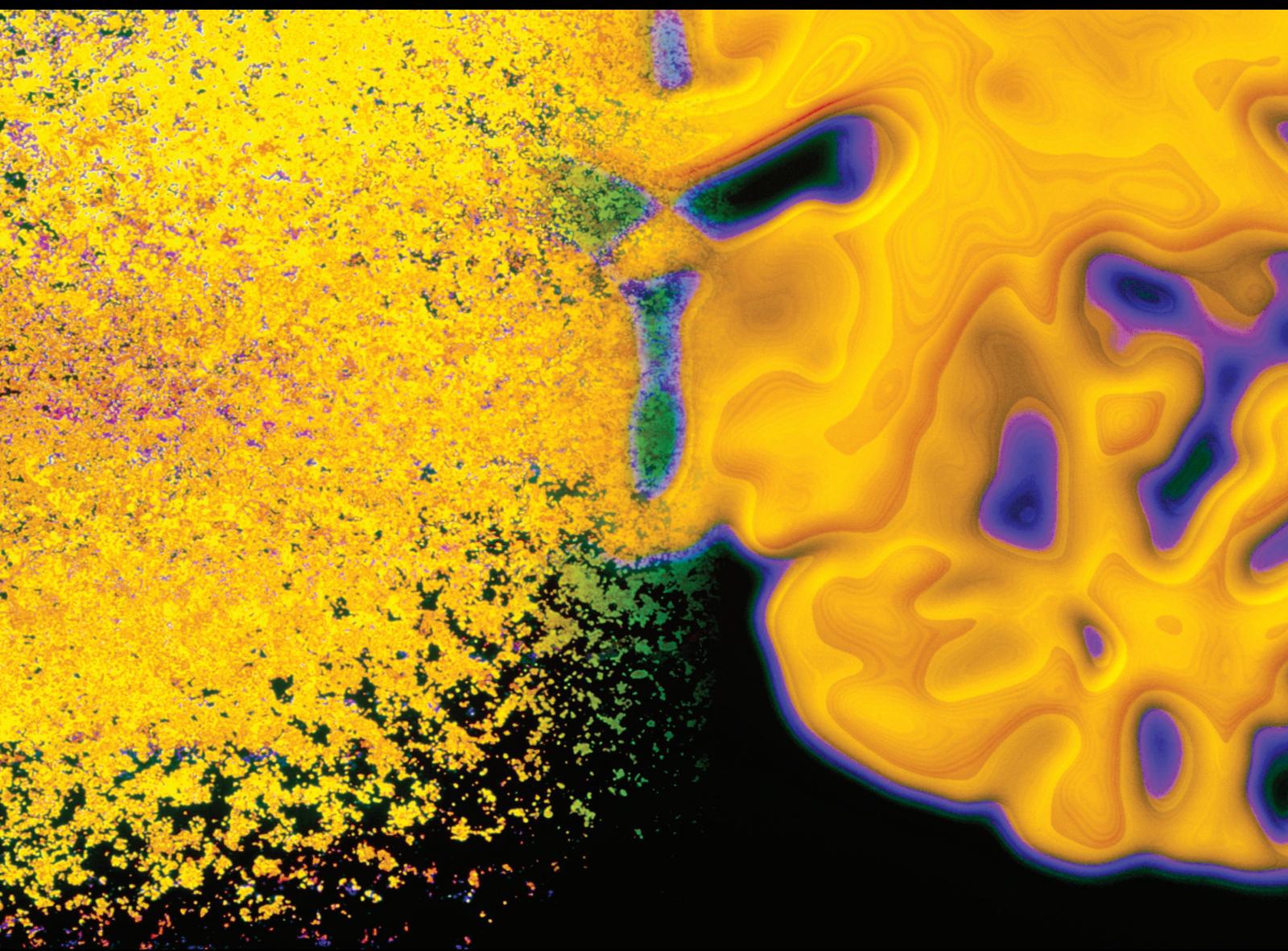


Long-Term Functional and Psychosocial Consequences and Health Care Provision after Traumatic Brain Injury

Guest Editor: Nada Andelic, Solrun Sigurdardottir,
Juan Carlos Arango-Lasprilla, and Alison K. Godbolt





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Editorial

Long-Term Functional and Psychosocial Consequences and Health Care Provision after Traumatic Brain Injury

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Traumatic brain injury (TBI) has a wide range of severity ranging from concussion to severe brain injury and death [1]. A wide body of literature has documented adverse outcomes in cognitive, behavioral, emotional, and physical functioning after TBI, as well as increased risk for poor family and social functioning [2–5]. TBI presents a major challenge to health care systems because of residual functional impairments along with difficulties with activities of daily living, education, community integration, and employment [6–8]. To date, few studies have investigated these issues using longitudinal and mixed method research designs. Studies from different countries are required to allow a better understanding of international differences, cultural aspects, and patients' needs for health care services and additional support [9, 10].

The aim of this special issue is to present international multidisciplinary research on long-term functional and psychosocial consequences of TBI in populations of adolescents, adults, and the elderly. More specifically, authors of this issue addressed methods for the development of assessment tools in TBI, neurophysiology of cognitive capacity, cognitive, executive, emotional, behavioral, and vocational functioning, and health-related quality of life after TBI. It is our goal that the articles published in this issue will contribute to a better

understanding of the long-term consequences and health care needs after TBI.

The development of culturally meaningful assessment tools for the measurement of outcomes and needs in TBI has been limited, which may in part be due to a limited focus on cultural aspects of TBI in international classification systems. Researchers from New Zealand, H. Elder and P. Kersten, used Whakawhiti korero, an indigenous research method that emphasizes discussion and negotiation, in the development of a cultural needs assessment tool for Māori traumatic brain injury. This method may have wider applicability in other fields, such as mental health and addiction services, to ensure a robust process of outcome measurement and needs assessment.

Accurate assessment of level of awareness and cognitive capacity of patients in a state of disordered consciousness after severe TBI is of utmost importance for rendering a correct diagnosis and designing treatment plans. S. L. Hauger et al. from Norway employed electrophysiological approaches to assess residual cognitive capacity using two tasks that differed as a function of cognitive load and stimulus type in this unique patient population. The findings revealed that an active task performed by the patients was robust in probing

for volitional cognitive capacity, indicating that this can be an important tool for providing diagnostic information for patients in a minimally conscious state.

Suffering a TBI during adolescence may not only cause TBI-related impairments but also disrupt the adolescent's process of development towards an independent life as an adult. Thus adolescent TBI brings with it special issues and as such a research focus on this age group is welcomed. K. Doser et al. from Denmark focus on adolescents with severe TBI in their study of psychological outcome and agreement between self-ratings and proxy-ratings by "significant others." Whilst a good degree of agreement was found between patients' and significant others' ratings regarding somatic problems, a lesser degree of agreement was found for nonovert problems such as withdrawal and attention, thought problems, and personal strength.

Moving into adult populations of moderate and severe TBI, T. G. Finnanger et al. evaluated a number of issues regarding executive, emotional, and behavioral problems 2–5 years after injury. This Norwegian neuropsychological study demonstrates significantly more attentional, emotional regulation and psychological difficulties in the TBI group compared to healthy controls. Age, education, traumatic axonal injury, and early depression were important predictors of later executive dysfunctions. This study gives new information to guide the clinical management of TBI survivors.

Most studies of severe TBI have focused on deficits in memory, processing speed, visual spatial abilities, and abstract reasoning. The impact on affective functions as well as awareness during the early stages after brain injury has not been studied to the same extent. A Swedish Icelandic study by M. Stenberg et al. assesses the clinical course of cognitive and emotional impairments in patients with severe TBI from 3 weeks to 1 year after injury and its associations with global and cognitive functioning outcomes at 1 year. Cognition seemed to improve over time and appeared to be rather stable from 3 months to 1 year. Results indicate that early screening of cognitive function could be of importance for rehabilitation planning in a clinical setting.

Health-related quality of life (HRQoL) has only recently gained momentum in the TBI field with novel assessments scales becoming available to be applied to this population. Related to this N. von Steinbuechel et al. from 10 different countries evaluated psychometric performance of a disease-specific QOLIBRI (Quality of Life after Brain Injury) instrument and a generic HRQoL instrument (SF-36) in a large sample of TBI survivors ($N = 795$). QOLIBRI was recommended as the preferable instrument to differentiate between individuals within a health state. QOLIBRI can be an important tool to detect individual recovery patterns after TBI (e.g., disability, depression) and prioritize therapeutic goals.

Few studies have examined sexual functioning in women with TBI, and studies are particularly lacking from regions such as Latin America where a lack of resources for patients with brain injury is well documented. In order to close some of the knowledge gap on this topic, J. Strizzi et al. administered standardized questionnaires which assessed various aspects of sexual functioning, desire, and satisfaction

to a group of female TBI survivors and healthy controls from Colombia. Results indicated that nearly all aspects of sexuality are affected after moderate to severe TBI. Researchers also identified a number of unique predictors of poor sexual functioning, suggesting future research directions and rehabilitation interventions strategies.

Mortality and long-term outcomes are assumed to be worse in elderly compared with younger TBI patients. The assumed poor prognosis may influence the treatment strategies applied in older patients. C. Røe et al. evaluate the mortality and functional outcome in old (65–74 years) and very old (>75 years) patients with severe TBI and compare the observed mortality and outcome to the predicted outcome according to the CRASH (Corticosteroid Randomization After Significant Head Injury) models. Results indicated that the CRASH model overestimated mortality and unfavorable outcome in old and very old Norwegian patients with severe TBI. Using such a model in clinical practice may possibly bias treatment decisions in old patients.

In recognition of cultural aspects of TBI, J. Yu et al. reviewed the research and practice in rehabilitation services in Hong Kong. In their exploration of the TBI field they have focused on the Chinese cultural conception of work, stigma associated with TBI, and burden among families. This paper presents a review of 7 studies of rehabilitation trials for brain injured patients in Hong Kong. Existing research shows that rehabilitation services have generally satisfied most of the TBI patients' needs. J. Yu et al. find that future efforts must be diverted to improve vocational rehabilitation and to educate and inform caregivers on the patient's impairments.

In the aftermath of TBI, returning to work (RTW) may be highly desired but is a challenging process for many patients. E. Vikane et al. aimed to identify predictors of RTW 12 months after mild TBI for patients with persistent postconcussion symptoms (PCS) at 6 to 8 weeks of follow-up. Early functional outcomes (i.e., being on sick leave and having disability) together with psychological distress and sick leave during the last year before injury were predictors of RTW. Multidisciplinary outpatient treatment was negatively associated with RTW. Giving much attention to PCS symptoms rather than focusing on aspects concerning RTW may be one exploratory factor for the negative outcome. These findings should be taken into consideration when evaluating future vocational rehabilitation models.

Specific evaluation procedures and methods used by vocational rehabilitation providers have not been studied in depth, and in this special issue C. Dillahunt-Aspilla et al. from the USA present the results of their online survey of professionals on this topic. The authors discuss their findings in the context of the complexities which individuals with TBI face after injury and argue for evidence-based frameworks of vocational evaluation to be adopted by rehabilitation educators, counselors, vocational evaluators, and other rehabilitation providers.

Many patients who have suffered a TBI require some form of help from caregivers, and it is often relatives who become caregivers. Rehabilitation programs that take caregivers' needs into account have the potential both to promote participation levels for patients and to minimize

possible health consequences for the caregivers themselves. L. F. Stevens et al. consider this second aspect, reporting an exploratory study from the USA, of training for caregivers of military service members who have suffered TBI and polytrauma. They find an association between caregiver training and mental health outcomes for caregivers. As the authors suggest, this is an area ripe for future research.

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Clinical Study

Predictors for Return to Work in Subjects with Mild Traumatic Brain Injury

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Objective. To predict return to work (RTW) at 12 months for patients who either were sick-listed or were at risk to be sick-listed with persistent postconcussion symptoms (PCS) at six to eight weeks after injury. **Method.** A prospective cohort study of 151 patients with mild traumatic brain injury (MTBI) admitted consecutively to outpatient clinics at two University Hospitals in Norway. The study was conducted as part of a randomised clinical trial. Injury characteristics were obtained from the medical records. Sick leave data from one year before to one year after MTBI were obtained from the Norwegian Labour and Welfare Service. Self-report questionnaires were used to obtain demographic and symptom profiles. **Results.** We observed a significant negative association between RTW at 12 months and psychological distress, global functioning, and being sick-listed at two months after MTBI, as well as having been sick-listed the last year before injury. **Conclusion.** Psychological distress, global functioning postinjury, and the sick leave trajectory of the subjects were negative predictors for RTW. These findings should be taken into consideration when evaluating future vocational rehabilitation models.

1. Introduction

The majority of patients suffering a head injury sustain a mild traumatic brain injury (MTBI) [1]. The true population-based incidence for MTBI is likely more than 600 patients per 100 000 people, and, as such, it is a major public-health concern [1, 2]. A systematic review concluded that most workers return to work (RTW) within three to six months after MTBI, with approximately 5% to 20% facing persistent problems [3]. The existing literature demonstrates that RTW after one year varies from approximately 42% to 97%, likely due to varying patient characteristics, geographic regions, occupational categories, compensation systems, and definition of MTBI [3–8]. To be unemployed affects several dimensions of physical, psychological, and social health [8–10]. RTW and vocational status represent one of the

best indicators of real world functioning [11]. Identifying predictors for delayed RTW may help to identify those who may benefit from a follow-up rehabilitation program [3, 12–14].

Several authors underline the need for a greater focus on the management of persistent postconcussion symptoms (PCS) to improve RTW [15, 16]. However, the majority of patients who return to work still present symptoms, and recently published reviews found different predictors for functional recovery in general as compared to RTW [3, 17, 18]. Preinjury variables, such as education, occupational factors (job independence and decision-making latitude), and age, are well-documented predictors for RTW [3, 4, 8, 12, 19].

Injury-related factors for RTW include multiple bodily injuries and intracranial abnormalities, where the associations between RTW and intracranial computed tomography

abnormalities are inconsistent [3, 8, 13]. Nolin and Heroux concluded that patient characteristics, injury severity indicators, and cognitive functions postinjury were not associated with vocational status 12 to 36 months after MTBI. Only the total numbers of symptoms reported at follow-up 12 to 36 months after MTBI were related to vocational status at follow-up [20]. Other postinjury predictors for RTW are nausea or vomiting on hospital admission, severe pain early after injury, fatigue, dizziness, number of subjective symptoms, cognitive variables, financial compensation-seeking, and environmental factors such as social interaction [3, 4, 8, 12, 19, 21, 22]. Among several postinjury factors, headache and widespread pain are a common complication after MTBI [23–26]. Acute headache and pain after MTBI affect quality of life and daily function, with potential long-term effects on cognition, mood, sleep, and PCS [25]. However, to the best of our knowledge, little is known about the association between RTW and long lasting pain after MTBI.

Several authors emphasise that patients with persistent symptoms may differ from the majority of patients with MTBI who recover within three months [12, 20, 27]. Therefore, we must better identify which factors are predictive for RTW for patients with remaining symptoms a few months after injury. In a clinical setting, it is important to know which variables are likely to predict the outcome at follow-up consultations, and there is a need for better screening batteries based on predictors, which can be easily administered to the patients in the subacute stage. The optimal timing to evaluate the outcome after MTBI is not clear. The majority of workers return to work within six months after MTBI. Cancelliere et al. concluded that further research is needed to determine long-term RTW more than two years after MTBI, and Stulemeijer et al. concluded that six months is too early to determine final outcome after MTBI because many patients are in the process of rehabilitation [3, 13]. Gjesdal et al. found that absence from work beyond 20 weeks was a predictor of disability pension among persons who had long-term sickness absence in Norway [28]. It is therefore import to focus on early RTW after an injury to avoid forced retirement, and we therefore addressed the outcome RTW at 12 months after MTBI in this study.

The objective of this study was to identify which clinical characteristics predict RTW at 12 months for patients who were either sick-listed or at risk to be sick-listed with persistent PCS six to eight weeks after MTBI.

2. Methods

2.1. Study Design. This was a prospective cohort study of patients with MTBI known to have persistent symptoms. The study was conducted as part of a randomised clinical trial (RCT). The effect of the intervention is prepared as a separate submitted manuscript. Preinjury, injury-related, and postinjury clinical variables presented at six to eight weeks after MTBI together with some relevant clinical data from the emergency stay at hospital were used to find any significant associations with RTW 12 months after MTBI.

2.2. Participants. Adult patients aged 16–55 years who were hospitalised acutely at the Department of Neurosurgery for MTBI and who were either sick-listed or at risk to be sick-listed with persistent PCS six to eight weeks after injury were consecutively recruited to the study. MTBI was defined using the criteria from the Task Force on MTBI and the American Congress of Rehabilitation Medicine, defined as a Glasgow Coma Scale (GCS) measure of 13–15 within 30 minutes or the lowest score during the first 24 hours after injury, unconsciousness for less than 30 minutes, and posttraumatic amnesia for less than 24 hours [29, 30].

Exclusion criteria included current major psychiatric disease, major head trauma, or other diseases that had a significant impact on working skills, unemployment in the last six months, lack of Norwegian language skills, diagnosis with substance abuse problems given in the medical records, or lack of informed consent.

2.3. Study Settings. Patients hospitalised acutely after a trauma at the Department of Neurosurgery, with an ICD-10 diagnosis of S06.0–S06.9, were offered a planned clinical follow-up at an outpatient clinic at the Department of Physical Medicine and Rehabilitation at Haukeland University Hospital, in Bergen, and Oslo University Hospital, Oslo, Norway, from March 2009 to February 2012. The population was restricted to inhabitants of Hordaland, Oslo, and Akershus County including the cities of Bergen and Oslo, respectively, a mixed rural and urban community where the majority of the inhabitants are Norwegian residents (Caucasians).

2.4. Procedures. When potential participants were discharged from the emergency hospital, they received a self-report questionnaire by mail and an appointment by a specialist in physical and rehabilitation medicine at an outpatient clinic six to eight weeks after injury.

The questionnaire screened for postconcussion symptoms (PCS), psychological distress, disability, and pain.

The rehabilitation specialist conducted a clinical interview and a clinical examination with reassurance of an expected favourable outcome after the injury. Patients meeting the inclusion criteria were then offered to participate in the study and to participate in an additional RCT. The participants received a multidisciplinary examination and were then randomised into two groups; they were either randomised to a multidisciplinary outpatient treatment (intervention group) or referred back to their general practitioner with good advices and directions for further treatment if needed (control group). The multidisciplinary outpatient treatment consisted of individual consultations and a psychoeducational group intervention for four days over a period of four weeks. The participants shared experiences and received education about common problems after MTBI including topics related to RTW. Individualised treatment and clinical follow-ups in the first year were provided as needed.

2.5. Measures. RTW 12 months after injury was used as the main outcome and was the dependent variable. Data regarding sick leave one year before and the first year after the injury were collected from a national register, the

Norwegian Labour and Welfare Service (NAV). Regardless of the diagnosis, the subjects were categorised as sick-listed or not.

Preinjury factors, injury-related factors, and postinjury factors were examined as potential predictors for RTW.

2.5.1. Preinjury Factors. Preinjury factors assessed from the questionnaire consisted of age in years, sex, relationship status, number of children still living with parents, education, and employment status. Education was categorised as lower or higher education (13 years or more of formal education).

The self-report questionnaire contained information about smoking habits, alcohol consumption, and earlier diseases such as anxiety, depression, prior head injury, headache, and neurological disease, as well as other diseases. In the final analysis, we used information about earlier sick leave from NAV.

2.5.2. Injury-Related Factors. Injury mechanisms classified as traffic accidents, falls, violence, and others (sports) were collected from the questionnaire. Occupational injuries were also registered in the questionnaire. The Glasgow Coma Scale (GCS) score, neurological status, headache, neck pain, findings on CT scan, alcohol intoxication, and length of hospital stay were registered during the emergency stay and were obtained from the medical record. GCS was used to classify MTBI. GCS was assessed to indicate the depth and duration of unconsciousness within 30 minutes or, subsequently, the score over the first 24 hours [31].

In the preliminary analyses, findings on CT were categorised as type of bleeding, contusion, location of injury, and fractures of the skull, face, and neck. In the final analyses, we either used intracranial injury or not. Length of posttraumatic amnesia (PTA) was based on both the medical records and the clinical interview six to eight weeks after injury, during which the patients were asked to recall events retrospectively.

2.5.3. Postinjury Factors Were Collected Six to Eight Weeks after MTBI. Postconcussion symptoms (PCS) were measured using the Rivermead Post-Concussion Symptoms Questionnaire (RPQ). In RPQ, the patients are asked to rate the degree to which 16 items of the most frequently reported TBI-related symptoms are a problem compared with preinjury levels. The degree of the problem is rated on a 5-point Likert scale: 0 = not experienced at all, 1 = no longer a problem, 2 = a mild problem, 3 = a moderate problem, and 4 = a severe problem [32]. RPQ is documented to have high reliability for PCS, yet lacking good validity, and several authors argue against using the total sum score as recommended by King et al. [32–34]. Other authors have used the number of symptoms or a symptom by symptom comparison as an outcome [12, 20, 34]. Hence, we counted the total number of complaints with a RPQ score ≥ 2 six to eight weeks after injury when analysing predictors for RTW at 12 months.

Posttraumatic Stress Syndrome 10-Questions Inventory (PTSS-10) is a patient-reported inventory where 10 single items specific for posttraumatic stress disorder are rated from 1 to 7: 1 = never and 7 = always. PTSS-10 is found to be

reliable and valid for screening out psychiatric risk cases among traumatized subjects [35–37]. In our analysis, we used the total score for PTSS-10.

Hospital Anxiety and Depression Scale (HAD) consists of 14 items detecting states of depression (7 items) and anxiety (7 items), rated on a 4-point scale from 0 to 3: 0 = no symptoms and 3 = a severe symptom or symptoms most of the time. It is validated for traumatic brain injuries (TBI) and documented to have high reliability [38, 39]. The total sum of scores for HAD was used in the analyses.

The subjective health complaints (SHC) questionnaire is a generic questionnaire that consists of 29 questions concerning severity and duration of subjective somatic and psychological complaints rated from 0 to 3: 0 = not at all, 1 = a little, 2 = some, and 3 = serious problems. The SHC is validated and is reliable for scoring subjective health complaints. The total number of complaints at SHC was used in our analysis [40, 41].

The numerical rating scale (NRS) registers pain in the head, pain in the neck and shoulders, and pain in the back and legs, rating pain from 0, which is no pain, to 10, which is pain as bad as it can be [42]. The NRS is reliable, easy, and commonly used measure for pain [43]. In our preliminary analyses, we used the NRS for pain in the head, the neck, and the back, and in addition we used both the total score for the three items and the highest score of the three items as a single item.

A pain drawing registered the location and numbers of areas affected by pain (rated from having 0 to 10 areas), where higher scores indicated widespread pain [44].

Glasgow Outcome Scale Extended (GOSE) is an ordinal, global 8-point scale for assessment of function within the areas of independence, work, social and leisure activities, and participation in social life. GOSE is a reliable and valid outcome measure widely used after TBI [45, 46]. Before inclusion in the study, a physician scored GOSE at baseline six to eight weeks after MTBI. In the final analyses, the categories were divided into good recovery (GOSE = 7 or 8), moderate disability (GOSE = 6), and severe and moderate disability (GOSE = 5 or less).

In the questionnaire, we asked if the patients had an expectation of a favourable outcome. If they answered yes or were recovered, they were classified as having a favourable expectation. If they answered no or did not know the outcome, they were classified as having a negative expectation of the outcome [47].

Data registered in the study were entered by two independent persons unfamiliar with the aim and content of the study. A statistician who did not participate in the treatment was responsible for the statistical analyses and controlled the analyses in instances where it was performed by the first author.

2.6. Statistical Methods. Data analyses were completed with IBM SPSS Statistics for Windows, Version 22.0, Armonk, NY: IBM Corp.

Descriptive analyses were used to characterize the sample at baseline (six to eight weeks after injury).

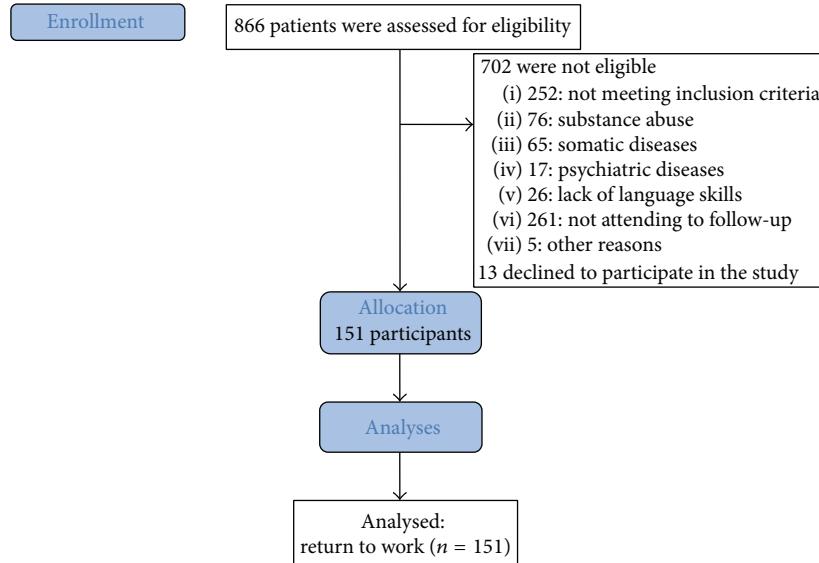


FIGURE 1: Flow diagram.

We used a logistic regression model to assess the predictors for RTW where we stepwise reduced the dimension. In the first step, we estimated the unadjusted model for each of the preinjury, injury-related, and postinjury factors (mentioned under Section 2.5 above) with RTW as outcome to detect all predictors with an association with RTW. In the second step, we estimated the fully adjusted model for all significant predictors from the first step. Additionally, we ensured that we have age and sex as essential properties of the cohort as well as at least one representative for each of the predictor groups (preinjury, injury-related, and postinjury) included in the model [48]. This was done to take into account potential confounding and reflect all aspects of the study in the fully adjusted model. In the third step, we estimated the final model including only the significant predictors from the fully adjusted model. The final model was developed to avoid multicollinearity, increase the power, and improve the precision (SE, CI) of the estimated odds ratios.

We used pairwise deletion for the missing data to ensure that we use all available data and achieve maximal power in the estimated models. The significance level was set to 0.05 for all analyses.

2.7. Ethics. The study protocol is registered in Government Clinical Trial registry, NCT00869154. The study was approved by The National Committees for Research Ethics in Norway and Norwegian Social Science Data Services, identifier NSD 20425.

3. Results

3.1. Participant Flow. We identified 866 patients with MTBI admitted consecutively to the Department of Neurosurgery, of whom 164 patients were eligible, 13 declined to participate, and 151 patients were included in the analyses, shown in

Figure 1. Of these patients, 81 were in the intervention group and 70 in the control group in the RCT.

3.2. Baseline Data. Table 1 lists baseline characteristics. Briefly, the median age was 32 years, and 61% of the participants were men. The majority of the injuries comprised a fall (37%). A CT scan was performed on 96% of the participants and showed intracranial injury for 27% of the patients. GCS was 15 for 74% of the participants, and 28% reported PTA for more than 1 hour. At baseline six to eight weeks after MTBI, 56% of the patients were sick-listed compared to 34% at 12 months after MTBI.

The results of the logistic regression analysis are seen in Table 2. Here, we abstain from presenting the predictors which were not included in the fully adjusted model. Age, sex, and intracranial injury as injury-related factor were included in the fully adjusted model even if they were not significant in the unadjusted model (see description of the statistical analyses above). We observed in the logistic regression model at a 5% significance level a significant association between RTW at 12 months and HAD, sick-listing variables, and GOSE. To have been sick-listed the last year before injury had the largest odds ratio (OR) 7.29 (2.6, 20.3) and being sick-listed at two months after MTBI had an OR of 6.84 (2.3, 19.9). None of the physical measures like CT findings or different measures for pain was significantly associated with RTW. We estimated a pseudo- R^2 of 0.56 (Nagelkerke) and classified 86% of the patients correctly.

4. Discussion

Several variables predicted RTW at 12 months in subjects with persistent PCS six to eight weeks after injury. However, in our final model, four variables contributed uniquely to RTW at 12 months, namely, having been sick-listed the last year

TABLE 1: Demographic data and clinical characteristics at baseline 6–8 weeks after mild traumatic brain injury.

Variable	Total	n (%)
<i>Preinjury factors</i>		
Age, years ¹	151	32 [16, 55]
Sex, men	151	92 (61%)
Single		77 (51%)
Higher education >13 years	150	64 (43%)
Employment status	150	
Full time		112 (75%)
Part-time		5 (3%)
Unemployed		9 (6%)
Student		24 (16%)
Have been sick-listed the last year before injury	151	69 (46%)
<i>Injury-related factors</i>		
Cause of injury	151	
Traffic accident		44 (29%)
Fall		56 (37%)
Assault		27 (18%)
Sports injury and others		24 (16%)
Glasgow Coma Scale (GCS) ^{1,2}	151	15 [13, 15]
GCS 13		8 (5%)
GCS 14		31 (21%)
GCS 15		112 (74%)
PTA > 1 hour	142	39 (27%)
Radiological examination ²		
Intracranial injury (CT scan)	151	41 (27%)
Skull fracture	151	22 (15%)
<i>Postinjury factors</i>		
The Rivermead Post-Concussion Symptoms Questionnaire (RPQ)		
Number of symptoms (0–16) ¹	151	8 [0, 16]
The Hospital Anxiety and Depression Scale (HAD)		
Total score (0–42) ¹	143	10 [0, 30]
HAD anxiety (0–21) ¹	143	7 [0, 19]
HAD depression (0–21) ¹	143	4 [0, 14]
Posttraumatic stress (PTSS-10) ¹	150	24 [6, 68]
Expectation of favourable outcome	149	105 (70%)
Subjective health complaints (SHC) ¹	151	10 [0, 29]
Widespread pain (numbers of painful body areas) ¹	149	2 [0, 8]
Headache (NRS) ¹	148	4 [0, 10]
Neck pain (NRS) ¹	148	4 [0, 10]
Low back pain (NRS) ¹	146	2 [0, 10]
Glasgow Outcome Scale Extended (GOSE)	149	
Severe and moderate disability (GOSE < 6)		22 (15%)
Moderate disability (GOSE = 6)		100 (67%)
Good recovery (GOSE > 6)		27 (18%)
Sick-listed at 2 months (baseline)	151	85 (56%)
Sick-listed at 12 months after injury	151	52 (34%)

¹Median [min, max].²Measured at time of injury.

TABLE 2: Logistic regression analyses of baseline data in relation to return to work after mild traumatic brain injury.

	N	Unadjusted models		Fully adjusted model, N = 135		Final model, N = 141				
		OR	CI (95%)	P value	OR	CI (95%)	P value	OR	CI (95%)	P value
<i>Preinjury factors</i>										
Age	151	1.03	(1.0, 1.1)	0.061	0.98	(0.9, 1.0)	0.410			
Sex	151	1.39	(0.7, 2.7)	0.347	0.77	(0.2, 2.8)	0.693			
Have been sick-listed the last year before injury	151	6.90	(3.2, 14.8)	<0.001	8.48	(2.6, 27.9)	<0.001			
<i>Injury-related factor</i>										<0.001
Intracranial injury (CT scan)	151	1.38	(0.6, 3.0)	0.415	1.46	(0.4, 5.3)	0.568			
<i>Postinjury factors</i>										
Postconcussion symptoms (RPQ)	151	1.07	(1.0, 1.1)	<0.001	1.08	(0.9, 1.4)	0.512			
Posttraumatic stress (PTSS-10)	150	1.06	(1.0, 1.1)	<0.001	0.96	(0.9, 1.0)	0.331			
Anxiety and depression (HAD)	143	1.14	(1.0, 1.2)	<0.001	1.16	(1.0, 1.3)	0.035			
Expectation of favourable outcome	149	2.28	(1.1, 4.7)	0.026	0.61	(0.1, 3.2)	0.554			
Subjective health complaints (SHC)	151	1.08	(1.0, 1.1)	<0.001	1.01	(0.9, 1.2)	0.883			
Widespread pain (numbers of painful body areas)	149	1.35	(1.1, 1.7)	0.003	0.83	(0.5, 1.3)	0.379			
Headache (NRS)	148	1.20	(1.1, 1.4)	0.004	0.90	(0.7, 1.2)	0.463			
Neck pain (NRS)	148	1.29	(1.1, 1.5)	<0.001	1.08	(0.8, 1.4)	0.577			
Low back pain (NRS)	146	1.19	(1.1, 1.3)	0.005	1.15	(0.9, 1.5)	0.280			
Glasgow Outcome Scale Extended (GOSE)	149			0.001			0.017			
Severe and moderate disability (GOSE < 6)		1			1		1			
Moderate disability (GOSE = 6)		0.32	(0.1, 0.8)		0.17	(0.0, 0.7)		0.24	(0.1, 0.9)	
Good recovery (GOSE > 6)		0.05	(0.0, 0.2)		0.03	(0.0, 0.5)		0.06	(0.0, 0.6)	
Sick-listed at 2 months (baseline)	151	7.78	(3.3, 18.3)	<0.001	10.16	(2.6, 40.0)	0.001	6.84	(2.3, 19.9)	<0.001

Significance: $P < 0.05$ marked bold.

before injury, being sick-listed at two months after MTBI, severe and moderate disability at two months (GOSE), and psychological distress (HAD).

Among preinjury variables, only having been sick-listed the last year before injury was associated with RTW at 12 months. This is partly in line with other studies that indicate that premorbid factors such as preinjury mental health are well known as predictors for PCS, but not well documented for RTW [3, 18]. Musculoskeletal pain, depression, and anxiety are the major causes of all sick leave in Norway and were the most common diagnoses preinjury in our study [49].

Several authors have found an association between age and RTW, but Stulemeijer et al. did not [8, 12, 13, 19, 50]. One explanation may be that RTW after MTBI tends to be "U" shaped, explained by more common MTBI-related claims among younger and older age groups [50]. According to Kristman et al., this is most likely due to a "healthy worker" effect, where more susceptible workers experience injury earlier in their careers, causing them to move out of the profession, but "healthier" workers experience a lower rate of injury midcareer. On the other hand, later in life, the physical effect of age may make these "healthier" workers more susceptible to injury [50]. Both in our study and in the study by Stulemeijer et al., patients were under 55 or 60 years, respectively, excluding the oldest patients with the poorest prognosis [13]. This may explain why we found no association between RTW and age unlike other studies [8, 12].

In contrast to a recently published review, we found no association between education and RTW [3, 13]. Varying patient characteristics and different job demands between different geographic regions could be one explanation for our results [3]. However, in studies of patients from Norway with multiple severe injuries or with musculoskeletal pain, low education was a negative predictor for RTW [49, 51]. Therefore, it is less likely that geographic differences could explain the difference between our study and the previously mentioned review. Another explanation could be an overestimation of higher education in our study, as we used self-reported data, because patients may have a tendency to overestimate their formal education when they answered their questionnaires.

Studies that recruited a heterogenic MTBI population have found an association between intracranial abnormality and slower RTW [8, 52]. In our model, injury-related factors were not associated with RTW, likely because we recruited a selected group of patients with persistent symptoms six to eight weeks after MTBI. Guérin et al. highlight in their study the fact that a significant proportion of their patients had an intracranial injury (43%) at CT which might have reduced the comparability of this study with other studies [12]. Our results resemble those by Guérin et al. and Nolin and Heroux in that we found that none of the trauma severity-related variables GCS, PTA, length of hospital stay, or mechanism of injury were associated with RTW [12, 20].

It is noteworthy that there were several variables that contributed to RTW at 12 months after MTBI, including symptom burden (RPQ), posttraumatic stress (PTSS), pain and health complaints (SHC). However, only psychological distress (HAD) made a unique significant impact in our

final model. Because there is a high correlation between these variables and our sample size was relatively small, care must be taken to differentiate between symptom burden and psychological distress when interpreting the findings into clinical practise. Guérin et al. and Nolin and Heroux found at long-term follow-up that the number of subjective symptoms was associated with RTW. In their studies, symptom burden and psychological distress were included in the subjective symptoms [12, 20].

We investigated several variables for pain, including headache and neck pain at admission and NRS six to eight weeks after injury for pain in the head, neck, and back. There was no significant association between these single variables and RTW. Our results are largely consistent with the findings of Guérin et al. and Nolin and Heroux. In these studies, more than six symptoms and the total number of subjective complaints were reported at follow-up as associated with RTW and not a single item [12, 20].

5. Strengths and Limitations

A strength of this study is the avoidance of missing follow-up data for the dependent variable RTW that could bias the results, as we used data from a national register of sick leave [53, 54]. However, using data from a national register has some limitations. The register did not contain complete information if the participant was partly or completely sick-listed. It was difficult to interpret from the register if the sick leave was a result of the MTBI. Therefore, we defined all participants independent of diagnosis, whether they were partly or completely sick-listed, as not having RTW. Participants who were either students or unemployed have to be disabled for one year before they can receive any benefits from NAV. If they then received any benefits from NAV, they were defined as being sick-listed 12 months in advance. To control for this flaw, we conducted the analyses excluding students and unemployed cases (unpublished). When excluding students and the unemployed from the analyses, we found the same predictors for RTW at 12 months with one exception, GOSE. Some reviews exclude studies that have cases of intentional MTBI as assault, because the recovery is complicated by victimisation and litigation [3]. Because we used only a subgroup of patients with MTBI, those with persistent symptoms admitted to the University Hospital, our sample size was relatively small for accurately predicting the outcome. To avoid additional reduction of our sample, we therefore included both students and patients where the cause of injury was assault in our analyses. In our study, there was no association between the cause of injury and RTW.

Only 151 out of 866 patients fulfilled the inclusion criteria for the study. We missed approximately 10% of the cases in the adjusted models due to incomplete information at baseline. Missing data could be handled with statistical imputation [48]. For this small sample, a few cases can make a difference and bias the results, even with statistical imputation if the cases are not missing at random. Therefore, we choose to not use statistical imputation in our analyses. A selection bias due

to missing data cannot be excluded, but in the final model the power of the model was improved by reducing missing cases from 16 (11%) to 10 (7%). Another study limitation is the collection of clinical data on the emergency stay from the medical records, where relevant information was missing such as the intensity of acute pain. CT scan was performed by 96% of the participants, which indicates that our results regarding intracranial findings are valid. Finally, strongly correlated predictors with a correlation above 0.7 were removed due to the nonsignificance in our final model, and collinearity is only a problem in the fully adjusted model.

Further research should focus on determining which preexisting and comorbidity problems have an association with RTW. As recommended by Cancelliere et al., further research should additionally focus on the association between RTW and workplace support, social support, and the role of economic factors such as compensation after an injury [3].

Our study may have some implications for rehabilitation after MTBI. Clinically, a questionnaire is easily administrated to screen for symptom burden, psychological distress, and functional outcome approximately two months after MTBI. Early functional outcomes such as being sick-listed and disability (GOSE) at baseline six to eight weeks after MTBI together with psychological distress and a premorbid variable, such as having been sick-listed the last year before injury, were predictors for RTW. By using these predictors for RTW, vulnerable patients could be offered treatment to improve RTW in further randomised controlled intervention studies addressed to improve vocational rehabilitation.

6. Conclusion

Psychological distress postinjury was the main predictor for RTW in addition to global functioning and the sick leave trajectory of the subjects. These findings have implications for clinical follow-up in MTBI and should be taken into consideration when evaluating future vocational rehabilitation models.

Conflict of Interests

The first author, Eirik Vikane, was financially supported by EXTRA funds from the Norwegian Extra Foundation for Health and Rehabilitation. The authors declare that they have no potential conflict of interests to disclose.

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Research Article

Assessment of Health-Related Quality of Life after TBI: Comparison of a Disease-Specific (QOLIBRI) with a Generic (SF-36) Instrument

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Psychosocial, emotional, and physical problems can emerge after traumatic brain injury (TBI), potentially impacting health-related quality of life (HRQoL). Until now, however, neither the discriminatory power of disease-specific (QOLIBRI) and generic (SF-36) HRQoL nor their correlates have been compared in detail. These aspects as well as some psychometric item characteristics were studied in a sample of 795 TBI survivors. The Shannon H' index absolute informativity, as an indicator of an instrument's

power to differentiate between individuals within a specific group or health state, was investigated. Psychometric performance of the two instruments was predominantly good, generally higher, and more homogenous for the QOLIBRI than for the SF-36 subscales. Notably, the SF-36 “Role Physical,” “Role Emotional,” and “Social Functioning” subscales showed less satisfactory discriminatory power than all other dimensions or the sum scores of both instruments. The absolute informativity of disease-specific as well as generic HRQoL instruments concerning the different groups defined by different correlates differed significantly. When the focus is on how a certain subscale or sum score differentiates between individuals in one specific dimension/health state, the QOLIBRI can be recommended as the preferable instrument.

1. Introduction

After traumatic brain injury (TBI) patients often experience important physical progress within the first six months of recovery. However, cognitive and psychosocial problems continue to persist for the majority of individuals with severe TBI [1]. Patients who have suffered from moderate TBI also report a similar pattern of recovery. Yuh et al. [2] found in their study on individuals after TBI that poorer outcome in physical recovery after three months was associated with abnormalities in MRI, after adjusting for demographic, clinical, and socioeconomic factors. Other imaging studies have described that psychological disorders, such as PTSD, are associated with changes in brain structure [3].

In the past 20 years researchers have reiterated that physical, psychological, and social constraints following TBI present a major challenge to the patients' rehabilitation and their reintegration into society. It has been known in the context of other conditions affecting the brain, such as epilepsy [4], that these factors can exert considerable influence on the HRQoL of patients. Compared to other fields of neurology, research into HRQoL in TBI has only quite recently gained momentum. HRQoL measures capture the patient's own perspective as the best expert of his or her wellbeing and HRQoL. Earlier assumptions that individuals having suffered a TBI would not be able to adequately rate their own HRQoL have more recently been challenged. Now a significant number of studies in TBI successfully employed HRQoL approaches [5].

HRQoL assessment combines multiple domains including physical, psychological (emotional, cognitive), Social, and Daily Life aspects [6]. Measurement of generic HRQoL allows for a comparison across disease states and populations. However, generic tools may not be particularly sensitive for specific aspects and sequelae of a defined disease or health condition. Disease-specific measurement of HRQoL, on the other hand, identifies and targets meaningful, disease- and condition-specific aspects and may therefore be more sensitive to the impacts of the patient's specific health condition.

HRQoL assessment can provide standardized information on recovery patterns and frequency over time, on associations with correlates of disabilities, and on restrictions of wellbeing as viewed from the patient's perspective [6]. Another approach is the use of item banks such as PROMIS [7] and Neuro-QOL [8], which are based on probabilistic measurement models replacing individual instruments and assuring generic and specific evaluation, with the possibility of cross-disease comparability. The application of these systems in TBI is yet still rare [9–11].

It has been evidenced in a number of studies on generic HRQoL that patients afflicted by TBI suffer from a deterioration of HRQoL across all severity degrees [5, 12, 13]. Among the publications using generic HRQoL assessment, the SF-36 health survey is the most widely administered self-rating questionnaire [5]. Overall, studies using the SF-36 have found lower mean scores on all of its eight scales (see below), and on the Mental Component Summary (MCS) and Physical Component Summary (PCS) score for patients with TBI compared with control groups, reflecting poorer health [14, 15].

In disease-specific measurement of HRQoL after TBI the QOLIBRI is the first instrument developed simultaneously in multiple languages. To date there are over 10 studies published reporting on the development and psychometric qualities of the QOLIBRI in TBI populations [6, 16–19] and a number of papers on the application of the QOLIBRI in clinical contexts [20–22]. However, no publication yet has been identified presenting a comprehensive comparison of disease-specific and generic HRQoL after TBI.

A large number of studies have found that sociodemographic characteristics and clinical symptoms are associated with HRQoL, suggesting that the impact of neurological deficits and a changed life situation may lead to poorer HRQoL after TBI [15, 23–27]. Studies also indicate that depression, anxiety, and functional disability have a detrimental effect on HRQoL after TBI [1, 17, 28, 29]. In addition, Stålnacke [25] described that a large proportion of individuals after mild TBI experienced both postconcussion symptoms and psychosocial difficulties, combined with low levels of life satisfaction three years after TBI. Furthermore, elapsed time since injury has been found to also have an impact on generic HRQoL [23]. Results however are not unequivocal; Andelic et al. [30] found no association between HRQoL and functional competence or Employment Status of TBI patients. One paper however briefly examined differences between a disease-specific tool (QOLIBRI) and a generic tool (SF-36) inspecting the associations of the summary scores of the two instruments with the GOSE [17]. Authors concluded that HRQoL assessed with the SF-36 is generally captured also by the QOLIBRI but that there is also additional information available from QOLIBRI scores which was not provided by the SF-36. This study will investigate and compare in detail correlates specific for generic versus disease-specific HRQoL.

Concerning compliance with classical psychometric criteria, validity and reliability of both, the QOLIBRI [16, 17] and SF-36 after TBI [31, 32], have been proven elsewhere. Differences do exist in the QOLIBRI and SF-36 in conceptualization of subjective health, in inclusion of HRQoL domains and items, and in the algorithms used to derive summary

scores. Differences in assessing HRQoL in a disease-specific or a generic fashion might have the undesirable effect that the distinct instruments yield different results for similar health states. Furthermore which instrument provides the most solid outcomes with respect to understanding interindividual differences in scale scores is not yet understood. Thus this paper aims at the examination of the discriminative power within a comprehensive sample of TBI patients.

Usually the comparison of HRQoL after TBI determined with a generic [31, 32] and a disease-specific instrument [16, 17] is based on classical psychometric criteria, in which the concepts of reliability, validity, sensitivity, and responsiveness are characterized by the ability to distinguish between "true" different levels of health/HRQoL states [33]. In the study presented here a different approach is applied, the Shannon index H' . It originates from the field of information theory but can be applied to any classification, including health classifications and HRQoL systems such as the SF-36, the EQ-5D [34], and the QOLIBRI. The index H' translates the difference between individuals in a given health domain/subscale of an instrument into discriminative power [24, 35]. It also captures a complementary aspect of reliability which cannot be analysed sufficiently when solely investigating consistency coefficients [34].

To gain insight into the diversity of patients the two instruments are able to detect, the current paper analysed the absolute informativity of the QOLIBRI and SF-36 sum scores and subscales. By absolute informativity, we mean the degree to which certain characteristics are distributed among a specific group. If, for example, in a question on educational background with four response options 25% of the sample chooses one option each, high informativity or diversity is detected. However, if 75% of the sample chooses one option and the remaining 25% chooses the other options, informativity of these characteristics with regard to the specific group is low. Furthermore, to be able to investigate whether disease-specific and generic HRQoL are correlated with similar variables, as this may explain variation in discriminative power (H'), the QOLIBRI Total score and SF-36 MCS and PCS as outcomes and a number of sociodemographic, psychosocial, and health-related variables as predictors (correlates) were analysed via a stepwise linear regression analysis. (In this paper, in view of terminology differing between disciplines the term correlate is applied instead of the psychometrically correct term predictor.)

2. Methods

2.1. Participants. The study sample was recruited in six languages (The Netherlands, UK/USA, Finland, France, Germany, and Italy). Data from this patient sample was also published in von Steinbüchel et al. [16, 17]. Around 45% of the patients were in outpatient treatment during participation in our study, and the other did not receive any treatment during the assessment. *Inclusion criteria* entailed the following: ICD-10 diagnosis of TBI, minimum age at injury of 15 years, 17–68 years of age at interview, outpatient treatment (currently not admitted to a ward), and ability to provide informed consent. By the inclusion criterion "outpatient

treatment" the exclusion of patient being currently admitted to a ward was intended. *Exclusion criteria* were as follows: a Glasgow Outcome Score Extended (GOSE) [36] below 3, serious current or preinjury psychiatric issues, current severe addiction, diagnosis of a terminal illness, inability to cooperate in the study, and incapability to understand and answer the questions. Patients were asked in a clinical interview and/or records were checked whether they were ever given a psychiatric or addiction diagnosis. If this was the case, their participation was rejected. Ethics clearance was available from each of the recruiting centers.

2.2. Medical Information

2.2.1. Clinical Information Checklist. Professionals filled in a checklist which asked for information regarding the patient's clinical background, such as TBI diagnosis, Severity of TBI, current age, age at the time of injury, time since injury, interview mode, and outpatient status. Furthermore, patients' worst GCS score (24 h after injury) was reported as well as the presence of spinal cord injury, current or preinjury psychiatric problems, drug/alcohol dependence, terminal illness, and understanding and communication abilities.

2.2.2. Self-Reported Health-Status List [37]. This questionnaire consisted of a list of 29 symptoms and possible Comorbid Health Conditions with a binary (yes/no) response scale. Three subscales were computed for further analysis: comorbidity (with items on allergies, asthma, thyroid issues, diabetes, back problems, arthritis, high blood pressure, heart disease, angina pectoris, heart attack, use of a pacemaker, bowel inflammation, ulcer, kidney disease, and cancer), sensory/psychosomatic complaints (discomfort with smell, vision, hearing, sleep, headache, nervousness, depression, lack of energy, and lack of physical strength), and musculoskeletal complaints (including problems with movement, paralysis or neurological problems due to TBI, or other than TBI, and amputation of a limb).

2.2.3. Glasgow Coma Scale (GCS) [38]. The Glasgow Coma Scale is a measure of the depth and duration of consciousness impairment and coma. It assesses motor responsiveness, verbal performance, and eye opening and it ultimately classifies brain injury into mild (GCS 13–15), moderate (GCS 9–12), and severe (GCS 3–8). The participants' 24 h postinjury worst GCS score was obtained from medical records.

2.2.4. Glasgow Outcome Scale Extended (GOSE) [36]. This tool determines the grade of disability and recovery concerning the functional status of a patient. For analyses we applied a 3-level categorization of severe disability (GOSE 3–4), Moderate Disability (GOSE 5–6), and good recovery (GOSE 7–8).

2.2.5. Hospital Anxiety and Depression Scale (HADS) [39]. The patient's anxiety and depression levels were self-rated; scores of 8 to 10 represent mild symptoms, 11 to 15 moderate symptoms, and ≥ 16 severe symptoms [40].

2.3. Sociodemographic Data

2.3.1. Sociodemographic and Patient Questionnaire. Participants' Gender, Age, Relationship Status, time since injury, Education, former and current Employment Status, and Living Arrangement were recorded as well as self-perceived Independence, Leisure and Social Activities, and self-perceived health in the past 6 months. Furthermore, the amount of reliance on other people's help (Help Needed) was assessed covering basic personal needs, mobility, daily activities, transportation and organization, and "management of things" in life. Participants were asked to respond on a Likert scale from 1 ("no help needed") to 5 ("constant help needed").

2.4. Disease-Specific and Generic HRQoL Instruments

2.4.1. Quality of Life after Brain Injury (QOLIBRI) Scale [16, 17]. This disease-specific HRQoL instrument consists of 37 items associated with six subscales including Cognition, Self, Daily Life and Autonomy, Social Relationships, Emotions, and Physical Problems. The first four subscales inquire about the participant's "satisfaction" with different health-related domains of quality of life. The last two subscales ask about how much the participant felt "bothered by" a variety of issues. Answers are given on a 5-point Likert scale that ranges from "not at all," "slightly," "moderate," and "quite" to "very." The scale means are converted to the 0–100% scale by subtracting 1 from the mean and then multiplying by 25. This produces scale scores with a lowest possible value of 0 (worst possible HRQoL) and a maximum value of 100 (best possible HRQoL). The QOLIBRI provides a disease-specific HRQoL profile over six domains in addition to a total score. Depending on the participant's background, the recruiting centers administered the appropriate language version of the QOLIBRI.

2.4.2. SF-36 Health Survey Version 1 [41]. To capture the patients' subjective health status SF-36 version 1 was administered in all countries but one as a generic outcome measure. In Australia with around 60 patients the SF-36 v2 was applied with subsequently transformed data [16]. It is a multi-item instrument with eight subscales assessing the following domains: Physical Functioning (PF), Role Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role Emotional (RE), and Mental Health (MH). For each domain, a summation of item responses is linearly transformed into a score ranging from 0 to 100. Additionally, a Physical Component Summary (PCS) and a Mental Component Summary (MCS) score are reported. PCS and MCS are calculated by standardizing patients' scores through subtracting US subscale means from each individual's subscale scores. For more details, please look at the manual [41].

2.5. Treatment of Missing Values. If less than one-third (33%) of the items were missing, means for each QOLIBRI subscale were calculated, prorated, and expressed as a score from 0 (lowest possible HRQoL measured by the questionnaire), to 100 (best possible HRQoL). A total QOLIBRI score was also

calculated as the mean of all individual items, using prorating if necessary. With the missing values in the SF-36 we dealt by overall mean substitution per subscale. The missing values in all other variables (correlates) were treated as missing.

2.6. Procedure. Between 2006 and 2008 individuals after TBI were recruited primarily from rehabilitation clinics or from convenience samples in all countries but one. In Germany, patients were consecutively retrieved from community and university hospitals. Patients were identified via archive search and contacted by mail. When interested in participating they were contacted via telephone by the recruiting centers. Upon initial contact, consent was obtained from the participants and arrangements were made for the completion of the questionnaires, considering the physical and cognitive abilities, residence, and mobility constraints of the participants. Those who were able to fill in the questionnaires independently received questionnaires by mail to be returned after completion. When participants needed support, a face-to-face contact was arranged and the GOSE and the inclusion/exclusion criteria were completed in one interview. When postal administration was performed, inclusion/exclusion criteria and the GOSE were completed in a telephone interview. The GCS was then retrieved from the patient record forms.

2.7. Data Analysis. Concerning the generic and disease-specific HRQoL instruments (SF-36 and QOLIBRI, resp.) classical psychometric criteria were investigated (mean, standard deviations (SD), skewness of item distribution, floor and ceiling effects per scale, kurtosis, and Cronbach's alpha, as well as convergent and discriminant validity). Probabilistic test theoretical analyses have already been applied for the QOLIBRI [16]. Frequencies, means, SD, and percentages are given for the covariates/correlates of HRQoL. Kolmogorov-Smirnov [42] and Shapiro-Wilk test [43] were used to test if the data were normally distributed. Ceiling and floor effects were defined as answers which fell into the highest or lowest 10% of possible answers per subscale. These effects should be minimal for an instrument to be able to discriminate well.

To be able to investigate whether disease-specific and generic HRQoL share similar correlates, the QOLIBRI Total score and SF-36 MCS and PCS representing the outcomes (predicted values) and a number of sociodemographic, psychosocial, and health-related variables, known from the literature as predictors and correlates, were submitted to a stepwise linear regression analysis (SPSS 22.0). The variables included in the first step were as follows: Years since Injury, Age, Relationship Status, Education, Change of Job, Employment, Living Arrangement, the Degree of Help Needed, Independence, Social Activities, Internet Activities and other Hobbies, Comorbid Health Conditions, Sensory and Psychosomatic and Motor-Skeletal Complaints, GOSE score, and HADS Depression and Anxiety scores. As many of the variables were skewed, we ranked data before subjecting them to regression analyses [44]. The criterion for inclusion of a variable in the final model was that it should independently explain 1% or more of the variance (increase in R² > 1%) [17].

2.8. Shannon Indices. Two different indices will be reported in this paper, H' as the measure for absolute informativity expressed by the number of categories tagged (addressed in detail) and J' as a relative measure that takes into account the maximum informativity which can be reached given a certain number of categories. H' is the absolute informativity captured considering each predictor, whereas J' (evenness) provides the relative informativity. A higher H' means that more information is obtained. The evenness as a relative measure is defined between 0 and 1. A high evenness value indicates a uniform distribution of the response options for a variable. A low evenness index is a sign of a skewed distribution.

The Shannon index H' ([45]; see also [33–35]) was calculated for the summary scores and for the separate HRQoL dimensions/subscales. The basic characteristic of Shannon's indices can be explained as follows. In an item with two response categories in which one response category has a very high (or low) endorsement, for example, more than 0.95 (or less than 0.05), the response category transmits very little information because one can predict with more than 95% certainty in what response category the answer will be located [33]. Conversely, in the case of an even distribution, the HRQoL dimension is being most efficiently used, which means that the discriminant ability of the descriptors is maximal. The Shannon index H' combines the number of nonempty categories defined by a system and measures to what extent the information is (empirically) evenly spread over the nonempty categories. As stated above, the higher the index H' is, the more the information is captured by the system. However, the value of the index also depends on the logarithm applied for calculation. Hence, when the logarithm dualis is utilized values are higher than when applying the logarithm naturalis. The logarithm base 2 is defined by $\log(p_i)/\log(2)$, and in our case p_i is the probability of a summary score. We calculated H' by the following formula:

$$H' = -\sum_{i=1}^C p_i * \log_2 p_i. \quad (1)$$

C_i refers to the number of nonempty categories; p_i is the probability of category C_i and \log_2 is logarithm base 2. The probability p_i of category C_i is estimated by the relative frequencies defined by n_i/N , where n_i is the frequency of category C_i and N is the total number of cases. The Shannon index H' results from summing up the product $p_i * \log_2(p_i)$ for all categories. In most cases, especially in information theory, the formula of the Shannon index (SI) is calculated by the natural logarithm and entropy is defined using logarithm base 2. However, in HRQoL research SI has been defined using logarithm base 2 in the formula [34]. In order to assure continuity we decided to define the Shannon index by logarithm base 2. Therefore, we also determined that each score defined a category. After summing up the answers of each person to an individual person score, these scores were used as categories. No grouping was applied. H' max is therefore estimated; it is defined as the maximum value of H' (H' max = $\log_2(C_i)$) and indicates the maximum available information. The second index in the context of the Shannon

index is J' and is derived from H' . J' presents a measure for the spread of the frequencies or categories [34]. The advantage of J' , unlike H' , is its independence from the number of categories available in the dataset. Statistically, J' quantifies how equally the numbers of categories are distributed. So J' , defined by $J' = H'/H'$ max, indicates how close the number of different categories is. J' ranges between 0 and 1. The more J' deviates from 1, the less the scores are evenly distributed.

Shannon indices were calculated for stratified groups according to differential correlates of disease-specific and generic HRQoL identified through regression analyses for the summary scores and the different subscales of the two instruments (see results section for details). QOLIBRI Total, MCS, the PCS, and the respective subscales are compared with respect to these different correlates of HRQoL. In order to calculate H' for MCS and PCS, we rounded up nonintegers to build categories.

3. Results

3.1. Patients' Clinical and Sociodemographic Data. Of the 921 enrolled patients 126 were excluded from subsequent analyses as GCS were missing. Thus, for GCS and GOSE 100% of the data were present in the remaining 795 patients; some additional data, however, were missing to different degrees. For demographics concerning Gender and Age, 100% of the data were present and for Living Arrangements, Employment Status, and Relationship Status 93% to 95.6% were present. For Years since Injury 99% of the data was available and 92% for self-reported health-related complaints. HADS Anxiety and Depression scores existed for 99%, for SF-36 subscales for about 91% before imputation. There were less than 5% missing responses per QOLIBRI subscale before imputation. Demographic and clinical characteristics of the final validation study are presented in Table 1. In this TBI sample ($N = 795$), there were a greater number of men ($n = 537$) than women ($n = 222$). Within the age range covered (from 17 to 68 years), three groups of almost equal size were formed (17 to 30 years, 31 to 44 years, and 45 to 68 years).

The mean age was 39 years ($SD \pm 13.3$ years). By GCS criteria, more than half of the sample was severely injured, and for 25% the injury had occurred between 2 to <4 and for 49.6% between four years and 18 years earlier. Less than a quarter of the sample was in full-time employment (which cannot be taken as representative for other TBI samples) and only half in a relationship at the time of the interview. In the different countries, zero (Germany, Australia, and England) to 45% of the patients were still undergoing some kind of therapy or rehabilitation at the time of the assessment. Over half of the TBI survivors were living independently and did not "need help to carry out Daily Life tasks." Over half of the population reported four or more health-related conditions concerning Comorbidity, Sensory and Psychosomatic, and Motor-Skeletal Complaints. According to the GOSE, the majority (72.4%) of participants were disabled by consequences of their TBI (Severe and Moderate

TABLE 1: Demographic and clinical characteristics of the TBI population.

Demographic and clinical variables		Frequency (%)
Age	17–30	271 (34.1%)
	31–44	247 (31.1%)
	45–68	277 (34.8%)
Gender	Male	573 (72.1%)
	Female	222 (27.9%)
Time since injury	<1 year	93 (11.7%)
	1 to <2 years	102 (12.8%)
	2 to <4 years	203 (25.5%)
	4 to 18 years	394 (49.6%)
Relationship Status	Partnered	403 (50.7%)
	Not partnered	303 (38.1%)
Highest Education level	Primary school	42 (5.3%)
	Secondary school and trade or technical certificate	403 (50.7%)
	College diploma or degree	173 (21.8%)
	University degree	88 (11.1%)
Living	Living at home independently	420 (52.8%)
	Living at home supported	245 (30.8%)
	Nursing home	75 (9.4%)
Help Needed	Yes	306 (38.5%)
	No	427 (53.7%)
Leisure activities	Individual activities (internet + hobbies)	425 (53.5%)
	Social activities (socializing + physical activities)	505 (63.5%)
	Hobbies (hobbies + music)	395 (49.7%)
Health Complaints	Comorbidity	440 (55.3%)
	Sensory/Psychosomatic	631 (79.4%)
	Motor/Skeletal	363 (45.7%)
GCS	Severe (GCS < 8)	464 (58.4%)
	Moderate (GCS 8–12)	76 (9.6%)
	Mild (GCS ≥ 13)	255 (32.1%)
Glasgow Outcome Scale-Extended Score	Severe Disability (GOSE 3–4)	143 (17.9%)
	Moderate Disability (GOSE 5–6)	433 (54.5%)
	Good Recovery (GOSE 7–8)	219 (27.6%)
HADS Anxiety score	Normal	496 (62.4%)
	Mild	144 (18.1%)
	Moderate/Severe	152 (19.1%)
HADS Depression score	Normal	537 (67.5%)
	Mild	120 (15.1%)
	Moderate/Severe	132 (16.6%)

Disability). The mean period of follow-up was 5 years ($SD \pm 3.9$).

3.2. Psychometric Analyses of QOLIBRI and the SF-36. As data of the QOLIBRI as well as of the SF-36 ($P < .001$) were not normally distributed, nonparametric tests were applied [16, 17].

In this study additional psychometric criteria, as shown in [16, 17], were investigated in order to compare the metric qualities and the appropriateness of both instruments for administration to individuals after TBI (Table 2).

Concerning item response distributions of the two instruments, for the QOLIBRI subscales no extreme responses (overall $\leq 20\%$ of extreme responses), for example, no floor or ceiling effects in the responses, were detected, except for subscale Emotion with 24.7% of the answers ranging from 90% to 100% very good to excellent HRQoL (ceiling effects). The ceiling effect for the subscale Emotions had been enhanced by mean imputation. The SF-36, on the other hand, showed both types of effects in most of its subscales: RP resulted in 26.3% responses with floor and 35.7% with ceiling effects, RE had 24.4% floor and 46.2% ceiling effects, and PF,

TABLE 2: Psychometric characteristics of the QOLIBRI and SF-36 subscales and summary scores.

Descriptive statistics	Mean	(SD)	Floor [%]	Ceiling [%]	Skew	Kurtosis	Cronbach's α
<i>QOLIBRI</i>							
Physical Problems	67.91	(23.47)	1.4	15.2	.09	.02	.76
Emotions	71.71	(24.69)	2.9	24.5	-.87	.02	.84
Social Relationships	63.65	(22.64)	1.4	14.3	-.41	-.43	.82
Daily Life/Autonomy	66.41	(22.38)	1.3	14.5	-.61	-.11	.87
Self	60.03	(21.96)	2.1	6.2	-.42	-.31	.89
Cognition	61.26	(21.77)	1.0	7.2	-.42	-.34	.89
QOLIBRI Total	64.58	(18.24)	0.4	6.8	-.48	-.04	.82
<i>SF-36</i>							
Role Physical	55.13	(38.84)	26.3	35.7	-.21	-1.42	.84
Physical Functioning	76.39	(23.75)	2.3	36.8	-1.15	.71	.93
Bodily Pain	71.28	(26.92)	2.5	36.4	-.61	-.58	.87
Role Emotional	61.01	(39.46)	24.4	46.2	-.46	-1.31	.82
Mental Health	63.90	(20.00)	1.1	8.8	-.46	-.08	.84
Social Functioning	68.01	(25.12)	2.2	22.4	-.59	-.15	.76
Vitality	54.63	(21.51)	4.4	6.5	-.27	-.16	.82
General Heath	63.60	(20.75)	1.1	11.7	-.35	-.33	.76
PCS	46.70	(10.13)	0	0	-.44	-.54	.91
MCS	43.91	(11.94)	0	0	-.40	-.59	.91

BP, and SF demonstrated 36.8%, 36.4%, and 22.4% ceiling effects and considerably lower floor effects (see Table 2).

Table 2 indicates that psychometric properties of all QOLIBRI and SF-36 subscales, as well for the QOLIBRI Total score and MCS and PCS, were predominantly satisfactory to very good. The two instruments differed in terms of skew, kurtosis, and alpha values. Values for skew as well as for kurtosis all fell within a tolerable range of ± 2 , which is considered acceptable for a normal univariate distribution [46]. Negative skew for all subscales (Table 2) reflected a pronounced use of the right side of the scales. The latter was confirmed by a significant Kolmogorov-Smirnov test ($P < .001$). Negative kurtosis denoted a flat distribution across all scales with a more pronounced peak to the right as indicated by negative skew. Subscales RF, RE, and SF of the SF-36 were characterized by floor/ceiling effects, as displayed in Table 2, with more than 50% of the responses for the subscales RP and RE located at the extremes of the answering scales. Cronbach's alpha for both instruments ranged from $\alpha = .76$ to $.93$ which is considered good to excellent [47].

3.3. Correlates of Disease-Specific and Generic HRQoL. To answer the question whether correlates of disease-specific and generic HRQoL do differ, the following variables from the final stepwise regression models for the total score of the QOLIBRI and the summary scores of SF-36 were selected for further analyses: HADS Depression, HADS Anxiety, Help Needed, Social Activities, Comorbidities, Sensory and Psychosomatic Complaints, Motor-Skeletal Complaints, and GOSE categories. With regression analyses in psychometric terms predictors of HRQoL are identified. However, in order to enhance interdisciplinary comprehensibility, we are using the term correlates of HRQoL even though these were

identified by multiple regression analyses and not by simple correlation analyses.

The strongest correlates of the QOLIBRI Total score were aspects of the current emotional situation, namely, in descending sequence: HADS Anxiety (27.9%), HADS Depression (10.8%), Functional Outcome (GOSE) (6.3%), Sensory and Psychosomatic Complaints (2.2%), Degree of Help Needed (1.6%), and Social Activities (1%). The strongest correlates for MCS of the SF-36 were HADS Depression (30.5%), HADS Anxiety (9.8%), and Sensory and Psychosomatic Complaints (1.4%), which qualified for further analyses. The strongest correlates for the PCS were Motor-Skeletal Complaints (22%), Comorbidities (6.1%), Degree of Help Needed (5.4%), and Social Activities (3%), as well as Functional Outcome (GOSE) (1.8%), and hence those were suitable for further analysis (Table 3). As expected, the correlates of MCS had mental/psychological aspects in common, and the correlates of PCS captured physical aspects. The correlates of QOLIBRI Total score on the other hand represented a mix of both.

3.4. Shannon Indices of Disease-Specific and Generic HRQoL. Here the discriminative power of the two instruments by means of the Shannon index H' was calculated, as was the evenness index J' . J' was close to 1 for all Shannon indices H' , indicating a uniform distribution of data. However, since the range and directionality of the J' results did not essentially deviate from H' , that is, they were comparable, $J' (.64$ to $.97)$ was not considered for further analyses (data available upon request).

As high Shannon indices indicate high informativity the results clearly showed that SF-36 subscales RP (2.17), RE (1.83), and SF (2.01) had a significantly lower Shannon

TABLE 3: Results of the stepwise regression analysis.

Dependent variable	Proportion of explained variance	Change in R^2	Significance of change in R^2
QOLIBRI Total			
HADS Anx.	.278	.279	.000
HADS Dep.	.385	.108	.000
GOSE	.447	.063	.000
Sensory/Psychosom.	.468	.022	.000
Help Needed	.483	.016	.000
Soc. Act.	.492	.010	.001
SF-36-MCS			
HADS Dep.	.303	.305	.000
HADS Anx.	.401	.098	.000
Sensory/Psychosom.	.414	.014	.001
SF-36-PCS			
Motor/Skeletal	.218	.220	.000
Comorbidity	.278	.061	.000
Help Needed	.331	.054	.000
Soc. Act.	.359	.030	.000
GOSE	.376	.018	.000

index/grade of informativity (ranging from 1.83 to 2.17) as well as H' of BP (2.82) in comparison to all other subscales. The Shannon index of the PF was above 3.5, and for MCS and PCS it was above 5. In contrast, all Shannon indices of the QOLIBRI were around 4 (ranging from 3.90 to 4.83) indicating a high discriminative power of all subscales and the total score. As seen in Figure 3, the Shannon indices of PCS and MCS were high. These values can be explained by the great number of categories used in these two summary scales applied for calculation of H' .

Next, we inspected the H' index (diversity/absolute informativity) with respect to the two HRQoL instruments for the single correlates in detail.

With respect to Help Needed and Social Activities, the QOLIBRI subscales differentiated well within the correlates, with H' ranging from Physical Problems 3.76 to 4.75 total QOLIBRI. The SF-36 subscales RP, SF, and RE, as expected, did not discriminate well within the correlates (with lowest indices for RE <2); the summary scores MCS and PCS however did differentiate well (with highest index of 5.11 for MCS). Unlike the QOLIBRI subscales, the SF-36 subscales PF and BP differed significantly in their informativity for Help Needed and Social Activities.

Absolute Shannon indices H' of all QOLIBRI subscales indicated that for the three health complaints all differentiated better than did the SF-36 subscales in the whole sample. The Shannon indices H' for the summary scores MCS and PCS, however, were significantly higher than for all other subscales and for the total QOLIBRI score. The subscale Physical Problems (QOLIBRI) transmitted more absolute informativity concerning the single individuals in all three groups of self-reported health complaints than did RP and BP of SF-36. Yet, the informativity of the PF was comparable to the Physical Problems scale of the QOLIBRI.

The Shannon indices H' for the RP, RE, and SF reproduced the same pattern as in Figures 1–3 with low informativity concerning individuals belonging to the specific GOSE groups compared to all other scales and summary scores (Figure 4). The QOLIBRI indices, however, ranged from 3.64 (Physical Problems) to 4.57 (Self). Within the QOLIBRI subscales Emotions, Social, Daily Life, Self, and Cognition, the Shannon indices differentiated in the Moderate Disability GOSE category better than in the Good Recovery category, whereby the latter index was lower.

For RP, PF, RE, PCS, and MCS the SF-36 results in a higher informativity for Moderate Disability over Good Recovery. In addition, informativity of MCS and PCS was significantly higher for Moderate Disability than for Severe Disability and significantly differed between Severe and Moderate Disability and between Moderate Disability and Good Recovery.

The Shannon indices H' for all QOLIBRI scores (ranging from 3.69 for Physical Problems to 4.51 for QOLIBRI Total) and the three GOSE scores were generally higher than for the SF-36 subscales (Figure 4). The Shannon indices did not differ between the score categories per subscale. In the SF-36 subscales, however, we observed considerably more variability. The H' indices range from 1.66 (RE) to 5.14 (MCS). Within the SF-36 subscales, the indices differed significantly for RP with a higher H' for Mild Depression as for Normal and Moderate/Severe Depression. Also, the subscales PF, BP, and RE presented significantly different patterns: HADS Mild and Moderate/Severe Depression scores differed significantly, as did Moderate/Severe and Normal Depression scores but Mild and Normal Depression scores did not. The subscale PF showed the highest H' index for Moderate/Severe Depression scores being, along with the Mild Depression scores, significantly higher than the Normal Depression score H' index. For BP, the Moderate/Severe Depression score was different

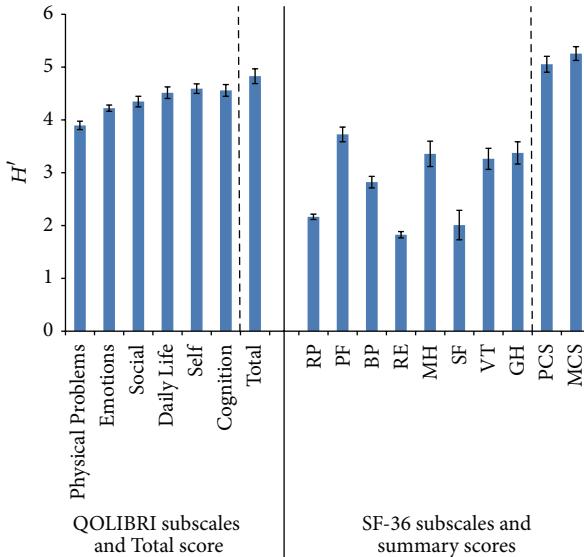


FIGURE 1: Shannon indices H' (confidence intervals 95%) of all QOLIBRI and SF-36 subscales, QOLIBRI Total score and summary scores.

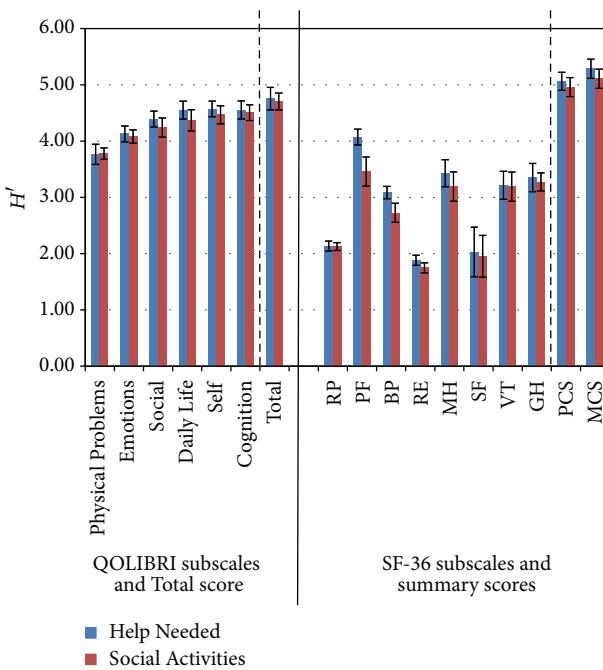


FIGURE 2: Shannon indices H' (confidence intervals 95%) of all QOLIBRI and SF-36 subscales, QOLIBRI Total score and MCS and PCS for the correlates: Help Needed and Social Activities.

from the Normal Depression score with the highest H' index. For subscale RE, the Mild Depression score presented with the highest H' index and differentiated significantly between Normal and Moderate/Severe Depression scores. All other indices were comparable to each other (Figure 5).

Also with regard to the HADS three levels of anxiety, the QOLIBRI was characterized by higher indices than the SF-36. The QOLIBRI subscale indices range from 3.39 (Physical

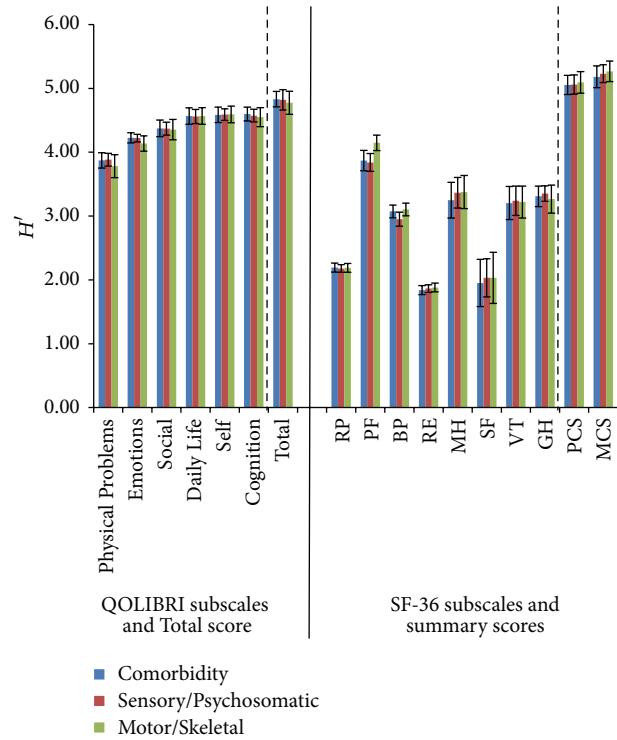


FIGURE 3: Shannon indices H' (confidence intervals 95%) of all QOLIBRI and SF-36 subscales, QOLIBRI Total score and MCS and PCS for the correlates: Comorbidity, Sensory/Psychosomatic and Motor/Skeletal Complaints.

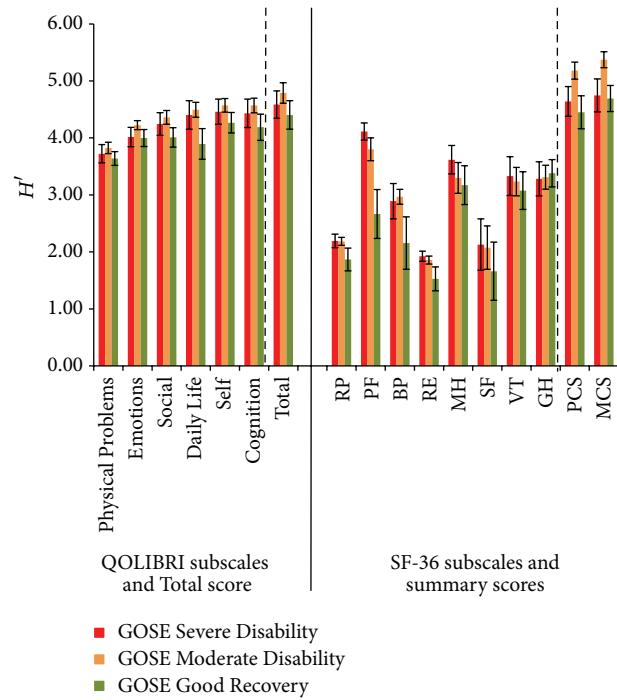


FIGURE 4: Shannon indices H' (confidence intervals 95%) of all QOLIBRI and SF-36 subscales, QOLIBRI Total score and MCS and PCS for the correlate GOSE scores.

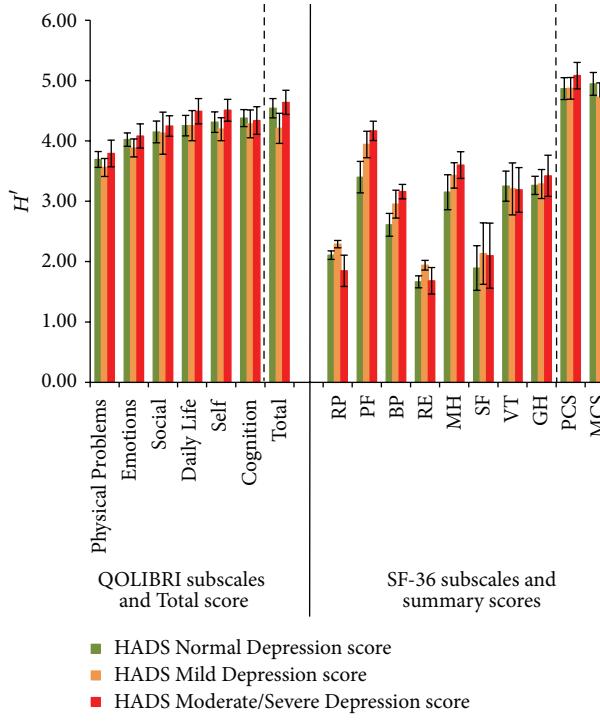


FIGURE 5: Shannon indices H' (confidence intervals 95%) of all QOLIBRI and SF-36 subscales, QOLIBRI Total score and MCS and PCS for the correlate HADS Depression scores.

Problems) to 4.63 (Daily Life). The Shannon indices H' of the subscales between the score categories were comparable. The subscales of the SF-36 resulted in indices ranging from 1.57 (RE) to 4.04 (PF) and to 5.01 for the PCS. Within the SF-36 subscales, the indices differed for RE, with H' for the Mild Anxiety score being higher than the Normal Anxiety score, PF and BP between Moderate/Severe and the Normal score (Figure 6).

4. Discussion and Conclusions

The aim of this paper was a detailed investigation of classical psychometric criteria and the discriminative power/absolute informativity of a disease-specific (QOLIBRI) and a generic (SF-36) HRQoL instrument in the field of TBI.

Psychometric properties of both instruments in a TBI sample were satisfactory to very good, in this and in previous studies. Both instruments are valid and reliable. Item distribution of the QOLIBRI showed no floor effects, but some ceiling effects for the Emotional subscale. For the SF-36 prominent floor (RP, RE) and ceiling effects (RP, PF, BP, RE, and SF) were identified for the majority of subscales. These effects may already indicate that the subscales of the SF-36 might not differentiate sufficiently in a population of TBI survivors.

When comparing the mean values of PCS and MCS with those found in the literature, an overarching effect becomes apparent. In the study of Scholten et al. [48], for example, patients have lower PCS ($M = 45$, $SD = \pm 10.1$) than MCS

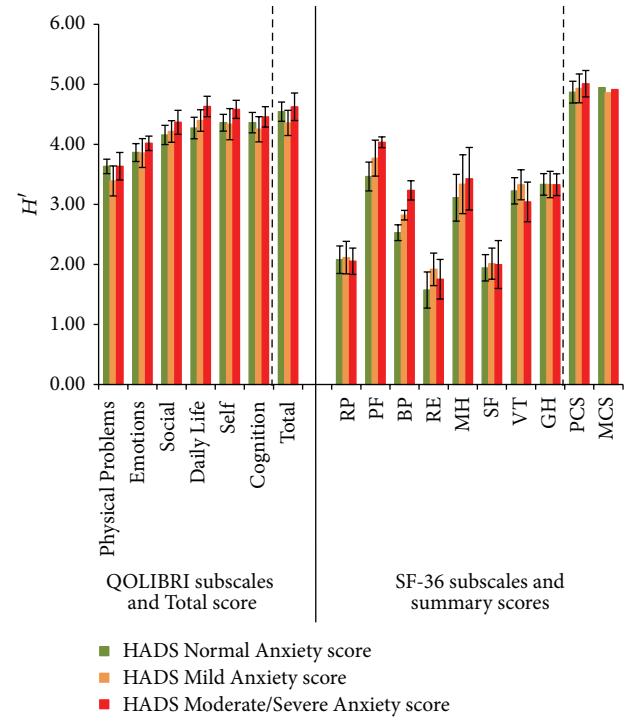


FIGURE 6: Shannon indices H' (confidence intervals 95%) of all QOLIBRI and SF-36 subscales, QOLIBRI Total score and PCS and MCS for the correlate HADS Anxiety scores.

values ($M = 47.2$, $SD = \pm 11.6$). This pattern is confirmed by Forslund et al. [49], Jacobsson et al. [50], and Grauwmeijer et al. [51]. The latter argued that this finding might be ascribed to the limited awareness of patients after severe TBI who participated in their sample. For our study the results of MCS and PCS are reversed: Values for the PCS ($M = 46.70$, $SD = \pm 10.1$) are higher than for the MCS ($M = 43.9$, $SD = \pm 11.9$). Hawthorne et al. [12] found similar results in mild TBI. These individuals may be less impaired by awareness problems, which subsequently could result in lower MCS values. However, in our study the number of patients who had sustained a severe TBI was twice as large as those who had endured a mild TBI. Thus, these findings have to be analysed in more detail in further studies. A Structural Equation Modeling (SEM) approach incorporating the covariates identified within this study may facilitate understanding of these interactions. In general a measure of awareness can be recommended [52] to scrutinize the relationship between HRQoL ratings in the field of TBI. When comparing the QOLIBRI subscale means and the total score to other studies applying it, mean values are comparable across studies [20–22]. The highest score was determined for the subscale Emotions, followed by Physical Problems. Lower scores were found for Cognition and lowest for the subscale Self. High scores in the subscale Emotions could have been influenced by negative wording, the reversing/recoding of the answers, and the use of mean imputation method. Initially employed to counteract acquiescence response style, empirical evidence exists that reverse coding may actually impair response accuracy [53]. Subsequently, the high scores for the subscale Emotions are

not likely to be due to an awareness problem of the patients, especially since the scale Cognition (not reversely scored) presents low values, indicating that an overestimation of cognitive capacities is not present.

Differences observed between the means of the SF-36 and the QOLIBRI may be confounded by different evaluation and/or scoring methods of the instruments. First of all, there are important differences in the applied health/HRQoL state evaluation technique: In the SF-36 response options vary from binary to a six-point Likert scale and weighted summary scale scores. The QOLIBRI in contrast consists of a five-point Likert response and a simple summed up total score.

To investigate the relationship between the instruments applied and the sociodemographic as well as clinical variables, via stepwise regression analyses, correlations of the PCS, MCS (SF-36), and the QOLIBRI Total score were performed. The following correlates of disease-specific and generic HRQoL were identified: for the PCS: Motor/Skeletal Complaints, Comorbidity, Help Needed, Social Activities, GOSE; for MCS: HADS Depression and Anxiety and Sensory/Psychosomatic Complaints. For the QOLIBRI Total score HADS Anxiety and Depression, GOSE, Sensory/Psychosomatic Complaints, Help Needed, and Social Activities correlates were identified. Only a small number of studies use a comparable comprehensive approach for the identification of correlations. Soberg et al. [20] selected correlates for disease-specific HRQoL by multiple regression: the HADS evolved as the most relevant, followed by RPQ, GOSE after 12 months, GOSE after 3 months, and Employment Status. These results correspond partly to ours. We share the authors' assumption that the association between injury severity and HRQoL may dissolve over time, as we also did not find a relationship to GCS in a previous univariate analysis [17]. For over 60% of individuals in our sample the injury had occurred 2 to 18 years prior to participation in the study. In our initial calculations, "time since injury" resulted in significant effects only on three subscales of the questionnaires, for QOLIBRI (Cognition, Self, and Social Relationships) and the SF-36 (RP, BP, and GH). Due to space-constraints, we decided not to focus on time since injury in more detail in this paper. However, the importance of other variables (e.g., psychological and social components) may increase for HRQoL at the later stages of injury.

Since HRQoL is a multifaceted dynamic process affected by many different factors [53] further research with extended correlate models is required. Single correlates such as Functional Recovery, Anxiety/Depression, Race, Gender, and Severity of TBI have been investigated, showing detrimental effects on generic HRQoL in different settings and for varying degrees of severity [27, 51, 54–56]. Unfortunately, in our paper the influence of higher order factors could not be investigated with the analyses applied. A hierarchical linear model will most likely be able to shed light on the complex interplay of variables on different levels.

Subsequently, we discuss our results with respect to differentiating individuals contained in one health state or HRQoL dimension, presented by the Shannon index (H'). The SF-36 data implied that the three subscales RF, RP, and RE generally did not have good discriminative power. H' of

the remaining SF-36 subscales as well as the two summary scores discriminated well in our TBI population. On the other hand, all QOLIBRI scores displayed high Shannon indices, a result which underlines the necessity of applying specifically tailored instruments to certain diseases. Whereas the generic SF-36 can be used for cross-disease comparisons, the QOLIBRI focuses on consequences important for TBI survivors. Consequently, it should have higher discriminatory power in a specific disease group, which is supported by the results presented within this study. Even though this was not assessed in the present study, but will be in future ones, higher discriminatory power of the QOLIBRI could result in higher sensitivity of this instrument.

As the SF-36 is known to discriminate well between different health/HRQoL states/dimensions in TBI [5], these differences in Shannon indices may initially seem contrainuitive and surprising. Inspecting the response distribution in corresponding individual items and subscales we have however determined pronounced floor and ceiling effects in many of the SF-36 subscales but not for the QOLIBRI. These effects resulted in lower Shannon indices, as frequencies have an impact on the calculation of H' . Therefore, these subscales seem to be less sensitive in detecting differences within certain TBI subgroups, when compared to all scores of the QOLIBRI.

TBI outcome is heterogeneous, encompassing a broad spectrum of HRQoL with many problems reported in the physical, emotional, and social functioning domain. In the field of TBI—as in nearly all other medical fields—there is a lack of consensus on preferred HRQoL instruments. To enable straightforward comparisons with other disease groups and with general population norms, it is necessary to measure the consequences of TBI using generic health status measures (as the SF-36 or the EQ-5D) [35]. However, the domains may be not specifically relevant for TBI survivors, as can be deduced from many of our results. There are other important problems that are often identified to be common in TBI, such as cognitive consequences [57], alterations in social relationships [58], limitations to activity and participation [59], changes in the sense of self [60], emotional problems [61], and physical problems. HRQoL in some of these areas typically affected by TBI is not well assessed or not assessed at all by generic HRQoL instruments. In contrast, the QOLIBRI captures multiple of these domains, encompassing especially the psychological (emotional and cognitive), social, and also, to a lesser extent than the SF-36, physical and functional domains [6, 17]. The use of SF-36 in combination with the QOLIBRI is recommended, depending on the focus of a study. For in-group discrimination of patients, requiring a specifically tailored health intervention, the QOLIBRI should be the tool of choice. For comparison and differentiation of individuals between certain health states, health conditions, or HRQoL domains, the SF-36 is an appropriate instrument also. Consensus on preferred methodologies of HRQoL assessment in TBI would facilitate comparability across studies, resulting in improved understanding of recovery and the burden of TBI.

Limitations of the reported study are inherent to the comparison of generic and disease-specific HRQoL instruments.

Individual subscales are not directly comparable, as they consist of a different number of subscales and a different number and content of items per subscale, which are not always based on the same theoretical concept. Therefore H' was applied for comparison. Another limitation may be due to the use of version 1 of the SF-36 in this study because of being available in the public domain. Some of the psychometric problems however, especially concerning the physical scales, are described to be solved in version 2 of the instrument [62]. Thus, Shannon indices of the SF-36 v2 subscales remain to be investigated. The currently conducted prospective longitudinal Center-TBI study (<https://www.center-tbi.eu/>) will allow for this. Furthermore, the influence between the correlates selected and HRQoL could not be investigated in this paper. A Structural Equation Modeling (SEM) approach, as proposed by Williamson et al. [63], could determine whether the correlates are of importance on a precedent level. Interestingly, in recent years many experts refer to TBI as a chronic disease [64], according to whom TBI should be also managed as such. If this chronic nature of TBI is recognized, research could be directed at discovering therapies that may interrupt the disease processes months or even years after the initial event. This paradigm shift would also have an impact on the importance of measuring HRQoL after TBI. Strengths of the study however lie in the attempt to embark in this comparison with a rather new methodology. Shannon indices were calculated in a large number of TBI survivors of all severity levels after applying a comprehensive regression model. In line with our expectations, HRQoL differed depending on GOSE recovery and HADS Depression scores. The QOLIBRI subscales and total score detected more differences between the levels of recovery and depression than the SF-36. In accordance with most studies, lowest HRQoL was observed for severe/moderate depression as well as severe disability. Consistently, HRQoL increased for patients with only Mild Depression and good recovery [30, 65]. Finally, there is a need for longitudinal studies that evaluate possible differential effects over time (such as Center-TBI and Track-TBI). It may well be that correlates are quite different at different time periods after injury.

5. Conclusion

Differential correlates were identified for generic and specific HRQoL. In order to better understand HRQoL of patients after TBI, we would like to accentuate a comprehensive assessment of correlates and the use of SEM for future studies. The complex interplay of these factors has to be scrutinized to ameliorate symptoms and tailor interventions for TBI survivors. Based on our novel investigation of the power to discriminate individuals in a health state or in a HRQoL dimension with the Shannon indices H' and J' in comparison with the SF-36, the QOLIBRI is recommended for assessment.

Disclosure

Nicole von Steinbuechel and Amra Covic shared first authorship.

Conflict of Interests

The authors declare that no competing interests exist.

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Research Article

Cognitive Impairment after Severe Traumatic Brain Injury, Clinical Course and Impact on Outcome: A Swedish-Icelandic Study

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Objective. To assess the clinical course of cognitive and emotional impairments in patients with severe TBI (sTBI) from 3 weeks to 1 year after trauma and to study associations with outcomes at 1 year. **Methods.** Prospective, multicenter, observational study of sTBI in Sweden and Iceland. Patients aged 18–65 years with acute Glasgow Coma Scale 3–8 were assessed with the Barrow Neurological Institute Screen for Higher Cerebral Functions (BNIS) and the Hospital Anxiety and Depression Scale (HADS). Outcome measures were Glasgow Outcome Scale Extended (GOSE) and Rancho Los Amigos Cognitive Scale-Revised (RLAS-R). **Results.** Cognition was assessed with the BNIS assessed for 42 patients out of 100 at 3 weeks, 75 patients at 3 months, and 78 patients at 1 year. Cognition improved over time, especially from 3 weeks to 3 months. The BNIS subscales “orientation” and “visuospatial and visual problem solving” were associated with the GOSE and RLAS-R at 1 year. **Conclusion.** Cognition seemed to improve over time after sTBI and appeared to be rather stable from 3 months to 1 year. Since cognitive function was associated with outcomes, these results indicate that early screening of cognitive function could be of importance for rehabilitation planning in a clinical setting.

1. Introduction

The annual incidence of traumatic brain injury (TBI) in Sweden is estimated at 250–350 000/year [1, 2]. Severe traumatic brain injury (sTBI) defined by a Glasgow Coma Scale (GCS) of 3–8 [3] is much rarer, with incidence estimates of 4–8/100 000/year [1]. However, sTBI constitutes a major health problem due to the major functional impact of the injuries and the individual suffering of patients and their families. Severe traumatic brain injuries comprise a heterogeneous group with varying complexity of deficits and impairments that may affect both physical and mental status. Over time, neuropsychological and cognitive impairments have been shown to contribute more than physical impairments to the overall disability after TBI [4]. The patients’ mental status is related to “disturbances in higher cerebral functions,” comprising not only cognition, but also the integration of cognition and

emotion [5]. Dysfunction is reflected in a range of symptoms, such as frustration, inappropriate affective reactions, and lack of spontaneity [6].

Cognitive deficits after sTBI have been relatively well investigated. Most studies have focused on deficits in memory, processing speed, visual spatial abilities, and abstract reasoning [7]. However, the impact on affective functions as well as awareness during the early stages after brain injury has not been studied to the same extent. Borgaro et al. [8] investigated disturbances in affective communication in the acute stage in TBI-patients and patients with stroke. Both patient groups performance was significantly inferior to a control group as regards affect, expression, perception, and spontaneity. In a previous study by Prigatano and Wong [9], cognitive and affective impairments were shown to affect the achievement of rehabilitation goals in the early stages after TBI. Prigatano [10] states that the assessment

of higher cerebral functions including both affective and cognitive deficits seems to be important for outcome after TBI. Neuropsychological examination is time-consuming and patients in the acute phase may be too ill to take part in a lengthy assessment. Therefore, in a clinical setting, there is a need for a brief cognitive screening instrument that can be easily used to establish a cognitive baseline that includes a range of higher cerebral functions in order to follow the patient's improvement and recovery over time.

The Barrow Neurological Institute Screen for Higher Cerebral Functions (BNIS) [11] is an instrument that may be used to screen both cognitive and affective disturbances, in particular in patients in the early posttraumatic stages of brain injury. The BNIS begins with three prescreen items that assess level of arousal, basic communication level, and level of cooperation. If the patient passes the prescreen, the BNIS can be completed. The instrument has been used in several studies of TBI [12], in which memory, awareness, and affect have been reported as among the most impaired functions [6, 8].

Emotional disturbances, including symptoms of depression and anxiety, are a major cause of disability after TBI and comprise risk factors for poor recovery [5]. It is now recommended that patients undergoing rehabilitation following TBI should be assessed for mood disorders [13]. However, in studies on the prevalence of depression and anxiety in TBI patients the results vary widely. One possible reason may be related to different methods of assessment. There are several rating scales that can be used while other researchers may prefer structured interviews. One of the most common instruments used both in the literature and in clinical health care is the Hospital Anxiety and Depression Scale (HADS) [14]. It has been studied in a large number of different patient groups and has been suggested as a screening instrument of choice for anxiety and depression [15]. Since cognitive, affective, and emotional impairments all may play an important role in recovery after sTBI, we decided to study these factors during the first year after sTBI in adults admitted to neurosurgical departments as part of a large prospective multicentre cohort study ("PROBRAIN") [16–18]. Previous mental illness and cognitive problems may affect the patients' health and their posttrauma condition; we therefore considered that these factors were also of importance to investigate. Patients with such preexisting problems may also be more prone to TBI [19], so excluding this group would limit generalizability.

The aims of this study were to assess the clinical course of cognitive and emotional impairments as assessed by BNIS and by HADS from three weeks to one year after trauma and to study associations with outcomes at one year.

2. Methods

2.1. Patients. Inclusion criteria were as follows: (1) patients with severe TBI, who survived at least 3 weeks with a lowest nonsedated GCS [3] 3–8 or equivalent scores on the Swedish Reaction Level Scale (RLS) [20] in the first 24 hours after injury and who were able to complete a brief screening

test with BNIS prescreening, were then assessed with the full BNIS test; (2) age at injury: 18–65 years; (3) injury requiring neurosurgical intensive care or collaborative care with a neurosurgeon and a physician in another intensive care unit; (4) patients were required to speak and understand the Swedish or Icelandic language. Exclusion criteria were death or expected death within 3 weeks of injury.

The 8-point RLS is widely used in Sweden in some emergency departments and neurosurgical units instead of the GCS. The RLS criteria were therefore necessary to allow recruitment of patients from the centers using this scale. Scores on the GCS of 3–8 and on the RLS of 8–4 reflect similar severity of injury [21]. RLS scoring is in the opposite direction to GCS scoring, with the highest RLS score of 8 reflecting the most severe injuries (GCS 3).

2.2. Procedure. Patients from neurosurgical intensive care units at five neurotrauma centres in Sweden and one in Iceland were included. Patients were recruited prospectively by rehabilitation physicians from January 2010 until June 2011, with extended recruitment until December 2011 at 2 centres. The participating centres provide neurosurgical care to >80% of the respective populations of Sweden and Iceland. Patients were evaluated at 3 weeks, 3 months, and 1 year after injury. The patient gave written informed consent in cases where he or she had the capacity to do so. In the majority of cases, the patient lacked that capacity and the patient's nearest relative gave consent to inclusion. Assessments took place in the patient's current care setting or in a local outpatient department. Inclusion and follow-up were therefore independent of the patient's clinical course and care setting. Assessments were performed by rehabilitation physicians with assistance from rehabilitation nurses, psychologists, physiotherapists, and occupational therapists. The data regarding education and earlier cognitive problems were obtained by interviews of patients and/or significant others.

Patients were interviewed and administered the Barrow Neurological Institute Screen for Higher Cerebral Functions (BNIS), either by a clinical neuropsychologist or a physician who was a specialist in rehabilitation medicine. Prescreening was performed initially to evaluate whether it was meaningful to attempt further testing. The BNIS takes about 10–25 minutes to complete.

2.3. Instruments

2.3.1. The Barrow Neurological Institute Screen for Higher Cerebral Functions (BNIS). The BNIS [11] is a cognitive screening test for speech and language functions, orientation, attention/concentration, visuospatial and visual problem solving, memory, affect, and awareness. The BNIS test comprises a prescreen test (level of arousal 3 p, basic communication 3 p, and cooperation 3 p). The three items in BNIS prescreening must be assessed and the patients must achieve at least two points on each of the items for it to be meaningful to continue. Lower scores indicate that the patient will not be able to perform the BNIS. BNIS yields a total score and seven subscale scores. The total score (maximum 50

points) consists of the results from the prescreen plus the 7 subscale scores (speech and language 15 p, orientation 3 p, attention/concentration 3 p, visuospatial and visual problem solving 8 p, memory and learning 7 p, affect (generating happy versus angry affect, perception of facial affect, affect control, and ability to generate spontaneity) 4 p, and awareness of own performance 1 p). A total subscale score can be obtained, as well as a total BNIS raw score that is converted to an age-corrected standard *T*-score. Higher scores reflect a higher level of functioning. If the total BNIS score is below 47 points, further cognitive investigation is recommended [22]. The BNIS has been validated for a Swedish population [23, 24]. The BNIS was assessed at 3 weeks, 3 months, and 1 year after injury.

2.3.2. The Hospital Anxiety and Depression Scale (HADS). The Hospital Anxiety and Depression Scale (HADS) [14] was used to screen for presence and degree of anxiety and depression. It consists of 14 items (7 items in each subscale) which are assessed on a 4-point Likert scale (range 0–3), where the total score is the sum of each subscale (range 0–21). Cut-offs for both subscales of 8 or higher were used to determine “caseness” [25]. The HADS is an established screening tool for anxiety and depression and it has been used previously in patients with TBI [13]. The HADS has acceptable reliability, sensitivity, and specificity in assessing symptom severity in anxiety and depression in various populations [26]. The HADS was assessed at 3 weeks, 3 months, and at 1 year after injury.

2.3.3. Outcomes. Outcome variables were Glasgow Outcome Scale Extended (GOSE) [27] and Rancho Los Amigos Cognitive Scale-Revised (RLAS-R). The RLAS-R was used at 3 weeks, 3 months, and 1 year and the GOSE at 1 year.

2.3.4. The Glasgow Outcome Scale Extended (GOSE). The Glasgow Outcome Scale Extended (GOSE) [27] extends the 5 categories of the previously developed Glasgow Outcome Scale (GOS) [28] to 8, thereby increasing its sensitivity. The 8 categories span from “Dead” (score 1) to “Upper Good Recovery” (score 8). For those alive at one year, GOSE was dichotomized into “Unfavourable outcome” (GOSE 1–4) and “Favourable outcome” (GOSE 5–8). The GOSE has good interrater reliability [27] and validity [29] and is an established measure of global outcome after traumatic brain injury.

2.3.5. Rancho Los Amigos Scale of Cognitive Functioning-Revised (RLAS-R). To enable our findings to be considered in relation to phase of recovery after sTBI, the Rancho Los Amigos Scale of Cognitive Functioning (RLAS-revised) [30] was assessed. RLAS-R is a clinical scale with scores from 1 to 10, representing ten states of cognitive and behavioral functioning through which patients with TBI typically progress (see Table 1). Higher scores indicate improved functioning. The lowest level is “No Response, Total Assistance,” and the highest level is “Purposeful, Appropriate: Modified Independent.”

TABLE 1: Rancho Los Amigos Cognitive Scale-Revised, levels of cognitive functioning (RLAS-R).

Level	
I	No Response: Total Assistance
II	Generalized Response: Total Assistance
III	Localized Response: Total Assistance
IV	Confused/Agitated: Maximal Assistance
V	Confused, Inappropriate Non-Agitated: Maximal Assistance
VI	Confused, Appropriate: Moderate Assistance
VII	Automatic, Appropriate: Minimal Assistance for Daily Living Skills
VIII	Purposeful, Appropriate: Stand-By Assistance
IX	Purposeful, Appropriate: Stand-By Assistance on Request
X	Purposeful, Appropriate: Modified Independent

The RLAS originally had 8 levels, while the revision added levels 9 and 10 to better reflect the highest levels of recovery. The original levels and the revised levels of the RLAS-R levels were dichotomized into two categories: “inferior functioning” (RLAS-R 1–8) and “superior functioning” (RLAS-R 9–10).

2.4. Statistical Analysis. Data were analyzed with SPSS, version 21.0 for Windows. Data were reported as frequencies or median and IQR and means. Nonparametric tests were used as the samples were small and/or not normally distributed. Thus, the Mann-Whitney test was used for the comparison of continuous variables and Wilcoxon’s signed rank test for the study of paired observation variables. The Spearman correlation coefficient was used for the analysis of bivariate correlation. The Chi-square test was used for the comparison of proportions. The level of statistical significance was set as $p = 0.01$. Univariate binary logistic regression analyses were performed where statistically appropriate, to explore associations between the BNIS raw scores with outcome. Variables found to be significant ($p < 0.05$) with univariate analyses were incorporated into a multivariate model using a forward method, with a cut-off for rejection of variables from the model of $p = 0.10$.

3. Results

3.1. Patient Characteristics. Figure 1 is a flow chart depicting the study process. One hundred and fourteen patients were recruited and 78 completed the BNIS at 1 year after trauma. Seven patients died during follow-up (1 before the 3-week assessment, another 4 before the 3-month assessment, and 2 after that). A further 7 patients withdrew (2 before the 3-week assessment, another 2 before the 3-month assessment, and 3 after that). Basic patient descriptors are shown in Table 2. Patients who died were older (median age 61 years, range 19–64) and had lower acute GCS (median 3, range 3–7) while patients who withdrew were younger (median age

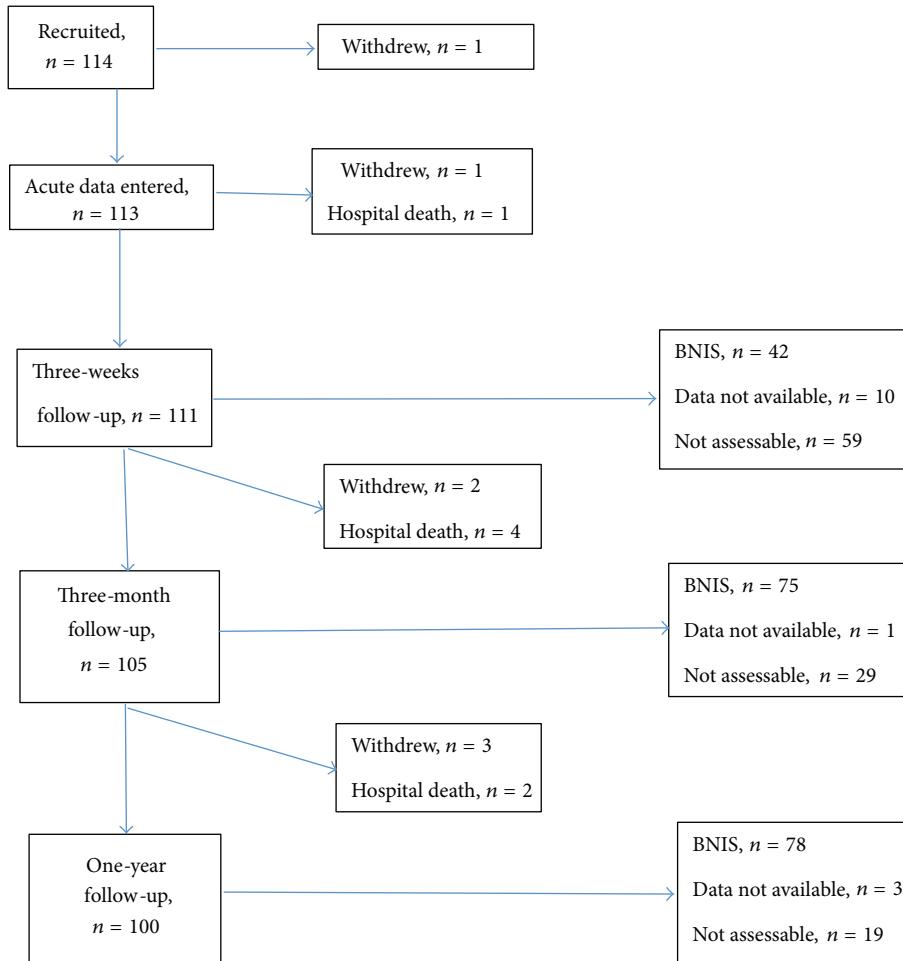


FIGURE 1: Flow chart of patients through the study.

32.5 years, range 20–56) and had higher median GCS 6 (3–7). The median age of patients who participated in the study was 42 years (range 17–65), and GCS during the first 24 hours was median 5 (3–8). One patient was included shortly before the patient's 18th birthday due to a minor protocol violation. Eighty-six were men and 28 were women. Less than 12 years of education was reported by 35 men (33%) and 10 women (9%).

3.2. The Barrow Neurological Institute Screen for Higher Cerebral Functions (BNIS). See Table 3. Three weeks after injury, the BNIS could be assessed in 42 patients, 59 patients could not be assessed due to ongoing disorders of consciousness (DOC) or sedation, and data were missing for 10 patients. Out of the 59 nonassessed patients, 7 patients were assessed with the prescreen at 3 weeks but they did not reach the level to perform the BNIS. At 3 months, 75 patients were assessed and 29 patients could not be assessed. There were missing data for 1 patient. At 1-year follow-up, 78 patients were assessed, 19 patients could not be assessed, and data were missing for 3 patients. Out of the 19 nonassessed patients, 8 patients were

assessed with the BNIS prescreen at 1 year and scored too low for administration of the BNIS to be possible. Both the BNIS total raw scores and *T*-scores improved significantly from 3 weeks to 3 months after injury (raw score: $p < 0.001$, *T*-score: $p < 0.001$) and from 3 months to 1 year on the raw score only ($p = 0.004$) and *T*-score ($p = 0.086$). The total subscales scores were significantly improved from 3 weeks to 3 months ($p < 0.001$) and from 3 months to 1 year close to significant ($p = 0.015$). Significant improvement on the separate BNIS subscales was shown from 3 weeks to 3 months for speech/language ($p = 0.002$) and memory ($p = 0.001$). From 3 months to 1 year, no further significant improvements were found. See Table 4.

When patients with more than 12 years of education were compared with patients with less than 12 years of education at 3 weeks, patients with the higher educational level had higher scores but the differences were nonsignificant. At 3 months and 1 year, patients with more than 12 years of education had statistically significant higher scores on the subscales speech/language (3 months = 0.001, 1 year: $p < 0.001$), orientation (3 months $p = 0.002$, 1 year: $p = 0.001$), attention/concentration (3 months: $p = 0.002$,

TABLE 2: Patient descriptors ($n = 114$).

Age at injury, years, median (range)		42 (17–65)
Gender (female/male)		(28/86)
Worst unsedated GCS ¹ 3–8 first 24 hours median, (range)		5 (3–8)
Cause of injury, n (%)		
Transport accident		46 (41)
Fall		50 (44)
Other		13 (11)
Missing		5 (4)
Length of stay in intensive care, days, median (range)		17 (1–78)
Economic support at time of injury, n (%)		
Employed/self-employed fulltime		57 (50)
Study grant		7 (6)
Unemployment benefit or social support		11 (10)
Sick pay		16 (14)
Other ²		8 (7)
Part-time employment/self-employment		6 (5)
Unknown		3 (3)
Missing data		6 (5)
	<i>n</i> /total n (%)	
Education <12 years, $n = 107$, missing = 7	Female	10/107 (9)
	Male	35/107 (33)
Previous brain injury requiring hospitalization, $n = 105$, missing = 9	Female	5/105 (5)
	Male	13/105 (12)
Previous brain injury requiring CT scan of the brain, $n = 105$, missing = 9	Female	6/105 (6)
	Male	12/105 (11)
Previous mental illness, $n = 109$, missing = 5	Female	6/109 (6)
	Male	12/109 (11)
Previous learning problem, $n = 108$, missing = 6	Female	3/108 (3)
	Male	9/108 (8)
Previous memory problems, $n = 108$, missing = 6	Female	3/108 (3)
	Male	12/108 (11)
Previous difficulty concentrating, $n = 108$, missing = 6	Female	3/108 (3)
	Male	17/108 (16)

¹Conversion from RLS scores to GCS scores for those patients not assessed with GCS ($n = 42$).²Other economic support.

1 year: $p = 0.004$), visuospatial and visual problem solving (3 months: $p = 0.002$, nonsignificant at 1 year), memory (3 months = 0.002, 1 year: 0.005), affect (3 months = 0.001, 1 year = 0.001), and awareness (3 months $p = 0.005$, 1 year $p = 0.005$). The distribution of patients above and below

the cut-off for cognitive dysfunction at 47 points and the corresponding levels for *T*-scores (22) are shown in Table 5.

3.3. The Hospital Anxiety and Depression Scale (HADS). No statistically significant differences were found for HADS

TABLE 3: BNIS total (raw) score at 3 weeks, 3 months, and 1 year and description of educational level and previous medical disorders (including any learning, memory, or concentration difficulties).

	Number (female/male)		42 (10/32)
3 weeks	Total (raw) score median (range)		38.5 (18–50)
	Total (raw) score mean (SD)		37.2 (8.3)
	Education <12 years total (raw) score mean (SD)		34.8 (7.9)
		n/total n (%)	
	Education <12 years	Missing = 1	5 female + 14 male/41 (46)
	Previous brain injury requiring hospitalization	Missing = 3	6/39 (15)
	Previous brain injury requiring CT scan of the brain	Missing = 0	6/42 (14)
3 weeks	Previous mental illness	Missing = 2	6/40 (15)
	Previous learning problem	Missing = 2	6/40 (15)
	Previous difficulty to remember	Missing = 2	8/40 (20)
	Previous difficulty to concentrate	Missing = 2	7/40 (17)
	Number (female/male)		75 (19/56)
3 months	Total (raw) score median (range)		41.0 (23–50)
	Total (raw) score mean (SD)		40.4 (7.0)
	Education <12 years, total (raw) score mean (SD)		38.2 (6.9)
		n/total n (%)	
	Education <12 years	Missing = 4	7 female + 22 male/71 (41)
	Previous brain injury requiring hospitalization	Missing = 8	12/67 (18)
	Previous brain injury requiring CT scan of the brain	Missing = 7	12/68 (18)
3 months	Previous mental illness	Missing = 4	11/71 (15)
	Previous learning problem	Missing = 4	7/71 (10)
	Previous difficulty remembering	Missing = 4	10/71 (14)
	Previous difficulty concentrating	Missing = 4	11/71 (15)
	Number (female/male)		78 (21/57)
1 year	Total (raw) score median (range)		42.0 (16–50)
	Total (raw) score mean (SD)		40.3 (7.8)
	Education <12 years, total (raw) score mean (SD)		38.1 (7.6)
		n/total n (%)	
	Education <12 years	Missing = 4	7 female + 25 male/74 (43)
	Previous brain injury requiring hospitalization	Missing = 8	13/70 (19)
	Previous brain injury requiring CT scan of the brain	Missing = 8	12/70 (17)
1 year	Previous mental illness	Missing = 4	13/74 (18)
	Previous learning problem	Missing = 4	7/74 (10)
	Previous difficulty to remember	Missing = 4	9/74 (12)
	Previous difficulty to concentrate	Missing = 4	12/74 (16)

anxiety from 3 weeks to 3 months ($p = 0.865$) and from 3 months to 1 year ($p = 0.702$), nor for HADS depression from 3 weeks to 3 months ($p = 0.915$) and from 3 months to one year ($p = 0.394$). Scores above cut-off for HADS anxiety occurred in 16 of 75 assessable patients at 3 months and in 16 of 74 patients at 1 year after injury. HADS depression scores above cut-off occurred in 11 of 75 assessable patients at 3 months and in 15 of 74 patients at 1 year. Significant correlations were found between HADS depression and BNIS total at 3 months ($r = -0.302$, $p = 0.009$) and at one year ($r = -0.361$, $p = 0.002$). No statistically significant correlation was found between HADS anxiety and BNIS at 3 months and 1 year.

3.4. Outcome as Assessed with the Glasgow Outcome Scale Extended (GOSE). Patients who completed the BNIS at 3 weeks, 3 months, and 1 year, and with “favourable” and “unfavourable” outcomes, respectively, on the GOSE are shown in Table 6. Univariate logistic regression analyses demonstrated that the following variables at 3 months were associated with “favourable outcome” on the GOSE at 1 year: BNIS total scores (OR = 1.200, CI: 1.072–1.343, $p = 0.002$) and BNIS subscales orientation (OR = 4.177, CI: 1.850–9.430, $p = 0.001$), visuospatial and visual problem solving (OR = 2.156, CI: 1.371–3.391, $p = 0.001$), memory (OR = 1.492, CI: 1.084–2.052, $p = 0.014$), affect (OR: 2.910, CI: 1.483–5.713, $p = 0.002$), and awareness (OR = 5.714, CI: 1.153–28.322,

TABLE 4: BNIS subscales scores, BNIS total score, and *T*-score conversion at 3 weeks, 3 months, and 1 year.

(a)				
BNIS score 3 weeks (<i>n</i> = 42)	Mean (SD)	Median	Range	
Data not available (<i>n</i> = 10)				
Not assessable (<i>n</i> = 59)				
Speech/language	12.4 (2.6)	14.0	5–15	
Orientation	2.3 (0.8)	2.5	1–3	
Attention/concentration	1.6 (1.1)	2.0	0–3	
Visuospatial and visual problem solving	5.1 (1.9)	5.0	1–8	
Memory	3.4 (2.3)	3.0	0–7	
Affect	3.0 (1.2)	3.0	0–4	
Awareness	0.4 (0.5)	0.0	0–1	
Total BNIS (raw) score	37.4 (8.3)	38.5	18–50	
Total <i>T</i> -score conversion	16.6 (19.6)	8.0	0.9–63	

(b)				
BNIS score 3 months (<i>n</i> = 75)	Mean (SD)	Median	Range	3 weeks versus 3 months
Data not available (<i>n</i> = 1)				
Not assessable (<i>n</i> = 29)				
Speech/language	13.4 (2.0)	14.0	7–15	0.002
Orientation	2.6 (0.7)	3.0	1–3	0.032
Attention/concentration	2.1 (0.7)	2.0	1–3	0.054
Visuospatial and visual problem solving	5.5 (1.9)	6.0	1–8	0.013
Memory	4.2 (2.3)	4.0	0–7	0.001
Affect	3.3 (0.9)	4.0	0–4	0.051
Awareness	0.5 (0.5)	0.0	0–1	0.860
Total BNIS (raw) score	40.4 (7.0)	41.0	23–50	<0.001
Total <i>T</i> -score conversion	25.1 (22.5)	23.0	0.9–63	<0.001

(c)				
BNIS 1 year (<i>n</i> = 78)	Mean (SD)	Median	Range	3 months versus 1 year
Data not available (<i>n</i> = 3)				
Not assessable (<i>n</i> = 19)				
Speech/language	13.1 (2.7)	14.0	2–15	0.322
Orientation	2.7 (0.6)	3.0	1–3	0.072
Attention/concentration	2.0 (1.0)	2.0	1–3	0.682
Visuospatial and visual problem solving	5.5 (0.9)	6.0	1–8	0.136
Memory	4.3 (2.3)	4.0	0–7	0.082
Affect	3.3 (1.0)	4.0	0–4	0.870
Awareness	0.5 (0.5)	0.5	0–1	0.712
Total BNIS (raw) score	40.3 (7.8)	42.0	16–50	0.004
Total <i>T</i> -score conversion	25.1 (22.4)	23.0	0.9–63	0.086

p = 0.033). The subscales were incorporated into a multivariate model. The analysis showed that statistically significant associations were obtained for orientation (OR: 2.762, CI: 1.140–6.695, *p* = 0.024) and visuospatial and visual problem solving (OR: 1.930, CI: 1.181–3.155, *p* = 0.009). No significant association was found between HADS anxiety and HADS depression at 3 months and GOSE (anxiety OR = 0.954, CI: 0.409–2.226, *p* = 0.914) and depression (OR = 0.717, CI: 0.233–2.211, *p* = 0.563).

3.5. *Outcome as Assessed with the Rancho Los Amigos Scale of Cognitive Functioning-Revised (RLAS-R)*. Patients who completed the BNIS at 3 weeks, 3 months, and 1 year and with “superior” and “inferior functioning” on the RLAS-R are shown in Table 6. Univariate logistic regression analyses demonstrated that the following variables 3 months after injury were associated with “superior functioning” at 1 year: BNIS total scores (OR = 1.218, CI: 1.090–1.362, *p* = 0.001), BNIS subscales orientation (OR = 4.480, CI: 1.974–10.165,

TABLE 5: BNIS total score and T-score conversion, cut-off level of cognitive function ($n = 114$).

	Points	3 weeks <i>n</i> (%)	3 months <i>n</i> (%)	1 year <i>n</i> (%)
Total score				
Low probability of cognitive dysfunction	≥ 47	6 (16)	18 (24)	20 (26)
Recommendation of further investigation of cognitive function	<47	36 (84)	57 (76)	58 (74)
Total		42 (100)	75 (100)	78 (100)
Total T-score conversion		<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Very low probability of cognitive dysfunction	>50	4 (7)	14 (19)	14 (18)
Low probability of cognitive dysfunction	40–50	3 (7)	9 (12)	11 (14)
Increased likelihood of cognitive dysfunction	30–39	3 (7)	10 (14)	10 (13)
High probability of cognitive dysfunction	<30	32 (76)	41 (55)	42 (54)
Missing			1 (1)	1 (1)
Total		42 (100)	75 (100)	78 (100)
Missing, <i>n</i> (% of all included)				
Data not available		10 (9)	1 (1)	3 (3)
Not assessable		59 (52)	29 (25)	19 (16)
Withdrew		2 (2)	4 (4)	7 (6)
Hospital death		1 (1)	5 (4)	7 (6)

$p < 0.001$), visuospatial and visual problem solving (OR = 2.476, CI: 1.527–4.017, $p < 0.001$), memory (OR = 1.502, CI: 1.124–2.006, $p = 0.006$), affect (OR = 2.812, CI: 1.482–5.335, $p = 0.002$), and awareness (OR = 5.167, CI: 1.309–20.309, $p = 0.019$). In a multivariate model, statistically significant associations were obtained for orientation (OR = 3.325, CI: 1.298–8.519, $p = 0.012$) and visuospatial and visual problem solving (OR = 2.336, CI: 1.371–3.980, $p = 0.002$). No significant association was found between HADS anxiety and depression at 3 months and GOSE.

4. Discussion

This study shows that it is feasible to use the BNIS instrument for the screening of cognitive functions in a significant minority of patients (42%) as early as 3 weeks after severe traumatic brain injury. Such a screening has the potential to allow individualization of rehabilitation interventions at the stage of recovery where neuroplasticity is maximal, with potential outcome benefits.

In accordance with previous studies, the majority were males [1, 31]. The severity of TBI on the acute GCS (median GCS) was consistent with other prospective studies of sTBI [6]. However, it should be noted that the patients who died were older and had lower GCS while the patients who withdrew were younger and were less severely injured according to the GCS. Falls are a common cause of TBI in children and elderly persons [1, 31] and were also the most frequent cause in our population of working aged adults. Transport accidents were the second most common cause. Similar findings of falls causing most of TBI have been reported in some previous Scandinavian studies [1, 31] while motor vehicle injuries dominate in American [32] and Australian [33] studies.

The BNIS scores of the patients who completed the test at 3 weeks improved substantially at 3 months and further

improvement was shown at 1 year. This is in keeping with clinical rehabilitation experience and highlights the importance of avoiding hasty decisions regarding discharge destination (nursing home or own home) and continued rehabilitation interventions based on overinterpretation of early cognitive performance. However, the number of patients who were able to complete the BNIS was relatively stable from 3 months to 1 year, such that few very severely injured patients who could not complete the BNIS at 3 months improved to a level where this could be completed at one year. When the BNIS total scores at 3 weeks were compared with the results reported by Borgaro and Prigatano [6] of a small population of sTBI patients early after the injury (around 20 days), the patients in our study performed better and the scores were even higher than a group of patients with moderate TBI, but lower than a control group. This finding can in part be explained by differences regarding study populations and a large variation in the ranges of postinjury time in the Borgaro and Prigatano study [6]. Although the BNIS-scores improved over time in our study, the scores at 1 year were in a range that was similar to that reported by Swedish TBI-patients from a neurorehabilitation clinic [24] indicating that the long-term results are probably relatively consistent. However, it is worth remembering that the BNIS is a screening instrument that can be used to detect patients in need of comprehensive cognitive neuropsychological assessment. According to the Swedish BNIS manual [22], the majority of our assessed patients at all the time points gained scores that were below the cut-off (less than 47 points) which means that they recommended further testing, but this proportion decreased over time from 84% to 74%.

About 35–40% of the patients in our study reported an education level of less than 12 years. In a recent Swedish study by Hofgren et al. [24], the BNIS in patient groups from a neurorehabilitation clinic was validated. An education level of less than 9 years was considered as being low since 9

TABLE 6: Patients who completed the BNIS total score and outcomes GOS-E and RLAS-R at 3 weeks, 3 months and 1 year.

		N (%)	Mean BNIS T score
	GOSE at 1 year		
	Unfavourable GOS-E 1–4	3 (7)	0.9
	Favourable GOS-E 5–8	35 (83)	19.1
	Missing	4 (10)	
BNIS 3 weeks (<i>n</i> = 42)	RLAS-R at 1 year		
	Inferior functioning	4 (10)	
	RLAS-R 1–8		
	Superior functioning	34 (81)	
	RLAS-R 9–10		
	Missing	4 (10)	
	GOSE at 1 year		
	Unfavourable GOS-E 1–4	12 (16)	8.8
	Favourable GOS-E 5–8	60 (80)	28.1
	Missing	3 (4)	
BNIS 3 month (<i>n</i> = 75)	RLAS-R at 1 year		
	Inferior functioning	15 (20)	
	RLAS-R 1–8		
	Superior functioning	55 (73)	
	RLAS-R 9–10		
	Missing	5 (7)	
	GOS-E 1 year		
	Unfavourable GOS-E 1–4	18 (23)	9.7
	Favourable GOS-E 5–8	59 (76)	29.9
	Missing	1 (1)	
BNIS 1 year (<i>n</i> = 78)	RLAS-R at 1 year		
	Inferior functioning	21 (27)	
	RLAS-R 1–8		
	Superior functioning	54 (69)	
	RLAS-R 9–10		
	Missing	3 (4)	

years is compulsory in the Swedish educational system. In our study, the level of low education was chosen as lower than 12 years because the majority of the Swedish population continue to study at upper secondary school. Regardless of where the education level limit is set, it seems that the results in our study confirm prior results of a relationship between education level and cognition [6, 24]. In a clinical context, it is important to consider this in order to optimize the setting of realistic rehabilitation goals for each individual patient.

When comparing the scores of the subscales at the different time points, significant improvements in our study were only shown from 3 weeks to 3 months. The results at 3 months and at 1 year were in line with the previous Swedish results by Hofgren et al. [24]. Moreover, the majority of patients who completed the BNIS at all the three time points experienced “favourable outcome” on the GOSE and “superior functioning” on the RLAS. Higher scores on the orientation and visuospatial and visual problem solving subscales at 3 months were also associated with good outcomes.

Disorientation, a key component of posttraumatic amnesia, has often been studied in patients in the acute phase after TBI and has been reported as a predictor of cognitive impairments after injury [34]. Borgaro et al. [12] examined the utility of the BNIS to assess orientation in patients with TBI and concluded that the instrument was shown to be a sensitive measure of disorientation in these patients. Both the orientation and the visuospatial and visual problem solving subscales include basic domains of importance for independence inside and outside the patients’ homes. It was therefore not surprising that these subscales were associated with outcome in the present study. Although the orientation and visuospatial problems could possibly have contributed to unfavourable outcome on the GOSE, there are also other causes of disability after sTBI, such as mental fatigue and executive dysfunctions. In a previous Swedish TBI-study, orientation and awareness on the BNIS were found to be two of the most common cognitive dysfunctions perceived as problems [24]. In our study, awareness on the BNIS subscale

was associated to the GOSE. This result is in line with earlier studies which have reported a relationship between self-awareness and long-term outcome in TBI-patients [35]. In a study by Kelley et al. [36], impaired awareness was shown more than 5 years after TBI and awareness of cognitive function was found to predict return to work. Although awareness may improve over time, it seems to be a complex construct including varying aspects.

Studies have reported depression and anxiety as a major cause of disability after TBI [5, 37]. In the present study, there were negative relationships between the BNIS total score and the HADS anxiety and depression scores at the one-year follow-up, indicating that patients with a cognitive dysfunction may also suffer from anxiety and depression symptoms over time. These findings confirm earlier results which have shown an association between self-reported depression and anxiety and poor performance on cognitive tests [38]. In a rehabilitation context, these results imply the importance of screening cognitive difficulties and depression and anxiety to identify those who should be further assessed.

Most prior studies using the BNIS have used heterogeneous study populations with a mix of diagnoses, different TBI grades, and small TBI populations [8, 12, 24] which were studied at different time points after the trauma. Our study has several strengths, such as a prospective design and a large and well-characterized multicentre study population of patients with sTBI. In addition, the follow-up and the BNIS testing were performed by experienced staff, a clinical neuropsychologist, or physician working in rehabilitation medicine. The follow-up rate of 69% completing the BNIS is satisfactory. Only 19 patients could not complete the BNIS at the 1-year follow-up and data were missing for three patients. Since the incidence of sTBI is low in comparison with moderate and mild TBI [1], the population size of 114 patients in our prospective multicentre study could be considered relatively high. In addition, the low number of missing data also strengthens the study.

However, our study is based on a clinical population and has some limitations. Although we had weekly contact with intensive care units, we cannot exclude that some patients were admitted and discharged between contacts and would therefore have been missed from the recruitment process. Some data was also missing which may be due to this multicentre study design that included many assessment instruments with follow-up of patients from a wide geographical area in Sweden.

5. Conclusion

The results indicate that cognition improves over time after sTBI and appears to be relatively stable from 3 months to 1 year. Since cognitive function was associated with outcomes, it seems that early screening of cognitive function could be of importance for rehabilitation planning in a clinical setting.

Ethical Approval

The study was approved by the Regional Ethics Committee of Stockholm, Sweden (no. 2009/1644/31/3).

Conflict of Interests

The authors declare no conflict of interests.

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Research Article

The Relationship between Training and Mental Health among Caregivers of Individuals with Polytrauma

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This was a hypothesis-generating exploration of relationships between caregiver training during TBI/polytrauma rehabilitation and caregiver mental health. In this cross-sectional study, 507 informal caregivers to US service members with TBI who received inpatient rehabilitation care in a Veterans Affairs' Polytrauma Rehabilitation Center from 2001 to 2009 completed a retrospective, self-report survey. Embedded in the survey were measures of caregiver mental health, including the National Institutes of Health's Patient Reported Outcome Measurement Information System (PROMIS) Anxiety and Depression Short Forms, the Rosenberg Self-Esteem scale, and the Zarit Burden Short Form. Though no groups endorsed clinical levels, mental health symptoms varied by caregiver training category (Trained, Not Trained, and Did Not Need Training). Caregivers who did not receive training on how to navigate healthcare systems endorsed higher depression and burden and lower self-esteem than those who did. Caregivers who did not receive training in supporting their care recipients' emotions endorsed higher anxiety, depression, and burden and lower self-esteem than those who did. Analyses also suggested a different association between training and mental health based on caregivers' relationship to the care recipient and the intensity of care recipient needs. Potential hypotheses for testing in future studies raised by these findings are discussed.

1. Introduction

Traumatic brain injury (TBI) is considered the signature injury of the Operation Enduring Freedom and Operation Iraqi Freedom (OEF/OIF) conflicts [1]. Approximately 327,299 US military service members have been diagnosed with TBI between 2000 and the first quarter of 2015 [2].

Among the 25,044 service members injured in 2014 alone, 146 (0.6%) sustained a severe TBI, 2,010 (8.0%) sustained a moderate TBI, 20,972 (83.7%) sustained a mild TBI, and 1,759 (7.0%) sustained unclassifiable injuries [2]. Service members who sustain a TBI often sustain additional and potentially life-threatening traumatic injuries to other body systems and organs, including fractures, burns, hearing loss, vision

loss, and amputation. This constellation of injuries is known as “polytraumatic injuries” [3, 4]. TBI with polytraumatic injuries are often accompanied by pain symptoms and a range of psychiatric comorbidities [3].

In 2005, the Department of Veterans Affairs designated a Polytrauma System of Care, which included Polytrauma Rehabilitation Centers (PRCs) that specialized in inpatient rehabilitation of TBI with polytrauma. The charge for the PRCs was to provide patient and family-centered inpatient care and life-long case management to those with polytrauma, especially those with moderate to severe war-related injuries. Patients present to the PRCs with mild to severe penetrating and nonpenetrating head injuries and have, on average, five injuries and six impairments. Nearly 90% have some cognitive impairment during their inpatient stay [4]. In the PRCs, the TBI defines the rehabilitation process, and therefore we refer to the constellation of injuries as TBI/polytrauma.

As TBI/polytrauma injuries result in a spectrum of behavioral, cognitive, emotional, and physical impairments [3, 5], injured individuals often require supervision and support from caregivers, usually parents or spouses [6]. Research within civilian populations indicates that TBI injuries impact caregiver psychosocial functioning, including financial and employment difficulty [7–9], marital strain [10], reductions in social activities [8, 9], poorer quality of life and perceived physical health [11, 12], higher prescription and nonprescription drug consumption [7–9], and higher levels of stress, anxiety, depression [13–16], and burden [8, 9, 13].

Despite the robust literature pointing to myriad biopsychosocial problems experienced by TBI caregivers in civilian healthcare settings, fewer studies have explored difficulties among caregivers of OEF/OIF service members with TBI/polytrauma injuries. Though there are similarities in caregiving experiences across TBI settings, adjustment to the caregiver role may be different between settings in several important ways. For example, as a prelude to the service members’ injuries, caregivers of US service members may experience adjusting to the caregiving role after having experienced predeployment stress and ongoing stress and worry for the service members’ well-being during deployment [17]. Further, the injury may signify not only a change in family roles, but also a potential loss of military identity, with transitions from military life to civilian life. Strong feelings of loss and abandonment can be part of the families’ transition from military to civilian settings [17]. Lastly, most veterans who have experienced TBI also have comorbid psychiatric diagnoses, with PTSD being among the most common [18].

Comprehensively training caregivers to engage in learning specific skills may improve rehabilitation outcomes for patients who sustained a TBI, while simultaneously improving longer-term physical and mental health outcomes for the caregiver. Caregiver information and training are known to have positive effects on the outcomes of caregivers of individuals with dementia [19, 20] and to reduce anxiety and stress among caregivers of critically ill patients, thus facilitating coping [21]. Among caregivers of stroke patients, the provision of information appears to improve mental health outcomes [22]. Little is known about the potential benefits of

targeted caregiver training in the OEF/OIF TBI/polytrauma context. Providing training and education to caregivers of injured service members who have sustained polytraumatic injuries may lead to outcomes similar to those found among caregivers of other conditions, especially TBI. However, with the constellation of injuries, the long-term visible (e.g., disfigurement, scarring, and vision loss) and invisible outcomes and comorbid conditions (e.g., PTSD, seizures, and attention difficulties), and the young age of the patients, the impact of training on caregiver outcomes may also be unique [3, 23]. Previous studies identified the effect of information provision to caregivers of TBI/polytrauma injured patients on their outcomes and questioned possible differential effects based on injury severity and the relationship to the patient [23, 24]. The current study on this unique population begins to fill this identified gap. The purpose of this hypothesis-generating study was to explore relationships between caregiver training and caregiver mental health outcomes in 507 family caregivers of US service members who sustained TBI/polytrauma injuries that necessitated inpatient rehabilitation care in one of four regional Polytrauma Rehabilitation Centers (PRCs).

2. Method

2.1. Participants. Study participants were the primary caregiver of patients identified in VA administrative records as having served during OEF/OIF; had polytrauma injuries or sequelae, including a TBI; received care and had been discharged for at least three months from one of four PRCs between September 2001 and February 2009; and were alive at the time the mailed survey was conducted [25]. This study explored characteristics of the 507 (out of 564) survey participants who responded to questions about two specific training needs. Table 1 provides sample characteristics for the caregivers. Characteristics of this subsample of 507 are comparable to the larger population of 564 presented by Griffin and colleagues [25].

2.2. Data Collection. Study protocols, including waivers of documentation of informed consent, were approved by the Institutional Review Boards at all sites. The next of kin of all patients identified from VA administrative data who met inclusion criteria ($n = 1,045$) were contacted. Data for each of these patients were also extracted from patient medical records. Initial survey packets included a cover letter, the questionnaire, a postage-paid return envelope, a \$20 cash incentive, and a caregiver nomination form for the next of kin to complete in case the next of kin did not consider him/herself the primary caregiver. Multiple attempts were made by mail and telephone to reach nonrespondents.

Among the caregivers reached by mail or phone who could verify they were a caregiver we had a 67% response rate. Caregivers of those with lower functional status (measured by Functional Independence Measure (FIM) at both PRC admission and discharge) were significantly more likely to respond than caregivers of those with higher functional status. There were no significant differences between survey respondents and nonrespondents by care recipients’ demographic characteristics, geographic location of injury

TABLE 1: Sample characteristics.

	N*	Caregivers
CG age (x , SD)	482	47.16 (12.56)
CG gender (count, %)	495	—
Male	—	95 (19%)
Female	—	400 (81%)
CG race (count, %)	507	—
White	—	375 (74%)
Black	—	43 (9%)
More than 1	—	17 (3%)
Other	—	27 (5%)
Unknown	—	45 (9%)
CG marital status (count, %)	495	—
Married	—	362 (73%)
Divorced	—	63 (13%)
Living with partner	—	19 (4%)
Separated	—	15 (3%)
Widowed	—	22 (4%)
Never married	—	14 (3%)
CG education (count, %)	494	—
Less than HS	—	11 (2%)
Some HS	—	15 (3%)
HS graduate/GED	—	103 (21%)
Vocational school	—	34 (7%)
Some college	—	138 (28%)
Associate's degree	—	57 (11%)
College degree	—	88 (18%)
M.S. or doctoral degree	—	48 (10%)
CG relationship to CR	507	—
Parent	—	302 (60%)
Spouse/partner	—	174 (34%)
Other	—	31 (6%)
CR months since injury (x , SD)	470	51.31 (24.13)
Months of caregiving (x , SD)	471	45.97 (23.65)

*The N varied for some of these variables due to missing or incomplete data for these items.

Note: 507 of the total 564 caregivers responded to the item regarding training for navigating the VA or DOD Benefits or Medical System. CG: caregiver; CR: care recipient.

(e.g., Iraq and US), or mechanism of injury (e.g., blast, motor vehicle crash, and fall).

2.3. Measures. The study questionnaire included questions about both the care recipient and caregiver. As part of the questionnaire, caregivers were asked if they had received training from a doctor, nurse, social worker, or some other health care provider on any of 11 specified tasks, including (1) navigating VA or Department of Defense (DoD) benefit or medical systems, (2) administering medications or helping with side effects, (3) changing bandages or dressings, (4) helping with pain, (5) helping with prosthetic devices or aids, (6) helping with assistive devices or aids, (7) helping with mobility devices or aids, (8) managing seizures, (9) supporting care recipients' emotions or feelings, (10) changing

external catheter or colostomy bag, or (11) other training. This list of training tasks was developed using data from interviews with PRC clinical staff on caregiver needs [3] and refined with interviews conducted with caregivers. Additionally, these were tasks that may occur early on or intermittently during rehabilitation for polytrauma, depending on type and severity of injuries, as well as more universal needs that were not dependent on injury severity and could persist well past the rehabilitation period.

At the time of this survey, the PRCs were relatively new, the complexity of injuries was new, and the patient population was much younger than what the rehabilitation units were accustomed to managing [3]. Although there were efforts made at individual sites to provide high quality care and support to caregivers, there were no requirements for training caregivers and no uniform or manualized training for caregivers across PRCs. Efforts began in 2007 to develop a unified approach with formal training for caregivers across the four centers, including work on the Family Care Map [26, 27], which provided a collaborative approach for establishing standards of practice. A Polytrauma Family Education Manual was developed in 2007 that offered information about (1) the rehabilitation process, (2) background education on the medical, behavioral, and cognitive effects of TBI, and (3) caregiver education on dealing with difficult emotions such as anxiety, unrealistic expectations, frustration, stress, and depression after a loved one has been injured. Within this context, the training questions were intended to identify areas where future training programs could be developed, not to assess which training programs had been used or were most effective. Therefore, it is unknown if any training offered to or received by respondents was through the VA or through other resources, whether any standardized protocols were used among all four centers prior to 2007, or whether the manual was utilized in a standardized way across all four centers after 2007.

From the list of eleven training needs, this study focused on two of the more universal needs: (1) the need for training in navigating the VA or DoD benefits or medical system, and (2) the need for training in supporting their care recipient's emotions or feelings. These needs were chosen because previous research showed these were the top two needs with which caregivers of injured US Service Members reported needing help [3]. Response choices were "yes," "no," or "not needed." For clarity we refer to these as "Trained," "Not Trained," and "Training Not Needed." Notably, there could be overlap between caregivers who selected that they did not receive training and those who endorsed not needing the training.

In addition to training-specific questions, caregivers were asked to report demographic information about themselves and their care recipient, to describe the relationship between caregiver and care recipient, and to provide information about their care recipient's injuries. The intensity of care that caregivers provide was measured using caregiver report of care recipient's ability to perform activities of daily living (ADLs) [28], such as eating, bathing, and toileting; independent activities of daily living (IADLs) [29], such as managing money, doing chores, or cooking; or other forms

of help and support, such as help with legal issues, navigating care systems, and managing pain or other symptoms. These activities were then coded into a variable with 3 categories: (1) assistance with one or more ADLs (high intensity), (2) assistance with one or more IADLs but no ADLs (moderate intensity), and (3) no assistance with any of the ADLs or IADLs (low intensity) [25].

FIM scores were aggregated from hospital discharge data. The FIM is a commonly used instrument in rehabilitation populations to assess motor and cognitive skills. Each item is scored 1 to 7. A score of 7 is categorized as “complete independence” and a score of 1 is “total assist” (performs less than 25% of task). Total functioning scores were calculated using both cognitive and motor skills.

Caregiving burden was assessed using the Zarit Burden Inventory (ZBI) scale (short-version), a 12-item, standardized, validated, reliable, and widely used measure of subjective burden associated with caregiving [30], including caregivers of those with TBI and PTSD [31, 32]. The ZBI uses a 5-point Likert scale ranging from “never” to “nearly always.” Generally, higher scores indicate higher burden. A score of 17 on the short form is considered the cutoff for high burden [30].

The National Institutes of Health’s Patient Reported Outcome Measurement Information System (PROMIS) Anxiety and Depression Short Forms [33] were used to assess depression and anxiety symptoms. The eight-item depression scale and the seven-item anxiety scale both utilize five response categories (never, rarely, sometimes, often, and always). Scores were converted to a *T*-score metric based on a representative calibration sample consisting of the US general population and multiple disease populations [33, 34].

Rosenberg’s Self-Esteem scale [35], a widely used assessment considered to be both reliable and valid with TBI populations [36], was used to assess caregiver self-esteem. The questionnaire consists of ten items with responses on a 4-point scale ranging from “strongly disagree” to “strongly agree” such that total scores range from 10 to 40, with higher scores indicating higher self-esteem [37].

2.4. Statistical Analyses. Statistical analyses were limited to descriptive statistics, given that descriptive analyses are more appropriate for hypothesis-generating studies, whereas inferential statistics are of more value for hypothesis-testing studies [38]. For each training task (i.e., navigating the VA/DoD; supporting emotions), descriptive statistics were compiled for all variables and means were compared, using *f*-tests from ANOVAs for continuous variables and chi-square tests for categorical variables, in order to determine if there were differences based on sociodemographics, injury and caregiver characteristics, and mental health outcomes between caregivers who received, did not receive, or did not need training.

Two stratified analyses were additionally conducted. First, considering the potential for relationship to the care recipient to impact caregivers’ mental health, participants were separated into two relationship groups: parent and spouse/partner. The “other” group was excluded due to the inability to sensibly interpret any significant result based

on the size of this group. Means were compared to explore if the three, nonoverlapping, training groups had different mental health outcomes within each relationship group. Second, because caregivers’ mental health might be different based on the intensity of care recipient needs, participants were separated into “high” (requiring assistance with ADLs), “moderate” (needing help with IADLs), and “low” (not needing help with ADLs or IADLs) intensity of needs. Means were compared using ANOVA to explore if the three, nonoverlapping, training groups had different mental health outcomes within each intensity group.

We included caregivers who endorsed not needing training, speculating that their experiences were different from those who received or did not receive training. For example, it was possible that their burden was lower, their care recipients were potentially less likely to need help with ADLs or IADLs, they may have had previous care experiences, or they may have been trained in a medical field. Further, it is possible that there was overlap among response choices. For example, caregivers could have received training without needing it or could have needed training but not received it. Therefore, in order to reduce confusion or overlap with the “Training Not Needed” group, the above-described comparisons were also made between the “Trained” versus “Not Trained” groups only. Though results are described for ANOVAs that included the “Training Not Needed” group, given our interest in exploring the relationship between caregiver mental health and caregiver receipt of training, the interpretation of results is based on the “Trained” versus “Not Trained” group comparisons.

The 507 participants who responded to the two training questions are the maximum number of people available for analysis. However, for each question posed, the number available for analysis varies, due to responses for each training item. For example, a sample of the 507 might not have received the training, because they had no need for it. The number of people available for each question is clearly displayed in the results below as well as in each of the tables.

3. Results

Of the 564 study participants, 507 caregivers responded to the item regarding training for “Navigating the VA/DoD Benefits or Medical System.” The majority ($n = 262$, 51.7%) reported not receiving training, another 165 caregivers (32.5%) reported receiving training, and 80 caregivers (15.8%) reported not needing training. Likewise, 507 caregivers responded to the item regarding “Training for Supporting Care Recipient’s Emotions or Feelings.” For this item, 226 caregivers (44.6%) reported receiving training, 215 (42.4%) reported not receiving training, and 66 caregivers (13.0%) reported not needing the training.

3.1. Navigating the VA/DoD

3.1.1. Demographics, Injury, and Caregiver Characteristics (Table 2). The three training groups were similar in terms of age, gender, race, marital status, and education. The groups

TABLE 2: Comparison of navigating VA or DoD training groups on sociodemographics, injury and caregiver characteristics, and mental health outcomes.

	N	Training (n = 507)			Significantly different?	
		Trained	Not Trained	Training Not Needed	Trained versus Not Trained	Trained versus Not Trained
CG age (x, SD)	482	48.22 (12.00)	46.51 (12.78)	47.00 (13.01)	p = .40 (N = 482)	p = .17 (N = 410)
CG gender (count, %)	495	—	—	—	p = .54 (N = 495)	p = .19 (N = 420)
Male	—	36 (22%)	46 (18%)	13 (17%)	—	—
Female	—	128 (78%)	210 (82%)	62 (83%)	—	—
CG race (count, %)	507	—	—	—	p = .77 (N = 507)	p = .69 (N = 427)
White	—	126 (76%)	194 (74%)	55 (69%)	—	—
Black	—	12 (7%)	25 (10%)	6 (7%)	—	—
More than 1	—	6 (4%)	8 (3%)	3 (4%)	—	—
Other	—	10 (6%)	11 (4%)	6 (7%)	—	—
Unknown	—	11 (7%)	24 (9%)	10 (13%)	—	—
CG marital status (count, %)	495	—	—	—	p = .33 (N = 495)	p = .20 (N = 420)
Married	—	122 (74%)	189 (74%)	51 (68%)	—	—
Divorced	—	19 (12%)	32 (13%)	12 (16%)	—	—
Living with partner	—	3 (2%)	11 (4%)	5 (7%)	—	—
Separated	—	8 (5%)	6 (2%)	1 (1%)	—	—
Widowed	—	10 (6%)	9 (3.5%)	3 (4%)	—	—
Never married	—	2 (1%)	9 (3.5%)	3 (4%)	—	—
CG education (count, %)	494	—	—	—	p = .16 (N = 494)	p = .19 (N = 419)
Less than HS	—	3 (2%)	6 (2%)	2 (3%)	—	—
Some HS	—	6 (4%)	7 (3%)	2 (3%)	—	—
HS graduate/GED	—	33 (20%)	52 (20%)	18 (24%)	—	—
Vocational school	—	9 (5%)	15 (6%)	10 (13%)	—	—
Some college	—	51 (31%)	71 (28%)	16 (21%)	—	—
Associate's degree	—	9 (5%)	37 (15%)	11 (15%)	—	—
College degree	—	36 (22%)	41 (16%)	11 (15%)	—	—
M.S. or doctoral degree	—	17 (11%)	26 (10%)	5 (6%)	—	—
CG relationship to CR	507	—	—	—	p = .01 (N = 507)	p = .08 (N = 427)
Parent	—	108 (65%)	145 (55%)	49 (61%)	—	—
Spouse/partner	—	52 (32%)	101 (39%)	21 (26%)	—	—
Other	—	5 (3%)	16 (6)	10 (13%)	—	—
CR months since injury (x, SD)	470	48.36 (22.41)	52.28 (23.89)	54.75 (28.09)	p = .12 (N = 470)	p = .10 (N = 400)
Months of caregiving (x, SD)	471	44.82 (22.04)	47.34 (23.39)	43.68 (27.75)	p = .40 (N = 471)	p = .28 (N = 401)
CR total FIM (x, SD)	497	104.68 (28.33)	109.40 (24.04)	116.87 (15.56)	p = .00 (N = 497)	p = .07 (N = 418)
Intensity of CR needs (count, %)	507	—	—	—	p = .00 (N = 507)	p = .72 (N = 427)
ADLs+	—	40 (24%)	72 (27%)	6 (8%)	—	—
Only IADLs+	—	90 (55%)	140 (54%)	33 (41%)	—	—
No help needed with I/ADLs	—	35 (21%)	50 (19%)	41 (51%)	—	—
CR injury severity (count, %)	425	—	—	—	p = .19 (N = 425)	p = .19 (N = 360)
Fully conscious	—	13 (9%)	21 (9%)	4 (6%)	—	—
Unconscious ≤ 30 min	—	15 (11%)	42 (19%)	9 (14%)	—	—
Unconscious ≥ 30 min, ≤ 1 week	—	33 (24%)	50 (23%)	22 (34%)	—	—
Unconscious ≥ 1 week	—	79 (56%)	107 (49%)	30 (46%)	—	—
CG anxiety	489	48.49 (9.21)	49.73 (10.94)	47.48 (11.73)	p = .22 (N = 489)	p = .23 (N = 418)
CG depression	489	46.92 (9.36)	49.79 (9.87)	47.14 (11.54)	p = .01 (N = 489)	p = .00 (N = 418)
CG self-esteem	486	33.65 (4.74)	32.43 (5.95)	33.40 (5.58)	p = .07 (N = 486)	p = .03 (N = 416)
CG subjective burden	495	12.17 (9.73)	14.49 (10.32)	5.67 (7.65)	p = .00 (N = 495)	p = .02 (N = 420)

Note: percentages based on column total; ADLs: activities of daily living; CG: caregiver; CR: care recipient; FIM: Functional Independence Measure; IADLs: instrumental activities of daily living; Min: minutes.

TABLE 3: Differences in caregiver mental health based on training received for navigating the VA or DoD based on caregivers' relationship to care recipient.

	N	Training			Significantly different?	
		Trained	Not Trained	Training Not Needed	Trained versus Not Trained	Trained versus Training Not Needed
Parents (<i>n</i> = 302)						
CG anxiety	287	46.95 (8.15)	47.19 (10.06)	48.94 (13.04)	<i>p</i> = .53 (<i>N</i> = 287)	<i>p</i> = .84 (<i>N</i> = 247)
CG depression	287	45.74 (8.49)	47.90 (9.39)	49.27 (12.83)	<i>p</i> = .08 (<i>N</i> = 287)	<i>p</i> = .06 (<i>N</i> = 247)
CG self-esteem	286	34.30 (4.52)	33.49 (5.23)	33.15 (6.00)	<i>p</i> = .34 (<i>N</i> = 286)	<i>p</i> = .21 (<i>N</i> = 246)
CG subjective burden	291	11.05 (8.91)	12.11 (9.64)	5.59 (7.39)	<i>p</i> = .00 (<i>N</i> = 291)	<i>p</i> = .38 (<i>N</i> = 247)
Spouses/partners (<i>n</i> = 174)						
CG anxiety	171	52.47 (10.22)	53.21 (10.70)	46.07 (10.14)	<i>p</i> = .02 (<i>N</i> = 171)	<i>p</i> = .69 (<i>N</i> = 150)
CG depression	171	49.98 (10.58)	52.79 (9.95)	45.55 (9.15)	<i>p</i> = .02 (<i>N</i> = 171)	<i>p</i> = .11 (<i>N</i> = 150)
CG self-esteem	170	32.36 (5.13)	30.69 (6.57)	33.21 (5.24)	<i>p</i> = .11 (<i>N</i> = 170)	<i>p</i> = .12 (<i>N</i> = 150)
CG subjective burden	174	14.59 (10.97)	18.31 (10.34)	5.71 (8.49)	<i>p</i> = .00 (<i>N</i> = 174)	<i>p</i> = .04 (<i>N</i> = 153)

Note: CG: caregiver.

differed significantly by caregiver's relationship to care recipient. This difference did not remain significant when the Training Not Needed group was excluded from analysis. Among injury and caregiver characteristics, the groups differed only by intensity of care recipient needs, but again, this difference did not remain when the Not Needed group was excluded.

3.1.2. Mental Health. Also shown in Table 2, caregivers in all three training groups endorsed anxiety and depression *T*-scores below 50, indicating that they were below the average compared to PROMIS measures' calibration sample consisting of the US general population and multiple disease populations [33, 34]. There were no differences in anxiety by training group. However, caregivers not trained in navigating the VA/DoD endorsed higher depression than those who received training or did not need training. Even after the Training Not Needed group was excluded from analyses, those who did not receive training had higher depressive symptoms than those who received training.

Caregivers among all three training groups endorsed high levels of self-esteem and there were no statistical differences among the groups. When the Training Not Needed group was excluded, those who received training had significantly higher self-esteem than those who did not receive training.

None of the three training groups endorsed clinically high levels of burden; however, burden was significantly higher among caregivers who did not receive training in navigating the VA/DoD compared to those who received training or did not need training. After the Training Not Needed group was excluded, caregivers who did not receive training endorsed higher burden than those trained.

Variation in mental health outcomes by caregivers' relationship to the care recipient was examined (Table 3). Among parents only, there was a significant difference in subjective burden by training, but this difference did not remain significant when the Training Not Needed group was excluded.

Among spouses/partners, there were significant differences for the three training groups in anxiety, depression, and subjective burden, but only subjective burden remained significantly higher among those who did not receive training when the Training Not Needed group was excluded. Additionally, spouses/partners who did not receive training were the only participants who endorsed clinically significant levels of burden.

Variation in mental health outcomes by intensity of care recipient needs (i.e., high, moderate, and low intensity, as defined previously) was also examined (Table 4). Among the high intensity group, there were no significant differences in mental health among the training groups. Among the moderate intensity group, caregivers who did not need training reported lower burden than those who received training or did not receive training, but when the Not Needed group was excluded, there was no difference between caregivers who did or did not receive training. However, when the Training Not Needed group was excluded, two other significant differences emerged among the moderate intensity group; those who did not receive training endorsed higher depression and lower self-esteem than those who did receive training. Among the low intensity care group, caregivers who did not receive training endorsed significantly higher burden than those who received training or did not need training. Even when the Training Not Needed group was excluded, those who did not receive training still endorsed higher burden than those who received training. Additionally, caregivers of high intensity care recipients who did not receive training were the only participants who endorsed clinically significant levels of burden.

3.2. Supporting Emotions

3.2.1. Demographics, Injury, and Caregiver Characteristics (Table 5). The three training groups were similar in terms of gender, marital status, and education. The three groups

TABLE 4: Differences in caregiver mental health based on training received for navigating the VA or DoD based on intensity of care recipient's needs.

	N	Training			Significantly different?	
		Trained	Not Trained	Training Not Needed	Trained versus Not Trained	Trained versus Training Not Needed
High intensity care recipient needs (ADLS+) (<i>n</i> = 118)						
CG anxiety	117	50.93 (10.29)	53.05 (10.64)	44.98 (10.43)	<i>p</i> = .16 (<i>N</i> = 117)	<i>p</i> = .31 (<i>N</i> = 111)
CG depression	117	50.83 (9.84)	52.76 (8.30)	46.90 (7.21)	<i>p</i> = .21 (<i>N</i> = 117)	<i>p</i> = .27 (<i>N</i> = 111)
CG self-esteem	114	32.78 (5.12)	31.49 (6.35)	35.02 (4.77)	<i>p</i> = .29 (<i>N</i> = 114)	<i>p</i> = .28 (<i>N</i> = 109)
CG subjective burden	115	15.94 (9.23)	18.54 (10.27)	12.20 (11.73)	<i>p</i> = .21 (<i>N</i> = 115)	<i>p</i> = .19 (<i>N</i> = 110)
Moderate intensity care recipient needs (only IADLs+) (<i>n</i> = 263)						
CG anxiety	257	48.73 (9.05)	50.10 (10.73)	50.25 (12.45)	<i>p</i> = .59 (<i>N</i> = 257)	<i>p</i> = .32 (<i>N</i> = 224)
CG depression	257	46.64 (9.20)	49.79 (10.38)	48.46 (12.67)	<i>p</i> = .08 (<i>N</i> = 257)	<i>p</i> = .02 (<i>N</i> = 224)
CG self-esteem	255	33.99 (4.54)	32.51 (5.85)	32.34 (5.22)	<i>p</i> = .10 (<i>N</i> = 255)	<i>p</i> = .04 (<i>N</i> = 223)
CG subjective burden	262	13.55 (9.50)	14.60 (9.49)	7.85 (8.52)	<i>p</i> = .00 (<i>N</i> = 262)	<i>p</i> = .42 (<i>N</i> = 229)
Low intensity care recipient needs (no help needed) (<i>n</i> = 126)						
CG anxiety	115	45.05 (7.35)	43.76 (9.67)	45.10 (10.86)	<i>p</i> = .76 (<i>N</i> = 115)	<i>p</i> = .51 (<i>N</i> = 83)
CG depression	115	43.20 (7.59)	45.40 (9.03)	45.83 (11.09)	<i>p</i> = .45 (<i>N</i> = 115)	<i>p</i> = .25 (<i>N</i> = 83)
CG self-esteem	117	33.80 (4.83)	33.55 (5.52)	34.18 (5.97)	<i>p</i> = .88 (<i>N</i> = 117)	<i>p</i> = .83 (<i>N</i> = 84)
CG subjective burden	118	3.59 (5.02)	8.38 (9.90)	2.84 (4.68)	<i>p</i> = .00 (<i>N</i> = 118)	<i>p</i> = .01 (<i>N</i> = 81)

Note: ADLs: activities of daily living; CG: caregiver; CR: care recipient; IADLs: instrumental activities of daily living.

differed statistically on age, with the Training Not Needed group being a few years older than the Trained or Not Trained groups. However, there was no age difference among those who did or did not receive training when the Training Not Needed group was excluded. The three groups differed significantly regarding caregiver's relationship to care recipient, and this difference remained significant when the Training Not Needed group was excluded, with more parents receiving training and more spouses not receiving training. Race was not statistically different among the three groups but was significantly different when the Training Not Needed group was excluded. Among injury and caregiver characteristics, the three groups differed only on intensity of care recipient needs (the Training Not Needed group had fewer care recipients with high intensity needs), but there was no difference on intensity of needs between those who did and did not receive training when the Training Not Needed group was excluded.

3.2.2. Mental Health. Caregivers in all three training groups yielded anxiety and depression *T* scores below 50, indicating that they were below the average compared to PROMIS measures' calibration sample consisting of the US general population and multiple disease populations [33, 34]. Caregivers who did not receive training in supporting their care recipient's feelings or emotions endorsed higher anxiety compared to those who did receive training or did not need training. Caregivers who did not receive training still endorsed higher anxiety than those who did when the Training Not Needed group was excluded. Similarly, those who were not trained in supporting emotions endorsed higher depression than those who did receive training or did

not need the training and continued to endorse significantly higher depression when the Training Not Needed group was excluded.

Caregivers among all three training groups also endorsed high levels of self-esteem. There were no statistical differences among the three training groups, but when the Training Not Needed group was excluded, those who received training had statistically significantly higher self-esteem than those who did not receive training.

None of the three training groups endorsed clinically high levels of burden; however, burden was higher among caregivers who did not receive training in supporting emotions compared to those who did receive training or did not need training. Caregivers who did not receive training continued to endorse higher burden than those who did receive training even after the Training Not Needed group was excluded.

Variation in mental health outcomes by caregivers' relationship to the care recipient was also examined (Table 6). Among parents only, those who did not need training reported significantly lower burden than those who did or did not receive training, but there was no difference in burden between caregivers who did or did not receive training when the Training Not Needed group was excluded. Among spouses/partners, there were significant differences for the three training groups in depression and subjective burden. Those spouses/partners who did not receive training endorsed significantly higher depression and burden than those who did receive training, and those who did receive training endorsed higher depression and burden than those who did not need the training. Even after excluding the Training Not Needed group, caregivers who did not receive training endorsed higher depression and burden than those

TABLE 5: Comparison of supporting emotions training groups on sociodemographics, injury and caregiver characteristics, and mental health outcomes.

	N	Training (n = 507)			Significantly different?	
		Trained	Not Trained	Training Not Needed	Trained versus Not Trained	Trained versus Training Not Needed
CG age (x, SD)	482	46.77 (12.14)	46.30 (13.32)	51.14 (11.55)	p = .03 (N = 482)	p = .70 (N = 424)
CG gender (count, %)	495	—	—	—	p = .58 (N = 495)	p = .22 (N = 432)
Male	—	36 (16%)	41 (20%)	13 (21%)	—	—
Female	—	186 (84%)	169 (80%)	50 (79%)	—	—
CG race (count, %)	507	—	—	—	p = .06 (N = 507)	p = .03 (N = 441)
White	—	169 (75%)	161 (75%)	47 (71%)	—	—
Black	—	19 (8%)	19 (9%)	4 (6%)	—	—
More than 1	—	10 (4%)	6 (3%)	1 (2%)	—	—
Other	—	17 (8%)	6 (3%)	4 (6%)	—	—
Unknown	—	11 (5%)	23 (10%)	10 (15%)	—	—
CG marital status (count, %)	495	—	—	—	p = .24 (N = 495)	p = .11 (N = 433)
Married	—	162 (72%)	156 (75%)	45 (73%)	—	—
Divorced	—	26 (11%)	29 (13%)	8 (13%)	—	—
Living with partner	—	6 (3%)	10 (5%)	2 (3%)	—	—
Separated	—	11 (5%)	3 (1%)	0 (0%)	—	—
Widowed	—	13 (6%)	5 (2%)	4 (6%)	—	—
Never married	—	6 (3%)	6 (3%)	3 (5%)	—	—
CG education (count, %)	494	—	—	—	p = .69 (N = 494)	p = .94 (N = 432)
Less than HS	—	3 (1%)	4 (2%)	4 (6%)	—	—
Some HS	—	8 (4%)	5 (2%)	2 (4%)	—	—
HS graduate/GED	—	46 (20%)	41 (20%)	15 (24%)	—	—
Vocational school	—	15 (7%)	14 (7%)	5 (8%)	—	—
Some college	—	67 (30%)	57 (27%)	13 (21%)	—	—
Associate's degree	—	26 (12%)	25 (12%)	5 (8%)	—	—
College degree	—	40 (18%)	37 (18%)	13 (21%)	—	—
M.S. or doctoral degree	—	19 (8%)	25 (12%)	5 (8%)	—	—
CG relationship to CR	507	—	—	—	p = .01 (N = 507)	p = .03 (N = 441)
Parent	—	143 (63%)	111 (52%)	47 (71%)	—	—
Spouse/partner	—	70 (31%)	92 (42%)	13 (20%)	—	—
Other	—	13 (6%)	12 (6%)	6 (9%)	—	—
CR months since injury (x, SD)	470	51.06 (23.44)	50.90 (23.60)	53.05 (28.00)	p = .83 (N = 470)	p = .95 (N = 411)
Months of caregiving (x, SD)	470	46.35 (22.96)	45.47 (23.23)	45.91 (27.23)	p = .93 (N = 470)	p = .70 (N = 412)
CR total FIM (x, SD)	496	107.74 (26.06)	109.92 (23.65)	113.23 (18.64)	p = .25 (N = 496)	p = .37 (N = 431)
Intensity of CR needs (count, %)	507	—	—	—	p = .00 (N = 507)	p = .12 (N = 441)
ADLs+	—	51 (23%)	60 (30%)	5 (8%)	—	—
Only IADLs+	—	118 (52%)	117 (53%)	30 (45%)	—	—
No help needed with I/ADLs	—	57 (25%)	38 (17%)	31 (47%)	—	—
CR injury severity (count, %)	425	—	—	—	p = .31 (N = 425)	p = .37 (N = 374)
Fully conscious	—	14 (7%)	17 (9%)	7 (14%)	—	—
Unconscious ≤ 30 min	—	28 (14%)	35 (20%)	4 (8%)	—	—
Unconscious ≥ 30 min, ≤ 1 week	—	49 (25%)	45 (25%)	13 (25%)	—	—
Unconscious ≥ 1 week	—	104 (54%)	82 (46%)	27 (53%)	—	—
CG anxiety	489	47.92 (10.12)	50.34 (10.63)	47.04 (11.12)	p = .02 (N = 489)	p = .02 (N = 431)
CG depression	489	47.10 (9.31)	50.05 (10.26)	46.64 (10.91)	p = .00 (N = 489)	p = .00 (N = 431)
CG self-esteem	487	33.56 (5.02)	32.32 (5.91)	33.52 (5.64)	p = .05 (N = 487)	p = .02 (N = 428)
CG subjective burden	496	11.56 (9.16)	15.02 (10.86)	5.33 (10.19)	p = .00 (N = 496)	p = .00 (N = 435)

Note: Percentages based on column total. ADLs: activities of daily living; CG: caregiver; CR: care recipient; FIM: Functional Independence Measure; IADLs: instrumental activities of daily living; Min: minutes.

TABLE 6: Differences in caregiver mental health based on training received for supporting emotions based on relationship to care recipient.

	N	Training			Significantly different?	
		Trained	Not Trained	Training Not Needed	Trained versus Not Trained	Trained versus Training Not Needed
Parents (<i>n</i> = 301)						
CG anxiety	286	46.59 (9.23)	47.70 (9.86)	47.26 (11.85)	<i>p</i> = .68 (<i>N</i> = 286)	<i>p</i> = .37 (<i>N</i> = 247)
CG depression	286	45.93 (8.74)	48.23 (9.98)	47.80 (11.33)	<i>p</i> = .15 (<i>N</i> = 286)	<i>p</i> = .06 (<i>N</i> = 247)
CG self-esteem	285	34.05 (4.80)	33.58 (5.13)	33.59 (5.75)	<i>p</i> = .74 (<i>N</i> = 285)	<i>p</i> = .46 (<i>N</i> = 245)
CG subjective burden	290	10.60 (8.60)	12.21 (10.15)	5.53 (6.84)	<i>p</i> = .00 (<i>N</i> = 290)	<i>p</i> = .18 (<i>N</i> = 248)
Spouses/partners (<i>n</i> = 175)						
CG anxiety	172	50.76 (10.67)	53.70 (10.61)	48.55 (9.60)	<i>p</i> = .10 (<i>N</i> = 172)	<i>p</i> = .09 (<i>N</i> = 159)
CG depression	172	49.60 (9.96)	53.11 (10.01)	44.99 (10.60)	<i>p</i> = .01 (<i>N</i> = 172)	<i>p</i> = .03 (<i>N</i> = 159)
CG self-esteem	171	32.56 (5.56)	30.50 (6.35)	32.77 (5.76)	<i>p</i> = .08 (<i>N</i> = 171)	<i>p</i> = .03 (<i>N</i> = 158)
CG subjective burden	175	13.53 (9.92)	18.94 (10.78)	4.77 (8.97)	<i>p</i> = .00 (<i>N</i> = 175)	<i>p</i> = .00 (<i>N</i> = 162)

Note: CG: caregiver; CR: care recipient.

TABLE 7: Differences in caregiver mental health based on training received for supporting emotions based on intensity of care recipient's needs.

	N	Training			Significantly different?	
		Trained	Not Trained	Training Not Needed	Trained versus Not Trained	Trained versus Training Not Needed
High intensity care recipient needs (ADLs+) (<i>n</i> = 116)						
CG anxiety	115	51.12 (11.11)	52.70 (10.14)	46.22 (9.50)	<i>p</i> = .37 (<i>N</i> = 115)	<i>p</i> = .44 (<i>N</i> = 110)
CG depression	115	50.92 (9.26)	52.34 (8.54)	49.10 (7.96)	<i>p</i> = .58 (<i>N</i> = 115)	<i>p</i> = .41 (<i>N</i> = 110)
CG self-esteem	113	33.14 (5.30)	31.29 (6.23)	34.80 (5.59)	<i>p</i> = .16 (<i>N</i> = 113)	<i>p</i> = .10 (<i>N</i> = 108)
CG subjective burden	114	17.05 (9.23)	17.85 (10.44)	9.25 (10.69)	<i>p</i> = .25 (<i>N</i> = 114)	<i>p</i> = .67 (<i>N</i> = 110)
Moderate intensity care recipient needs (only IADLs+) (<i>n</i> = 265)						
CG anxiety	259	48.12 (9.85)	51.04 (10.38)	49.19 (12.24)	<i>p</i> = .10 (<i>N</i> = 259)	<i>p</i> = .03 (<i>N</i> = 229)
CG depression	259	46.63 (9.09)	50.40 (10.83)	48.32 (12.13)	<i>p</i> = .02 (<i>N</i> = 259)	<i>p</i> = .01 (<i>N</i> = 229)
CG self-esteem	257	33.68 (4.90)	32.18 (5.73)	33.22 (5.51)	<i>p</i> = .11 (<i>N</i> = 257)	<i>p</i> = .04 (<i>N</i> = 227)
CG subjective burden	264	12.28 (8.40)	15.57 (10.49)	7.97 (8.27)	<i>p</i> = .00 (<i>N</i> = 264)	<i>p</i> = .01 (<i>N</i> = 234)
Low intensity care recipient needs (no help needed) (<i>n</i> = 126)						
CG anxiety	115	44.53 (8.78)	44.44 (10.25)	44.43 (9.66)	<i>p</i> = .99 (<i>N</i> = 115)	<i>p</i> = .96 (<i>N</i> = 92)
CG depression	115	44.55 (8.87)	45.32 (9.71)	43.92 (9.48)	<i>p</i> = .84 (<i>N</i> = 115)	<i>p</i> = .70 (<i>N</i> = 92)
CG self-esteem	117	33.70 (5.06)	34.32 (5.57)	33.62 (5.99)	<i>p</i> = .83 (<i>N</i> = 117)	<i>p</i> = .58 (<i>N</i> = 93)
CG subjective burden	118	4.80 (6.23)	8.77 (10.49)	1.81 (3.06)	<i>p</i> = .00 (<i>N</i> = 118)	<i>p</i> = .03 (<i>N</i> = 91)

Note: ADLs: activities of daily living; CG: caregiver; CR: care recipient; IADLs: instrumental activities of daily living.

who did. Spouses/partners who did not receive training were the only participants who endorsed clinically significant levels of burden. Additionally, significant differences between the Trained and Not Trained groups arose for spouses in self-esteem; spouses who did not receive training endorsed lower self-esteem than those who did receive training.

Variation in mental health outcomes by intensity of care recipient needs (i.e., high, moderate, and low intensity, as defined previously) was also examined (Table 7). Among the high intensity group, there were no significant differences in mental health among the training groups. Caregivers from both the Trained and Training Not Received groups

endorsed levels of burden right at the cutoff for clinical severity. Among the moderate intensity group, those who did not receive training in supporting emotions endorsed higher depression and burden than those who did not need the training or who did receive it. Even after excluding the Training Not Needed group, caregivers of care recipients with moderate intensity needs who did not receive training endorsed higher depression and burden than those who did receive training. Additionally, when the Training Not Needed group was excluded, two other significant differences emerged: caregivers of moderate intensity care recipients who did not receive training endorsed higher anxiety and lower

self-esteem than those who did receive training. Among the low intensity group, though, there were no significant differences regarding anxiety, depression, or self-esteem. Caregivers who did not receive training endorsed higher burden than those who did receive training or did not need training and continued to endorse higher burden than those who did receive training after the Training Not Needed group was excluded.

4. Discussion

This exploratory study investigated relationships between training and mental health outcomes in a sample of family caregivers of US service members who sustained TBI/polytrauma injuries serious enough to necessitate acute inpatient rehabilitation care. Though none of the groups endorsed clinical levels of mental health symptomatology, caregivers who received training in how to navigate healthcare, benefits, and disability systems endorsed lower depression, lower burden, and higher self-esteem than those who did not. Additionally, caregivers who received training in supporting the care recipient's emotions reported lower anxiety, depression, and burden and higher self-esteem than those who did not. These exploratory findings are unique in the polytrauma literature, raise hypotheses for future testing, and point to the potential for fruitful clinical research interventions.

A recent study found that emotional and instrumental support are the most frequently unmet needs among caregivers of injured patients receiving care at PRCs [39]. Previous research among caregivers of individuals with TBI provides evidence that spouses or partners experience higher stress levels, role changes, and health issues than parents [40, 41]. Similarly, our results suggest that the association between caregivers' training and mental health could differ based on relationship to the care recipient. For parents, receiving or not receiving training was not associated with mental health, but spouses who received training reported better mental health than spouses who did not receive training. This finding raises several hypotheses. The fact that training was not associated with mental health for parents may reflect parents' innate caregiving approach to their children and the relative ease they have in reverting back to previously held parenting roles. Training to emotionally support a child may not be as relevant for parents. In contrast, spouses may feel as though they have lost their partner, or that their partner has profoundly changed and, consequently, may undergo a more significant shift in roles when they become caregivers. They, therefore, may benefit more from such training. Future studies should test the hypotheses that caregiver needs differ by relationship and elucidate the underlying reasons.

Studies among caregivers of patients with dementia have shown that training programs aimed at improving management and emotional skills have positive effects on the health of caregivers [19, 20]. Similarly, this study suggests there is an association between caregivers' training and mental health and that these benefits varied by the intensity of care needed by care recipients. With no association observed between training and mental health among caregivers of

care recipients with high intensity needs, we suggest further research to test if training is not as beneficial because caregivers of patients with ADL dependence often have skilled, professional care to help and provide respite or if lessons from training are not easily absorbed because of the physical, emotional, and spiritual burden of care. Future research is needed to confirm whether the intensity of the care recipient's needs and their physical, cognitive, and behavioral functioning influence the mental health outcomes of caregivers and how training may benefit caregiver mental health outcomes and elucidate potential explanations. Furthermore, future research may provide helpful guidance to interdisciplinary teams as to whether the intensity of caregiver training should correspond with the severity of patient injuries or if targeted, specific training is equally important for caregivers of those with moderate- or mild-severity TBI injuries.

Multiple training and educational opportunities are now available through the Veteran's Affairs (VA) Polytrauma System of Care that was not available when these data were collected. A 2010 VA policy, in fact, mandates that therapists and providers document efforts to prepare family members for changes associated with severe injury [42]. Completion of caregiver training is also now a requirement for caregiver benefits authorized through the Caregivers and Veterans Omnibus Health Service Act of 2010 [43]. Benefits offered through the VA's Comprehensive Caregiver Program provide financial stipends, health care, respite, counseling, and travel reimbursement to eligible caregivers of veterans injured in OEF/OIF. No empirical studies have yet examined whether the training interventions lead to carryover of caregiver skills into real-world settings, or whether family members transitioning from an inpatient rehabilitation environment feel prepared for the realities of community reintegration. Given the heterogeneity of TBI/polytrauma clinical presentations, current rehabilitation interventions are highly individualized for both TBI and family systems, which impedes opportunities for more robust, longitudinal investigations on the effectiveness of any one targeted educational intervention for TBI/polytrauma caregivers. Future research could develop, implement, and test feasibility, efficacy, and effectiveness of caregiver training approaches that have shared basic foundational elements while also leaving room for individualized skill training. Future studies can also test the timing of caregiver interventions, called for in previous studies [23, 24], throughout the transitions from inpatient to outpatient care to optimize learning and carryover of important caregiver skills, especially for those caregivers who report negative longer term mental health outcomes.

Although this study's findings elicit important hypotheses and suggestions for future research, a number of limitations related to study design need to be acknowledged. First, this was an exploratory, hypothesis-generating, and cross-sectional study. Analyses were limited to descriptive statistics [38] and, as the mean comparisons via ANOVA and chi-square were meant to be exploratory, no effect sizes or equality of variances were reported. Further, the analyses did not control for variables that may complicate caregiver roles, such as mental health history of PTSD, depression,

or substance abuse. Second, the survey questions were retrospective. Though there is strength in exploring caregivers' perception of training experiences, family members/caregivers of patients in the acute phase of rehabilitation may be in states of emotional distress that render their later recollection of caregiver training unreliable. Third, the survey did not capture sources and types of training offered. With no standardized training protocols existing at the four PRCs during the time of data collection, it is unknown exactly what kind of training was offered by each of the four PRC sites. Fourth, it is possible that there was overlap among response choices for the training questions, in that caregivers could have received training without needing it or could have needed training but not received it. Finally, no caregivers for service members who received PRC care after 2009 were included; results may not generalize to families with service members who were injured after 2009. Available education and training developments across PRCs (plus the addition of a fifth PRC in San Antonio) could not have been taken into account in this study. Results therefore should be considered preliminary and informative for possible future research, as no strong causal interpretations about training can be made from these cross-sectional associations.

5. Conclusions

Though preliminary, results of this study suggest that caregiver training in navigating their care recipient's systems of healthcare and disability, or on how to support their care recipient's emotions, is positively associated with mental health outcomes among caregivers for OEF/OIF service members who have sustained TBI/polytrauma necessitating inpatient rehabilitation. Findings raise several hypotheses; first, caregiver needs may differ by relationship. Spouses/partners of individuals with TBI/polytraumatic injuries may have higher levels of emotional stress than parents, consistent with other literature. Second, training may not be as beneficial for caregivers of individuals with ADL dependence. This may be because they often have skilled, professional care to help and provide respite, or because these caregivers have physical, emotional, and spiritual burdens of care that impede learning or benefit from training. Future work should more rigorously test these hypotheses, as well as investigate the possibility of standardized caregiver training interventions that maintain clinical sensitivity for relationship to care recipient and intensity of care recipient's needs, while also allowing the interventions to be assessed empirically for efficacy and effectiveness.

Ethical Approval

The participating agencies' institutional review boards approved this study.

Consent

Informed consent was obtained after the details of the study were thoroughly explained to participants.

Disclaimer

The views expressed are those of the authors and do not necessarily represent the views of the VA or any of the institutions with which the authors are affiliated.

Conflict of Interests

The authors have declared that no competing interests exist.

Authors' Contribution

Lillian Flores Stevens, Treven C. Pickett, Kathryn P. Wilder Schaaf, Brent C. Taylor, Amy Gravely, Courtney Harold Van Houtven, Greta Friedemann-Sánchez, and Joan M. Griffin were responsible for study concept and design. Lillian Flores Stevens, Brent C. Taylor, Amy Gravely, and Joan M. Griffin were responsible for analysis of data. Lillian Flores Stevens, Treven C. Pickett, Kathryn P. Wilder Schaaf, Brent C. Taylor, Amy Gravely, Courtney Harold Van Houtven, Greta Friedemann-Sánchez, and Joan M. Griffin were responsible for interpretation of data. Lillian Flores Stevens, Joan M. Griffin, Treven C. Pickett, and Kathryn P. Wilder Schaaf were responsible for drafting of the paper. Lillian Flores Stevens, Treven C. Pickett, Kathryn P. Wilder Schaaf, Brent C. Taylor, Amy Gravely, Courtney Harold Van Houtven, Greta Friedemann-Sánchez, and Joan M. Griffin were responsible for critical revision of the paper for important intellectual content. Lillian Flores Stevens and Greta Friedemann-Sánchez were responsible for literature review. Joan M. Griffin was responsible for study supervision.

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Research Article

Mortality and One-Year Functional Outcome in Elderly and Very Old Patients with Severe Traumatic Brain Injuries: Observed and Predicted

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The aim of the present study was to evaluate mortality and functional outcome in old and very old patients with severe traumatic brain injury (TBI) and compare to the predicted outcome according to the internet based CRASH (Corticosteroid Randomization After Significant Head injury) model based prediction, from the Medical Research Council (MRC). *Methods.* Prospective, national multicenter study including patients with severe TBI ≥ 65 years. Predicted mortality and outcome were calculated based on clinical information (CRASH basic) (age, GCS score, and pupil reactivity to light), as well as with additional CT findings (CRASH CT). Observed 14-day mortality and favorable/unfavorable outcome according to the Glasgow Outcome Scale at one year was compared to the predicted outcome according to the CRASH models. *Results.* 97 patients, mean age 75 (SD 7) years, 64% men, were included. Two patients were lost to follow-up; 48 died within 14 days. The predicted versus the observed odds ratio (OR) for mortality was 2.65. Unfavorable outcome (GOSE < 5) was observed at one year follow-up in 72% of patients. The CRASH models predicted unfavorable outcome in all patients. *Conclusion.* The CRASH model overestimated mortality and unfavorable outcome in old and very old Norwegian patients with severe TBI.

1. Introduction

Traumatic brain injury (TBI) is a major health problem, with high mortality in severe TBI [1]. For survivors, the injury may cause long-standing deficits that interfere with independent living, reduced levels of functioning and restrictions on activities [2]. The incidence of TBI among the elderly is increasing, posing a significant challenge on health care services in this group [3].

Mortality is particularly high among elderly patients [4]. A review of the literature indicated an overall mortality of

65% in severe TBI among patients above 60 years old [5]. The mortality was nearly twice as high among very old patients (≥ 75 years), compared to patients between 65 and 74 years. Long-term outcome is also assumed to be worse in the elderly [6]. This may be attributed to the consequences of biological ageing as well as chronic disease prevalence [7], thus rendering the elderly more prone to complications [8]. Assuming a poor prognosis may also influence the treatment strategies applied in older patients [9] and subsequently results in a self-fulfilling prophecy regarding outcome. One should keep in mind that even old subject with very severe

TBI admitted with Glasgow Coma Scale scores between three and four may have a favorable outcome [10]. In addition, older age (>65 years) has even been shown to predict better long-term life satisfaction [11]. The progress in intensive care and neurosurgical options increase the possibilities for treatment and survival [12]. Such treatment is expensive [13], and it has been argued that clinicians treating these patients need prognostic models guiding their treatment choices [14], and the elderly group should be no exception.

Determining the prognosis after TBI is challenging, in particular when it comes to long-term functional consequences [15]. Large samples covering the entire specter of individual and medical variations are needed [16]. The Medical Research Council (MRC) CRASH (Corticosteroid Randomization after Significant Head Injury) trial is the largest clinical trial conducted in patients with traumatic brain injury [17]. A web-based prognostic calculator for mortality and 6-month outcome is developed based on these data, available for clinical use [18]. The Scandinavian countries are characterized by high income, equal access to health and social care services, and long life expectancy (<http://www.ssb.no/>). Even though none of the Scandinavian countries were included in the trial, the CRASH algorithm provides the option of high income country in the calculation. The data included in CRASH model are routinely documented in the Norwegian trauma centers, and the specification of the older subpopulation in this database provided the rationale for choosing this model.

Hence, the aim of the present study was to evaluate the mortality and functional outcome in old and very old patients with severe TBI and compare the observed mortality and outcome to the predicted outcome according to the CRASH models. We also aimed to evaluate if more detailed descriptions of CT scans improved the prognostic accuracy and to which extent there were differences in the old and very old patients.

2. Material and Methods

2.1. Design and Study Region. This project is part of a prospective, multicenter, cohort study, comprising patients admitted with severe TBI to the regional hospitals in all four health regions in Norway during 2009 and 2010. Norway consists of a land area of 323 758 km² and an adult population (aged ≥16 years) of 3.8 million (Statistics Norway). The Norwegian hospital structure includes local hospitals that serve small areas and regional trauma centres located in university hospitals that serve the local hospitals in the region.

2.2. Inclusion. In the current project, Norwegian residents ≥65 years of age who were admitted to their regional trauma centers within 72 hours of a severe TBI were included in the present part of the study. Severe TBI was defined by ICD 10 criteria (S06.1–S06.9) and a Glasgow Coma Scale (GCS) score between 3 and 8 within the first 24 hours after injury. The regional trauma centers were the University Hospital of North Norway for the northern region, St. Olav's

Hospital Trondheim University Hospital for the middle region, and Oslo University Hospital for the southeastern region. In the western part of the country, patients are equally distributed between Haukeland University Hospital and Stavanger University Hospital. Unfortunately, Stavanger University Hospital was not able to participate. Exclusion criteria were chronic subdural hematomas (SDH), preinjury cognitive disability, and severe psychiatric disease or drug abuse. This study was approved by the regional Committee for Medical Research Ethics, Southeast Norway (S-08378a, 2008/10441).

2.3. Data Collection. Data registration was based on a standardized review of hospital journals (paper and electronic records), CT scans, and data from the trauma registries. Follow-up at 12 months included clinical examination and collecting supplementary information regarding demographic data and functional levels which was collected from patients and their relatives.

2.4. Demographic, Medical, and Injury Characteristics. The causes of injury were classified as transport accidents, falls, violence, or other causes including sports injuries. Transport with intermediate stays at local hospitals prior to admittance to the trauma center was recorded as yes or no.

The comorbidity status was classified as none or having a medical disease at the time of injury. Anticoagulant status was defined by the use of warfarin or platelet inhibitors. The influence of alcohol or other substances at admission was categorized as yes or no, based on clinical judgment and blood or urine analysis, when available.

2.5. Injury Severity and Surgical Treatment. The GCS score was assessed at the accident scene and at hospital admittance. The lowest GCS score recorded within the first 24 hours is presented and used in the analysis. Dilatation of the pupils was recorded based on the prehospital charts and at admission and collapsed into no, one, or two dilated pupils. The Injury Severity Score (ISS) version 2008 was applied to indicate overall trauma severity. ISS of 9 or more added to the head injury abbreviated injury score (AIS) was considered as major extracranial trauma. The CT findings were described by a neurosurgeon or a radiologist. The presence of petechial hemorrhages, hematomas (epidural, subdural, and subarachnoid), obliteration of the third ventricle and basal cisternae, and midline shift were defined. Intracranial surgery was recorded, including ICP monitoring, cerebrospinal fluid (CSF drainage), craniotomy, and craniectomy. Information of craniotomy was used in order to evaluate whether the patient had a nonevacuated hematoma.

2.6. Outcome. Mortality within the first 14 days was assessed.

The TBI related, global functional outcome at 12 months was evaluated in survivors by structured interview using the Glasgow Outcome Scale Extended (GOSE) [19, 20]. GOSE is scored on an ordinal score from 1 (dead) to 8 (no functional sequel from TBI). Outcome was categorized as unfavorable (GOSE scores 1 to 4) and favorable (GOSE scores 5 to 8).

TABLE 1: Demographic characteristics and injury mechanisms of the old (65–74 years) and very old (75–92 years) are presented.

	Old (65–74 y, n = 46)	Very old (≥ 75 y, n = 51)	Chi square	p value
Male	74% (n = 34)	55% (n = 28)	3.79	0.05
Married/cohabitant	67% (n = 31)	53% (n = 27)	2.10	0.15
Comorbidity	76% (n = 35)	88% (n = 45)	2.47	0.12
Anticog. medication ^a	46% (n = 21)	73% (n = 37)	7.28	0.007
Injury mechanism				
Fall	78% (n = 36)	88% (n = 45)		
Transport	13% (n = 6)	12% (n = 6)	4.76	0.19
Violence	2% (n = 1)	0%		
Sports/other	7% (n = 3)	0%		
Transport via local hospital	57% (n = 26)	45% (n = 23)	1.26	0.26

y = years.

^a Anticoagulation and platelet inhibitors.

Furthermore, living situation (home, service home or institution, need for assistance (several times a day, daily, regularly, and never), and driving a car (yes/no)) was recorded at 12-month follow-up. Life satisfaction was measured with 1 global item: “Overall, how satisfied are you with your life situation now?” The item was rated on a 5-point ordinal scale: 1 (very dissatisfied), 2 (dissatisfied), 3 (neither satisfied nor dissatisfied), 4 (satisfied), or 5 (very satisfied) [21].

2.7. CRASH Prediction. Based on the MRC CRASH trial prognostic models including country, age, GCS score, pupil reactivity to light (both, one, or none) were developed and are available at the web (<http://www.trialscoordinatingcentre.lshtm.ac.uk/Risk%20calculator/index.html>). A second model also including CT characteristics (petechial hemorrhages, hematomas (epidural, subdural, and subarachnoid), obliteration of the third ventricle and basal cisterna, and midline shift) is also available. The CRASH models predict 14-day mortality and unfavorable outcome after 6 months. Death and GOSE score below 5 are assigned as unfavorable outcome.

2.8. Data Analysis and Statistics. The predicted mortality within 14 days and unfavorable outcome were calculated according to the web-based CRASH basic and CRASH CT prediction models for each patient. Dilated pupils were considered nonreactive to light and entered together with age and the lowest GCS within 24 hours. The percentage of patients predicted to be dead or having an unfavorable outcome was reported. Odds ratio (OR) with confidence intervals (CI) was used to calculate differences between the observed and CRASH based estimated 14-day mortality as well as differences in old and very old patients. In addition, the OR for predicted unfavorable 6-month outcome versus observed unfavorable outcome at 12 months was calculated. The chi square (χ^2) test for contingency tables was used to detect associations between categorical independent variables, including differences in outcome between the old (65–74 years) and very old patients (≥ 74 years). The analysis was conducted in IBM SPSS Statistics V21. A statistical significance level of 0.05 was adopted.

TABLE 2: Distribution of injury severity and CT based findings in the old and very old patients.

	Old (65–74 y, n = 46)	Very old (≥ 75 y, n = 51)
GCS (median, IQR)	6 (4–8)	4 (3–7)
Dilated pupils		
Both	15% (n = 7)	24% (n = 12)
One	22% (n = 10)	33% (n = 17)
None	63% (n = 29)	43% (n = 22)
Petechial hemorrhage	70% (n = 32)	71% (n = 36)
Obliteration of third ventricle/basal cisternae	67% (n = 31)	75% (n = 38)
SAH	76% (n = 35)	59% (n = 30)
Midline shift	46% (n = 21)	62% (n = 32)
Nonevacuated hematomas	37% (n = 17)	51% (n = 26)

3. Results

A total of 97 patients with mean age 75 (SD 7), 62 men and 35 women, were included. Hence, 52% of the patients were 75 years or older, with three persons over 90 years at the time of injury. The traditional predominance of males is less prominent among the oldest patients (Table 1). The most frequent mechanism of injury was fall (84%), followed by transport accidents (12%) and violence 1%, and 3% with other injury mechanisms in the cohort without statistically significant differences between the age categories. About half of the patients were transported via local hospitals. Prevalence of comorbidity and use of anticoagulation therapy increased with age (Table 1). Nonevacuated hematomas were more frequent in the very old group whereas other injury characteristics were rather similar across age (Table 2).

3.1. Mortality and One-Year Outcome. 48 patients died within 14 days; additionally, 12 patients died before 3 months and three patients before 12-month follow-up. Two patients were lost to follow-up at 12 months. Hence, 14-day overall mortality

TABLE 3: Characteristics of the surviving old and very old patients at one-year follow-up.

	Old (n = 24) (65–74 y, n = 24)	Very old (≥75 y, n = 8)
Living situation		
At home	20	7
Service home	2	0
Institution	2	1
Assistance at home		
None	14	5
Regularly	5	0
Daily	1	2
Several times a day	4	1
Driving a car	7	4
Satisfaction (mean, SD)	4.10, 0.83	4.25, 1.04

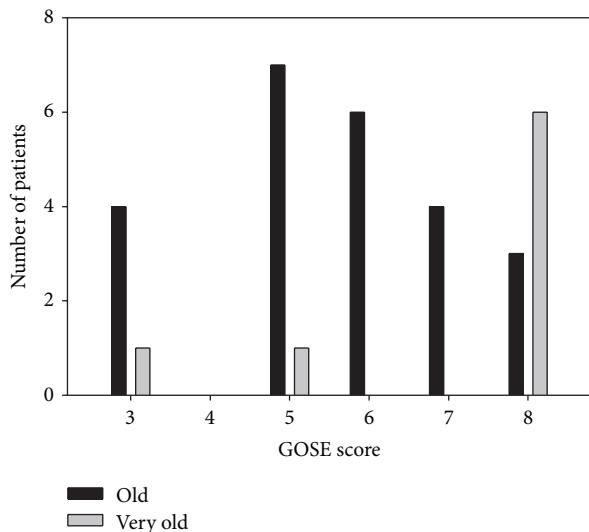


FIGURE 1: Distribution of GOSE score for the surviving old (black bars) and very old (grey bars) patients at 12-month follow-up.

was 50% in the present study. The observed mortality was significantly higher in the very old compared to the old group ($OR = 3.16$, $p = 0.006$). At one-year follow-up unfavorable outcome was observed in 72% of the patients. The observed outcome was significantly more favorable in the old compared to the very old patients ($OR = 4.84$, CI 1.80 to 12.99, $p = 0.002$). Although only eight very old patients survived, it is worth noting that the functional level of the majority of these patients was not heavily influenced as evaluated by GOSE (Figure 1). Furthermore, the majority was still living at home, with low level of assistance, and reported an overall high level of satisfaction (Table 3).

3.2. CRASH Predicted Compared to Observed Clinical Outcome. The predicted mortality according to the CRASH basic model was significantly higher than the observed ($OR = 2.65$, CI 1.46 to 4.40) ($p = 0.001$), with particular discrepancy in the old patients (Table 4). Adding CT findings to the

CRASH basic prediction model rendered an even higher OR of predicted versus observed mortality ($OR = 6.60$, CI 3.25 to 13.37) ($p < 0.001$). Unfavorable outcome (GOSE < 5) was observed at one-year follow-up in 72% of patients whereas the CRASH basic and CRASH CT models predicted unfavorable outcome in all patients (Table 4).

4. Discussion

The present study underscores the impact of severe TBI in elderly patients. Half of the patients died within 14 days and, additionally, 12% died within one-year follow-up. On the other hand, the outcome was strikingly better than the predicted outcome according to the CRASH algorithm. The reported level of life satisfaction in survivors was also rather high.

CRASH and the International Mission for Prognosis and Analysis of Clinical Trial in TBI (IMPACT) represent the largest datasets available for predicting outcome after TBI [17, 22]. Forty-eight countries participated and models for high compared to low income countries are developed and validated externally [18, 23]. The IMPACT differs from the CRASH model by using motor score instead of GCS score. In addition, hypoxia and hypotension are included in the prediction model. In the present Norwegian multicenter study we had complete dataset for GCS whereas only some centers recorded motor score. Focusing on the elderly rendered also the possibility to run statistical comparisons with the 902 patients above 64 years encountered in the CRASH study [17].

The efficacy of different treatment options in severe TBI varies according to injury and patient characteristics [15]. One of the best predictors is the pattern of recovery after TBI, particularly regarding level of consciousness [24]. However, in the acute phase of severe TBI decisions about surgical and neurointensive treatment have to be made promptly. Given the complexity of severe TBI, statistical models that combine data from patients to predict outcome are likely to be more accurate than simple clinical predictions [16]. Recent study from the Oslo University Hospital (OUH) on external validation of a prognostic model for early mortality after TBI developed at the University of Southern California (USC) showed that the USC model overestimated mortality in OUH population [25]. Similarly, in the present study of elderly Norwegian patients sustaining severe TBI, the agreement between the predicted and the observed 14-day mortality was low. Although the mortality in the elderly was high compared to the overall TBI mortality in Norway [26], these elderly patients had a substantially higher survival rate than predicted. One of the reasons for this could be related to general and neurotrauma-targeted improvements in our trauma services since late 2004 such as “a formalized trauma service, damage control resuscitation protocols, structured training, increased helicopter transfer capacity, consultant-based neurosurgical assessment, a doubling of emergency neurosurgical procedures, and improved neurointensive care” [27]. In general, the acute hospital care and postacute community-based health care in Norway are of high standard and are free for all citizens regardless of income. Hence, all of the patients in this study have had access to appropriate health

TABLE 4: Observed 14-day mortality and unfavorable outcome of 12 months and CRASH predicted 14-day mortality and 6-month outcome based on clinical (CRASH basic) and combined clinical and CT based information (CRASH CT). Results are shown for all patients ≥ 65 years, the old group (65–74 years), and the very old group (≥ 75 years).

	Observed	Predicted (CRASH basic)	Predicted (CRASH CT)
≥ 65 years ($n = 97$)			
Mortality	50%	64 (56–71)%	81 (73–87)%
Unfavorable outcome	72%	90 (86–92)%	95 (91–96)%
65 to 74 years ($n = 46$)			
Mortality	35%	54 (45–56)%	74 (64–81)%
Unfavorable outcome	44%	85 (80–87)%	92 (88–95)%
≥ 75 years ($n = 51$)			
Mortality	63%	73 (65–80)%	88 (81–92)%
Unfavorable outcome	86%	93 (91–95)%	97 (94–98)%

Unfavorable outcome is defined as dead and GOSE score <5.

care services. This may not be the case for all people in the sample of the elderly in the CRASH study, not even within the heterogeneous group of high income countries. For instance, recent study from the US reported that elderly patients with TBI who were designated as self-paying showed higher odds of death [28]. High general life expectancy in Norway could also be one possible cause of these results. The life expectancy in 2009 was 83 years for women and 79 years for men (<http://www.ssb.no/>), which is among the top ten countries in the world (<http://www.globalis.no/>). According to this, a generally better health among the elderly in Norway compared to other countries may also be a possible reason. However, the majority of the West European countries have life expectancies close to 80 years. Regarding quality of life, Norway is ranked number one by the United Nations (UN) statistics, which could be taken into account for a better health status in Norway than in many other European countries. Included in the UN statistics is also the economic situation which takes into account the level of health care service (Discovery News, February 11, 2013, <http://www.discovery.com/>). The survival rate for major trauma in the acute phase is also high in Norway [29].

Misclassification of predictors or outcome may also contribute to the discrepancy between the observed and predicted outcome. The mortality outcome was based on the hospital records supplemented with updated Norwegian death statistics, and we deem the possibility for misclassification as very low. In the Norwegian multicenter study functional outcome was evaluated by GOSE, whereas Glasgow Outcome Scale (GOS) was used in the CRASH study. GOSE subdivides the severe and moderate disability, but the threshold for favorable versus unfavorable outcome should be equal in GOSE and GOS. We can only speculate regarding whether assessments in the present study may have influenced outcome. However, the better performance of models predicting mortality compared to functional outcome is in accordance with the recent results of Majdan et al. [30]. Regarding the included clinical predictors misclassification of pupils not reacting to light is a possible bias. This parameter may also be prone to transport distance to hospital and present more frequently at admission with respect to comparable intracranial injuries when the transport distance is long.

The evaluation of substantial extracranial injuries was based on ISS of 9 or more caused by other traumas than the head. In CRASH model additional major trauma was defined as an injury which alone would be reason to hospital admission, and one could discuss if ISS is a very low level and thus contributed to the differences in observed and predicted outcomes.

One would also assume that including more information in the model, that is, CT findings, would improve the agreement. However, the actual agreement declined further when including CT findings. In the present study the CT with the most extensive injuries were chosen. The elderly have a higher frequency of hematomas [8], and the number of non-evacuated hematomas was high. These findings are generally associated with a poor prognosis [31]. We can only speculate whether the subdural and other hematomas in the elderly have a slightly different course and impact on outcome compared to younger patients, which are not fully accounted for in the model. Possibly the general atrophy in the old brain renders more space for expansion compared to the younger patients CT [32]. However, misclassifications of the CT parameters in the present study cannot be excluded, even though experienced radiologists evaluated the CT scans.

The CRASH model is developed to predict outcome after 6 months. The follow-up in the Norwegian national study was one year after injury. We cannot exclude that recovery from 6 to 12 months contributed to the much better outcome observed than the outcome predicted by the CRASH algorithm [33]. However, the effect of age will also increase with time to follow-up counteracting the effect of recovery in this elderly group. The CRASH algorithm includes the same predictors for 14-day mortality and for 6-month outcome. Gaetani et al. however documented that tSAH in the elderly influenced mortality but not long-term outcome [34]. It is also worth noting that, of the 32 survivors at 12-month follow-up, only five had a GOSE score below five. These results are in agreement with Flanagan et al. [35], also emphasizing a more optimistic prognosis in the elderly than previously assumed. The feared shifting from mortality to vegetative or reduced consciousness state over time does not seem to be supported [36]. Further, the rationale behind the algorithm could be questioned, as unfavorable outcome equals dead

with a disability level that implies a person with a functional level with some dependency of others, but the person can be alone for at least 8 hours. This is also emphasized in recent external validations using ordinal outcome of GOSE instead of dichotomizing in favorable and unfavorable outcome [37].

In conclusion, the present more favorable observed compared to predicted outcome and the reported general life satisfaction in the survivors are worth considering when deciding on neurosurgical treatment as well as rehabilitation in elderly TBI patients.

Conflict of Interests

The authors declare that there is no conflict of interests regarding the publication of this paper.

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Research Article

Whakawhitit Kōrero, a Method for the Development of a Cultural Assessment Tool, Te Waka Kuaka, in Māori Traumatic Brain Injury

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The importance of tools for the measurement of outcomes and needs in traumatic brain injury is well recognised. The development of tools for these injuries in indigenous communities has been limited despite the well-documented disparity of brain injury. The wairua theory of traumatic brain injury (TBI) in Māori proposes that a culturally defined injury occurs in tandem with the physical injury. A cultural response is therefore indicated. This research investigates a Māori method used in the development of cultural needs assessment tool designed to further examine needs associated with the culturally determined injury and in preparation for formal validation. Whakawhitit kōrero is a method used to develop better statements in the development of the assessment tool. Four wānanga (traditional fora) were held including one with whānau (extended family) with experience of traumatic brain injury. The approach was well received. A final version, Te Waka Kuaka, is now ready for validation. Whakawhitit kōrero is an indigenous method used in the development of cultural needs assessment tool in Māori traumatic brain injury. This method is likely to have wider applicability, such as Mental Health and Addictions Services, to ensure robust process of outcome measure and needs assessment development.

1. Introduction

The importance of tools for the measurement of outcomes and needs in traumatic brain injury (TBI) research is well recognized [1]. The development of tools for these injuries in indigenous communities has been limited despite the well-documented disparity of brain injury [2]. The lack of focus on cultural aspects of TBI in international classification systems may also have an influence [3]. Recent analysis and cross-checking of data across several data sets in Aotearoa, New Zealand, including Coroner's Office information, found that young Māori (Māori are the indigenous people of Aotearoa, New Zealand). According to the most recent population census there are approximately 600,000 people identified as Māori, 15% of the general population, or one in seven people. Māori are a steadily growing group, with a 6% increase in population compared to 2006. Population trends show this continuing growth (Statistics New Zealand [4])) are three

times more likely to sustain a TBI secondary to violence and that overall incidence of Māori hospitalizations secondary to TBI were also three times that of non-Māori [5]. Māori infants have also been found to have very high rates of subdural haematoma, likely caused by assault [6]. Hence there is a pressing need to develop culturally meaningful assessment measures for Māori. Such measures would also help inform cultural competencies required in the workforce, service development, and the ability to monitor Māori-determined outcomes. Ideally, development of such tools requires processes that can withstand critique from both Te Ao Māori and Western Science.

Despite the well-known Māori belief that he tapu te upoko (the head is sacred), there is a paucity of Rangahau Kaupapa Māori (research by Māori, for Māori, with Māori) and Kaupapa Māori Theory pertaining to TBI [7]. The wairua theory of traumatic brain injury (TBI) in young Māori

proposes that a culturally defined injury occurs at the same time as the physical injury [8, 9]. This injury is proposed to occur to wairua, a Māori specific expression of the connectedness between people and the universe, sometimes also translated as the spiritual dimension of being [10]. This means a cultural response is indicated and infers that without response to the cultural injury the whānau recovery will be limited. It is likely that cultural responses would include whānau specific activities that are deemed to address the injury to wairua, these might include deliberate use of Te Reo Māori me ōna tikanga, the Māori language, and protocols such as karakia (prayers) and whakawhanaungatanga (exploring and acknowledging the connections between people). However, there are no tools that assess the extent of this culturally defined injury. To this end, this study aimed to develop a new assessment tool, Te Waka Kuaka.

2. Methods

This study used a novel and unique Māori method, whakawhiti kōrero, literally the exchange of ideas and discussion, which predates the concept of cognitive interviewing, as part of mātauranga Māori (Māori knowledge systems) [11]. Whakawhiti kōrero is a term from Te Ao Māori (The Māori world) that expresses active discussion and negotiation. This method has not previously been specifically identified as useful in engaging with Māori participants to develop better statements used in the development of assessment tools. English terms such as “focus groups” [12] or “telephone interviews” [13] have been previously used with Māori participants. However, the premise here is that in using concepts from Te Reo Māori (the Māori language) this approach would promote ease of participation for Māori in the process of developing robust statements in the assessment tool.

Three wānanga (traditional fora) were held in Te Tai Tokerau (Northland), with community health and educational workers. A fourth wānanga with whānau (extended family) with experience of traumatic brain injury was also held to ensure that the statements were acceptable to these whānau, the future end users of such a tool. The initial version of the statements used in the tool came from statements made by participants during the phase of research previously reported [8, 9].

Two wānanga were organized by the author at centres of health work in rural and remote services affiliated tribally and at one meeting of predominantly educational workers. These locations were chosen because of the existing research partnership between these services and the first author's ongoing research programme. The final wānanga was held at a Kaupapa Māori Service provider “Kia ū ki te whānau, whatever it takes,” in order to offer participation to whānau with experience of TBI.

The first two and fourth wānanga were opened with karakia (prayer) and whakawhanaungatanga (introductions that emphasize the kinship linkages of participants). The third wānanga occurred during the lunch break of a hui (meeting) about Māori early childhood education where karakia had opened the day's proceedings. These cultural rituals of encounter are important for many Māori as they

ensure culturally safe whakawhiti kōrero. The background rationale of the research was then presented.

The consenting process occurred as part of a presentation about the rangahau by the first author and rationale for this part of the process to each group. The information sheets and consent forms were offered in both Te Reo Māori and English and discussion was invited. The option of having the wānanga filmed was offered. Notes were taken by the author during each wānanga, in particular of the final version of agreed statements from each wānanga.

Data analysis occurred via the author's repeated viewing of wānanga footage and noting commentary regarding the process.

Forty-seven statements were taken from previous research [8, 9]. These statements were in English language with appropriate use of Te Reo (the Māori language). They were presented on individual power point slides at each wānanga. Each statement was read out loud by the first author and comments were invited.

This study received ethical approval from the New Zealand Health and Disability Ethics Committee (14/CEN/17). Consent from the author's whānau was also given by kaumatua (elders) in the author's tribal area of origin.

3. Results

A total of thirty-nine people participated in the whakawhiti kōrero in four sites. No participants attended more than one wānanga. Eleven (Kaitaia), six (Te Hapua), sixteen (Waitangi), and six (Henderson) participants consented, respectively. Most (72%, 28) were Māori women, 13% (5) were Māori men, 13% (5) were non-Māori women, and one non-Māori man participated. The first three groups of participants were health and education workers with experience of and interest in working with Māori whānau. The final group were whānau who had direct experience of TBI.

Many of the original 47 statements, 23 (49%), were changed or removed during at least one wānanga. One new statement was added by the Waitangi wānanga “*Waiata is healing for those who do not understand Te Reo*,” the comments being that waiata, song, is such a common and important cultural practice that needed to be included.

Two statements were rejected by the participants, firstly, “*in hospital they treat the sickness not the wairua Māori that needs to be treated*.” This concept was put “on hold” by the first wānanga who found it “difficult to put into practice” and did not feel it would be easy to respond to. Subsequent wānanga participants concurred so the statement was removed from the final version of the assessment tool. In addition, the statement, “*time when whānau gather together builds healing*,” was thought to be almost exactly the same as “*whānau unity and strength builds healing*” and was therefore excluded.

One striking response was the participants dislike of the words “clinician” and “professional” with a preference for the terms “health worker” and “kaimahi” (worker). The participants discussed that they found words such as “clinician” distanced whānau from relating to the subject and to engaging in the process. They felt the concept of health worker was more inclusive and ensured inclusion

of “Whānau Ora workers (Whānau Ora is a specific type of contract to workers who are cross-disciplinary and who work to facilitate whānau rangatiratanga (self-determination) Turia [14].).” In addition, words such as “attended to” were found to be clumsy and were adapted. The reworking of statements commonly brought meaning for whānau to the fore. Collective ownership was taken around the concept of whānau, with the phrase “our whānau” being adopted in one statement.

The initial statement:

“the first thing that needs to happen is for wairua to be attended to,”

was modified by the Waitangi wānanga to

“starting the process of wairua healing is the first thing that needs to occur for our whānau”

and again by the Henderson wānanga to

“starting the wairua healing is the first thing that needs to happen for our whānau.”

Another reason for modification of statements was to refine the extent to which the statement reflected the majority of a concept or ameliorated that. Shifting from the concept of “most” to “some” and then to removing that modifier and including the concept “could” resulted in a statement that participants felt would be easier to respond to.

The initial statement:

“clinicians do not take enough time explaining what is going on to whānau,”

was modified by the Kaitaia wānanga to

“most health workers do not take enough time explaining what is going on for whānau.”

This was further modified at the Te Hapua wānanga to

“some health workers do not take enough time explaining what is going on with whānau.”

This was again refined by Waitangi to become

“health workers could take more time to help the whānau to understand what is going on.”

As the wānanga progressed the degree to which concepts of health workers, taking time, and meeting needs of whānau were woven together evolved to focus the statement more on the sense of responsibility of the kaimahi to bring the concept of flexibility to their work schedule in order to meet whānau needs.

The initial statement:

“clinicians expect whānau to take up as little of their time as possible,”

was modified in Kaitaia to

“most health workers expect whānau to take up as little of their time as possible.”

This was further adjusted in Te Hapua to

“some health workers schedules don’t match the needs of whānau.”

And finally Waitangi wānanga refined the statement to

“it is important that kaimahi (workers) are flexible in their schedules of work.”

Some statements began framed in a negative sense. Most were reframed in a positive way.

The initial statement:

“I get upset if time is not taken for wairua,”

was modified in Waitangi to

“I feel uplifted when time is taken for wairua.”

The group with whānau experience of TBI tended to strengthen statements regarding impact on whānau and with a positive reframe such as in this example.

The initial statement:

“professionals are not trained in the culture of the whānau,”

was modified in Waitangi to

“health workers do not always relate to the culture of the whānau”

and was further modified in Henderson to

“when health workers relate to the culture of the whānau, outcomes are improved.”

Half of the statements remained unchanged. These were most strongly clustered in the areas of “wairua practices.” For example,

“It doesn’t matter if you can’t understand Te Reo (the Māori language), the effect remains strong”, Karakia strengthens wairua, the closeness of whānau strengthens wairua, mirimiri (message) strengthens wairua, use of Te Reo Māori means wairua is being strengthened.”

A final version of the assessment tool called Te Waka Kuaka is now ready for validation procedures (see the Appendix). The name Te Waka Kuaka was chosen as it describes a flock of kuaka (godwits). The kuaka holds special significance for the iwi (tribal group) of the first author. Te Waka Kuaka supports whānau to organize their thoughts and needs which then enables them to navigate their healing journey, much as the flock of kuaka organizes themselves for their long migrations around the globe. This name was welcomed by kaumatua (elders).

4. Discussion

It was notable that participation was not declined by any of the potential participants. It is possible that this is related to at

least two aspects. Because of the longstanding research partnership between the first author and these groups there was a considerable amount of historical trust accrued. This may have assisted in enabling participants to more fully engage. In addition, the use of Māori protocols of encounter such as karakia and whakawhanaungatanga assisted in ensuring that all participants and the author could locate each other within the bonds of their collective ancestral ties. Without this history and use of cultural lore it is possible that the participants may have been less receptive to the whakawhitit kōrero.

The whakawhitit kōrero approach was well received by participants. They seemed to require little prompting as to their ideas about how the statements might best flow and be understood and responded to in the future. Key considerations at the Kaitaia meeting were that the participants did not feel the words “clinician” and “professional” were appropriate and might be off-putting for future respondents. The Waitangi meeting strongly advocated for turning negative statements into positive ones. However, there remain four statements with a negative element (11, 25, 39, and 45): “being inside buildings like hospitals does not help me,” “whānau switch off when they hear the word “clinical,”” “separating the whānau from the patient can damage healing,” and “it does not matter if you cannot understand Te Reo, the effect remains strong.” It is possible that the majority of statements formed in an affirmative manner reflect a strong preference for a nondeficit approach which resonated for the participants. These preferences are also articulated by Kaupapa Māori Theory and praxis scholars [15, 16]. Across all wānanga the participants discussed their ideas amongst themselves and came to shared agreement as to changes and to statements they did not wish to change.

While not specifically critiqued, the power of naming the process from within Te Ao Māori, the Māori world view, as whakawhitit kōrero seemed to contribute to an overall ease of participation and engagement in this study. The positive impact of using Māori ways of being from daily life as research methods rather than treating these as “other” in the research space has previously been described [17].

At each wānanga kaimahi from areas of health such as chronic care nurses and Whānau Ora workers commented that they would like to use the tool in their work, unrelated to TBI. The view expressed was that the tool would be useful to build rapport and to obtain a clear, shared profile of the cultural needs of whānau, whatever their index health concerns. The first author expressed caution while the research process was occurring and also suggested that future projects could be developed to investigate this possible use.

The development of robust assessment tools commonly involves the process of cognitive interviewing [18]. There is no universally accepted definition of this method. However, it involves practices that present draft questionnaire statements to participants, one to one interviews being the described modality, and using various techniques such as asking participants to think out loud, in order to help improve the statements such that they deliver the information needed. While some may understand whakawhitit kōrero as a modification of cognitive interviewing it is best understood

as a related but distinct method that comes from Māori mātauranga (Māori knowledge systems). Building a wider vocabulary of Māori research methods is a critical issue which has attracted considerable attention [16]. In particular, the need to make visible the “normal” aspects of Māori knowledge and practice has been highlighted as a site of rich and important methodological resource [17]. The use of a culturally determined meeting context such as wānanga demonstrated that group processes can be successfully used to refine assessment tool statements in preparation for validation.

This study is limited by its location in the north of Aotearoa, New Zealand. It is possible that the response to statements and the participant engagement would be varied in other areas. Given the original research that identified the forty-seven initial statements coming from marae wānanga (fora in traditional meeting houses) in nine urban, rural, and remote locations around Aotearoa, New Zealand, this reinforces the wide applicability of the results.

5. Conclusion

Whakawhitit kōrero is an indigenous concept that brings a practice from Māori daily life to serve as a method in Rangahau Kaupapa Māori. This method has been utilised in the development of cultural needs assessment tool in Māori traumatic brain injury in order to refine the tool based on robust theory building. This method may have wider applicability in other fields where outcome measures and needs assessments for Māori are needed such as mental health and addiction services and in assessment treatment of neurodegenerative disorders and others. This approach could itself be examined in more detail as to how it is received by participants and the features that this approach contributes to participation by Māori. This method adds to the suite of Rangahau Kaupapa Māori processes that map out a robust process of outcome measure and needs assessment development. A final version of the assessment tool, Te Waka Kuaka, is now ready for validation procedures.

Appendix

Te Waka Kuaka. Cultural Needs of Whānau with Possible Brain Injury

Date

Page 1 ID.....

Relationship of participant to patient

Main iwi of the participant

Age of participant

Gender of participant

Ethnicity of health worker

Profession of health worker

Age of health worker

Gender of health worker

Location area name

Mental health issues/addiction/birth hypoxia (circle)

(6) I get uplifted when time is taken for wairua

- 1
- 2
- 3
- 4

Possible TBI (circle) date (s)

Confirmed TBI (circle) date (s)

- Mild (Mild)
- Moderate (Mod)
- Severe (Sev)
- Unknown (circle) (Unk)

1 = strongly disagree

2 = disagree

3 = agree

4 = strongly agree

(7) Time needs to be taken to consider other trauma within whakapapa

- 1
- 2
- 3
- 4

(8) Whanaungatanga time builds, to keep hope and dreams alive

- 1
- 2
- 3
- 4

Wā (Time)

(1) Starting the process of wairua healing is the first thing that needs to happen for our whānau

- 1
- 2
- 3
- 4

(9) Whānau unity and strength builds healing

- 1
- 2
- 3
- 4

Comments -----

Wāhi (Place)

(10) The use of pepeha within treatment would support the healing

- 1
- 2
- 3
- 4

(11) Being inside buildings like hospitals does not help me

- 1
- 2
- 3
- 4

(12) It makes me feel better when we can go to the marae

- 1
- 2
- 3
- 4

(4) Health workers could take more time to help the whānau understand what is going on

- 1
- 2
- 3
- 4

(5) It is important that kaimahi are flexible in their schedules of work

- 1
- 2
- 3
- 4

(13) Whakaairo (carvings) teach important lessons that help with healing

- 1

2
 3
 4

(20) When the whānau are involved the healing outcome is better

1
 2
 3
 4

(14) Tukutuku (lattice-work) panels have important lessons for healing

1
 2
 3
 4

(21) Whānau have to go through their own healing process

1
 2
 3
 4

(15) The powhiri process ensures the wairua is settled for open discussion

1
 2
 3
 4

(22) Within whānau there are a lot of resources

1
 2
 3
 4

(16) Gathering, preparing, and eating food from home is an important part of healing

1
 2
 3
 4

(23) Within the whānau is the rongoā

1
 2
 3
 4

(17) Whānau from home are an essential link with home

1
 2
 3
 4

(24) Whānau fear judgment by health workers

1
 2
 3
 4

(18) Māori may feel the need to come home to heal

1
 2
 3
 4

(25) Whānau switch off when they hear the word “clinical”

1
 2
 3
 4

(19) Being on the marae is a good place to start to feel strong again

1
 2
 3
 4

(26) Māori have a different point of view from Pākehā

1
 2
 3
 4

Comments -----

(27) Māori cultural needs are different from Pākehā

1
 2
 3
 4

Te Waka Kuaka Measure for Whānau with Possible TBI

Page 2 ID.....

Tangata (People)

- (28) When health workers relate to the culture of the whānau outcomes are improved
- 1 2 3 4
- (29) When health workers support whānau to address wairua outcomes are improved
- 1 2 3 4
- (30) I call on the strengths of my tūpuna to cope
- 1 2 3 4
- (31) Trauma to one is trauma to all
- 1 2 3 4
- (32) Trauma to one is trauma to the whakapapa
- 1 2 3 4
- (33) Being whānau means you do not have to know everything yourself
- 1 2 3 4
- (34) Being whānau means we can use our collective strengths
- 1 2 3 4
- Comments -----
- (36) Karakia strengthens wairua
- 1 2 3 4
- (37) The presence of kaumatua strengthens wairua
- 1 2 3 4
- (38) The closeness of the whānau strengthens wairua
- 1 2 3 4
- (39) Separating whānau from the patient can damage healing
- 1 2 3 4
- (40) Te Reo Māori me ūna tikanga is important in maximizing healing of wairua
- 1 2 3 4
- (41) Oriori (chants) can be powerful healing tools
- 1 2 3 4
- (42) Mirimiri (type of massage) can be a powerful healing tool
- 1 2 3 4
- (43) Romirohi (type of massage) can be a powerful healing tool
- 1 2

Wairua Practices

- (35) Practices that strengthen wairua are as important as clinical interventions
- 1

- (43) Romirohi (type of massage) can be a powerful healing tool
- 1 2

3 4

(44) Waiata is healing for those who do not understand Te Reo

 1 2 3 4

(45) It does not matter if you cannot understand Te Reo, the effect remains strong

 1 2 3 4

(46) Use of Te Reo Māori means wairua is being strengthened

 1 2 3 4

Comments -----

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Conflict of Interests

The authors declare that there is no conflict of interests regarding the publication of this paper.

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Research Article

Psychological Outcome in Young Survivors of Severe TBI: A Cross-Informant Comparison

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Objective. To investigate the psychological outcome and the agreement between self-ratings and proxy-ratings in young individuals after severe traumatic brain injury (TBI). **Methods.** Twenty pairs of former patients who sustained a severe TBI in their adolescence or early adulthood and their significant others (SOs) were contacted around 66 months after injury to complete a measure of psychological and behavioral problems. The Adult Self-Report 18–59 and the Adult Behavior Checklist 18–59 were used. **Results.** Results showed significant differences compared to the normative sample in the domains withdrawal, attention, and intrusive and internalizing problems. Good or excellent levels of agreement were found between the self-rating and the proxy-rating in overt areas such as somatic complaints and aggressive and intrusive behavior. Fair or poor levels of agreement were found in nonovert areas such as anxiety and depression, withdrawal, thought and attention problems, and personal strength. **Conclusion.** The findings show that young patients experience psychological dysfunction. Our study suggests that the use of either a self-rating or a proxy-rating would be appropriate for evaluating overt domains, regarding the good to excellent levels of agreement. However, in nonovert domains, such as withdrawal and attention, an additional proxy-rating from a SO could provide supplementary information and build a more complete objective assessment.

1. Introduction

Traumatic brain injury (TBI), defined as damage of brain tissue caused by external mechanical force, is the foremost cause of acquired disabilities among young adults [1]. TBIs are also known as one of the leading causes of death [2], where adolescents, young adults, and the elderly are at the highest risk [3, 4].

After sustaining a severe TBI, impairments including physical, cognitive, emotional, psychosocial, and behavioral limitations are common [5–7]. Following the acute state, residual motor and sensory deficits may persist in a wide range [8]. These limitations have a significant short- and long-term impact on social, neuropsychological, behavioral, and academic domains for the majority of TBI victims [9, 10]. Adolescents are especially reported to be more susceptible

to long-term disability due to the vulnerability of the immature brain [11–16]. Consequently, young individuals have exhibited residual impairments in a range of areas including emotional, behavioral, adaptive, and cognitive dysfunction [14, 17]. Adolescence is defined as a period of transition from being a dependent child to an independent and a self-determined adult. A TBI within this time frame not only causes physical and cognitive impairments, but also interrupts the natural process of maturation. This interruption subsequently impairs still-developing skills and results in psychological difficulties [18, 19]. These psychological difficulties, such as depression, are significant, since they impact the quality of life for adolescents surviving TBI [20].

To assess the psychological outcome, standardized measures are commonly used. This can be done in two ways: asking the patient for his or her subjective opinion by using a

self-rating scale or asking a significant other (SO) to describe the patient by using a proxy-rating scale. For populations with cognitive disability, such as after TBI, some people may be unable to provide an accurate self-report due to impaired cognition or communication. Seel et al. [21] reported that people with very severe injuries tended to underrate their problems, whereas people with mild injuries typically rated problems as occurring more frequently than family members' reports. However, very often, either a self-rating scale or the proxy-rating scale is utilized. On the one hand, it can be difficult for patients to subjectively reflect and describe their perceived psychological impairments. On the other hand, challenges with proxy reports occur when specific measures of outcome require knowledge about unobservable, internal experiences [22]. Obtaining both a subjective opinion from the patient and a proxy opinion could lead to a more trustworthy evaluation. Proxy opinions can be obtained by a SO completing a cross-informant rating system.

Cross-informant ratings can be beneficial, for instance, when awkward social areas are assessed in which individuals tend to provide inaccurate but desirable answers due to youth and insecurities. Cross-informant rating systems are available in a variety of instruments and have been used in prior research [21–25]. However, it is important to consider that using different people to assess psychological functioning can provoke various results.

The level of agreement between the self-rating score of a patient and the proxy-rating score of a SO (parent, sibling, partner, or primary caregiver) has been used by researchers in the past to investigate psychological outcomes following a TBI. Also, by studying the agreement between patient and proxy reported scores, researchers have been able to examine a patient's level of self-awareness [22]. Impaired self-awareness is a common problem after TBI and is often associated with a decreased functional outcome and poor compliance with rehabilitation [26]. Impaired self-awareness can lead to over- or underestimation of the patient's own condition. A high level of agreement between self-rating and proxy-rating reports can, in turn, reflect a high level of self-awareness in a patient.

Previous research also suggests that the exclusive use of proxy responses should be used with caution when evaluating a patient's participation level in social activities. Researchers found that proxy responses could be biased and overly critical in evaluating the patient's social participation [24]. Therefore, independent proxy data can be acceptable for research purposes. However, in order to assess outcomes and set future clinical and rehabilitation goals, input from both sides, persons with TBIs and their SOs, should be considered [25].

The agreement between patient and proxy perceptions of psychosocial outcomes was previously assessed in an Australian study using the ASR 18–59 and the ABCL 18–59 on 33 individuals and their SOs 16 years after mild, moderate, or severe pediatric TBI (mean age at injury $M = 4.70$, $SD = 1.74$) [23]. The results showed a generally poor to fair agreement on most of the investigated subscales of internalizing and good to excellent agreement on communication and drug abuse.

Green et al. (2012) found there to be an excellent agreement between adolescents and their parents in the assessment of the psychological outcomes using the Sydney Psychosocial Reintegration Scale for Children (SPRS-C) after a childhood TBI (age at injury ranged from 0 to 5 years). However, there was less of an agreement regarding quality of life [22]. It is important to bear in mind, however, that quality of life is a subjective perception, which is very difficult to describe from an external perspective.

The main focus in previous studies has been either adulthood or early childhood. Apart from the small number of studies addressing pediatric patients after TBI, no study was identified as specifically addressing patients who sustained a severe TBI during their adolescence or early adulthood.

Most research has described consequences based on information from either a self-rating or a proxy-rating system.

Researchers generally agree that the perceptions of impairments and difficulties are most likely to differ between a self-reporting perspective and the perspective of a family member or caregiver [21–25].

Recent research reports mostly on mixed samples consisting of mild, moderate, and severe TBI. These studies have very small numbers of participants with severe TBIs [22, 23]. In future research, gaining more knowledge regarding the perception of impairments and difficulties of people with TBIs would lead to a better understanding of how the involvement of a SO would be beneficial in the identification of psychological problems.

2. Objective

The aim of this study was twofold. First, the study intended to investigate the psychological functioning of individuals after sustaining a TBI in their adolescence or early adulthood and compare the results to a normative sample. Second, the study investigated the agreement between the self-ratings by the young adults and the cross-informant ratings by the SOs.

Based on previous research, the expectation was to find higher levels of psychological dysfunction in the TBI sample than in the normative sample. The authors also expected to find a lower agreement between patient reporting systems and their SOs within internalizing domains and a higher agreement in externalizing domains. This paper reports the results of a study investigating the psychological outcome in young patients after severe TBI. The first part of the study investigated in which domains and at which level the young patients perceived difficulties, and the second part of the study addresses the agreement between the patients and their SOs and is reported in the current paper.

3. Methods

The patients included in the study had all been admitted to a subacute neurorehabilitation department between the years 2000 and 2013 and were contacted during 2014 for a follow-up assessment in the chronic phase after injury. The department has an admitting area covering the eastern part of Denmark

TABLE 1: Sample characteristics ($n = 20$).

Characteristics of patients	
Gender n (%)	
Male	16 (80%)
Female	4 (20%)
Age at injury, year, mean (SD)	18.1 (1.9) Range 6 (min 15, max 21)
Age at participation, year, mean (SD)	23.8 (4.9) Range 13 (min 18, max 31)
Time since injury, month, mean (SD)	66.1 (46.6) Range 145 (min 5, max 150)
Duration of PTA, days, mean (SD)	49.4 (34.8) Range 120 (min 10, max 130)
Length of stay, days, mean (SD)	70.5 (44.8) Range 185 (min 21, max 206)

SD: standard deviation; GCS: Glasgow Coma Scale; PTA: posttraumatic amnesia.

and provides subacute inpatient rehabilitation and follow-up visits to patients, who sustain severe brain injuries.

3.1. Inclusion Criteria.

Inclusion criteria were as follows:

- (1) Patients who sustained a TBI.
- (2) Glasgow Coma Scale (GCS) score under 9 at time of injury, indicating a severe TBI.
- (3) Between the ages of 14 and 21 at time of injury and at the age of 18 or older at the follow-up assessment.
- (4) Level of cognitive functioning, score 7 and 8 on the Rancho Los Amigos scale at discharge from subacute inpatient rehabilitation.
- (5) Living in Denmark, within the admitting area.

3.2. Exclusion Criteria.

Exclusion criteria were as follows:

- (1) Living outside the admitting area, that is, Greenland and the Faroe Islands (part of Denmark).
- (2) Not Danish speaking.

3.3. Participants and Procedure. Eighty former patients, who were admitted for subacute rehabilitation at the clinic of neurorehabilitation, between the ages of 14;1 years to 21;11 years were invited to participate in a questionnaire during the chronic phase after injury. Thirty-six completed and returned the questionnaires and 33 provided written consent to contact a SO, such as a parent, caregiver, or spouse, for a cross-informant rating of the measure. Of the contacted SOs, 20 completed and returned the sent materials (Figure 1). The mean time since injury was 66.1 months (SD = 46.6 months). Table 1 displays the sample characteristics.

The study was conducted according to the Regional Ethical Committee, the National Board of Health, and approved by the Danish Data Protection Agency (J. number 2007-58-0015).

3.4. Measures. To describe the severity of injury and the patient's condition, three indicators were used: the length of posttraumatic amnesia (PTA), the Rancho Los Amigos (RLA) score [27], and the length of stay (LOS) at the rehabilitation unit.

The mean length of posttraumatic amnesia (PTA) was assessed prospectively using the Galveston Orientation and Amnesia Test (GOAT) [28] by neuropsychologists. This test was used as a standard assessment during hospital rehabilitation. After scoring at least 75 points on two consecutive days, the PTA is considered as terminated.

The patient's level of consciousness was assessed using the Rancho Los Amigos (RLA) scale [27]. The scores range from Level 1, which describes a comatose condition with no observable response, to Level 8, which is a condition with purposeful and appropriate responses [27]. An RLA score of 7 (automatic, appropriate response) or 8 (purposeful, appropriate response) was chosen as inclusion criteria, to ensure that the contacted patients regained the ability to complete the study's measures.

The ASEBA material, developed by Achenbach and Rescorla [29], provides several age-related instruments to assess the psychological functioning of individuals in the form of a self-rating system as well as corresponding cross-informant rating system. The Adult Self-Report (ASR 18–59) and the Adult Behavior Checklist (ABCL 18–59) acted as the primary outcome measures of the study. These questionnaires assess competencies and adaptive functioning as well as behavioral, emotional, and social problems. The questionnaires consist of 123 closed and three open items as well as a set of questions regarding the living status and demographic information. Each item represents a statement scored by a Likert scale where 0 indicated "not true," 1 "somewhat or sometimes true," and 2 "very true or often true." The items are distributed between the Adaptive Functioning Scales ((1) friends, (2) spouse/partner, (3) family, (4) job, (5) education, and (6) personal strength), the syndrome scales ((1) anxiety/depression, (2) withdrawal, (3) somatic complaints, (4) thought problems, (5) attention problems, (6) aggressive behavior, (7) rule-breaking behavior, and (8) intrusive behavior), the combined scales ((1) internalizing, (2) externalizing, and (3) critical items), the DSM-orientated scales ((1) depressive problems, (2) anxiety problems, (3) somatic problems, (4) avoidant personality problems, (5) attention deficit/hyperactivity problems, and (6) antisocial personality problems), and the Substance Use Scales ((1) tobacco, (2) alcohol, and (3) drugs). The scores of the 126 items of the ASR 18–59 are allocated to the specific subscales. Raw scores, *t*-scores, and percentiles are calculated by the software or via hand-scoring for each scale and are presented in a profile. The *t*-scores describe whether the score of a subscale is within the normal range or in a border range or clinically significant. After scoring, a profile displays the levels of each subscale as normal, critical, or clinical range [30]. By using Pearson correlations, the reliability of this measurement was reported as generally very high, with "all test-retest *r*s being significant at $p < 0.01$ and most being in the 0.80s and 0.90s" [31].

For the present study, only *t*-scores of the syndrome scales as well as the combined scales for substance abuse,

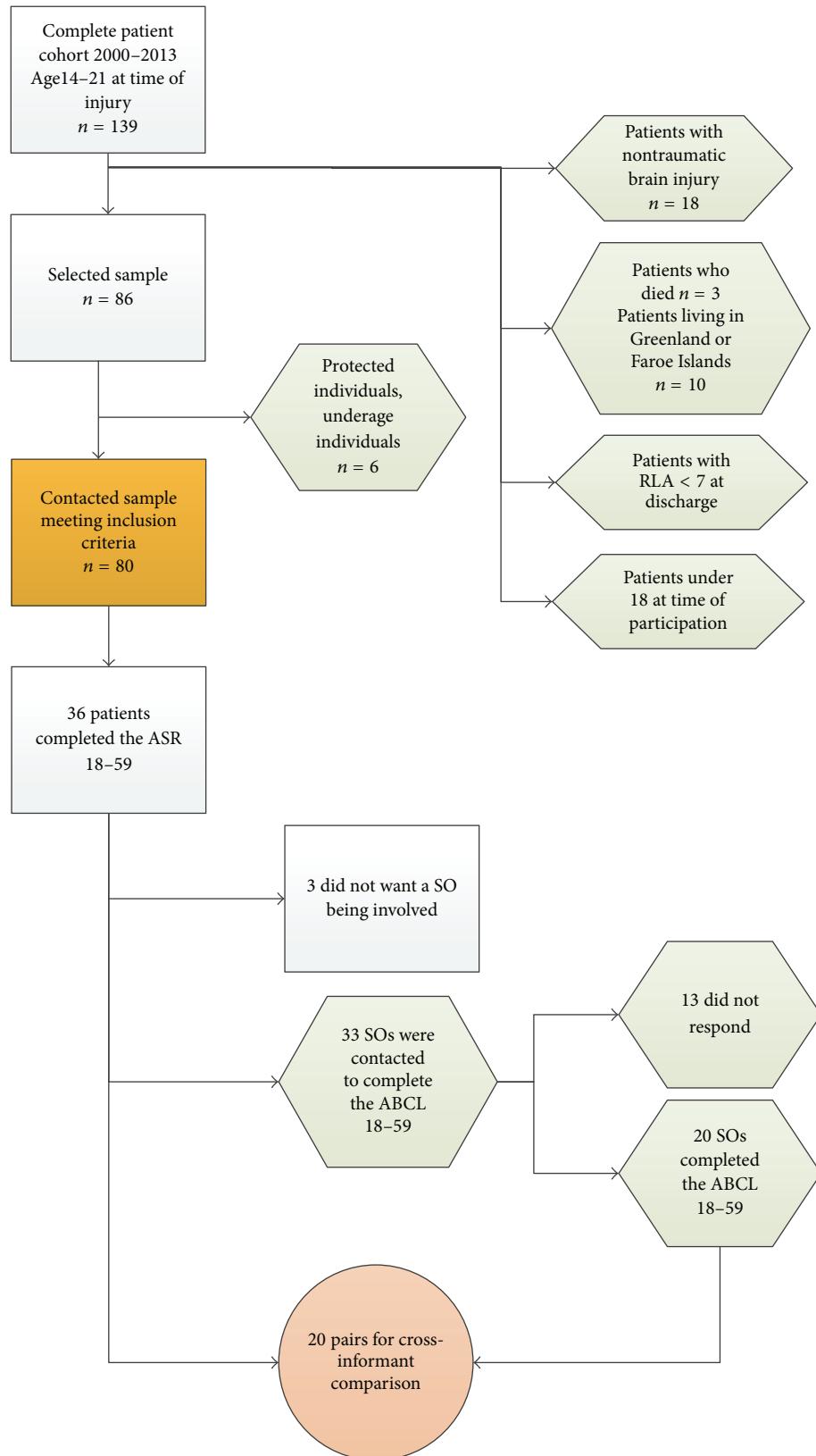


FIGURE 1: Flowchart of participant enrolment.

internalization, externalization behavior, critical items, and adaptive functioning were used to enhance interpretation. For the syndrome scales (clinical range > 64) and combined scales (clinical range > 61), a higher *t*-score indicates more problems, as opposed to the Adaptive Functioning Scales, where a lower *t*-score (clinical range < 32) indicates worse functioning.

3.5. Analysis. All data was entered into and screened for violations of normality and analyzed by SPSS version 19.00.

3.5.1. Demographic Data. To characterize the study participants, demographic information as well as injury related information was obtained. Patient demographic information consisted of gender, age at the time of injury and participation, and the time since the original injury occurred. The relationship between the patient and the SO as well as the cohabitation status was recorded for each pair. Measures of central tendencies, such as the mean, were calculated. Measures of variability, including standard deviation (SD), were also applied. All analyses were two-tailed and used a significance level of $p < 0.05$ (if not noted otherwise).

3.5.2. ASR 18–59 and ABCL 18–59. Means were computed based on the *t*-scores for the syndrome subscales as well as for the combined scales.

To investigate whether the values of the self-rating and the proxy-rating were significantly different to the normative sample, one-sample *t*-tests were performed. Therefore, the whole responding sample of the young patients ($n = 36$) (see Figure 1) and the responding SOs ($n = 20$) were compared with the normative sample from Achenbach and Rescorla (2003) using one-sample *t*-tests. Normative data for the age range 18–35 was used.

3.6. Cross-Informant Comparison. Each subscale's self-rating scores were calculated using the ASR 18–59, whereas the ABCL 18–59 was used to calculate the proxy-rating scores. Intraclass correlations (ICC) were used to test whether or not the self- and proxy-rating answers were consistent. The suggested levels of clinical significance were used to rate correlations: ICC < 0.40 indicates a poor correlation, an ICC of 0.40 to 0.59 a fair level, an ICC of 0.60 to 0.74 a good level, and an ICC of 0.75–1.00 an excellent level [32].

3.7. Supplementary Analysis. In order to compare the LOS and the PTA between the responding and nonresponding participants, independent *t*-tests were applied. Spearman correlations were carried out to investigate whether a relationship existed between the time since original injury and the patient's level of psychological functioning.

4. Results

4.1. Demographics and Status

4.1.1. Patients. The mean age of patients at the time of injury was 18.1 years ($SD = 1.9$) and 80% were male. The mean age at

TABLE 2: Status of patient and significant others ($n = 20$).

Characteristics		<i>n</i> (%)
Relationship toward patient	Parents	18 (90.0)
	Caregiver	1 (5.0)
	Spouse	1 (5.0)
Cohabitation status	Living at home	17 (85.0)
	Living with partner	1 (5.0)
	Shared accommodation	1 (5.0)
	Living in nursing home	1 (5.0)

participation was 23.75 ($SD = 4.9$), and the mean time since injury was 66.1 months ($SD = 46.6$) with a range between 5 and 150 months. The mean PTA duration was 49.4 days ($SD = 34.8$) and the mean LOS at the TBI unit was 70.5 days ($SD = 44.8$) (see Table 2).

4.1.2. Characteristics of the SOs. The majority of the SOs were parents ($n = 18$), except one who was a spouse and one who was a professional caregiver.

4.2. Psychological Outcome. Significant differences between the self-rating scores of the young patients and the normative sample were found in the subscales of withdrawal ($t(35) = 2.63$, $df = 35$, $p = 0.013$), attention ($t(35) = 2.81$, $df = 35$, $p = 0.008$), and internalization ($t(35) = 2.25$, $df = 35$, $p = 0.031$), all of which showed higher mean problem scores for the patients. Significantly lower patient reported scores were found in the subscale for intrusive behavior ($t(35) = -2.06$, $df = 35$, $p = 0.046$). No significant differences were found in the remaining subscales. The subscale of attention was the only category to result in significantly higher proxy-rating scores when compared to the normative sample ($t(20) = 3.00$, $df = 19$, $p = 0.007$) (Table 3).

4.3. Comparison between Self-Rating and Proxy-Rating. The scores of each subscale of the ASR 18–59 and the ABCL 18–59 were compared using paired two-sample *t*-tests. No significant differences were found between the mean ratings in the tested subscales (Table 4). The interrater agreement, assessed by using intraclass correlation (ICC), showed an excellent level of agreement within the subscales of somatic complaints. A good level of agreement was found within the aggressive and intrusive behavior of the syndrome scales, as well as a good level of agreement within the internalizing and critical items of the combined scales.

A fair level of agreement was found in the syndrome scales of anxiety and depression, attention problems, and rule-breaking behavior, as well as in the combined scales of externalizing and total problems. Finally, a poor level of agreement was found in the subscales of thought problems and personal strength (Table 4).

4.4. Supplementary Analyses. A set of supplementary analyses were conducted to investigate the effect that time since the original injury would have on the psychological functioning. Analyses were also run to compare responders'

TABLE 3: Comparison of self-rating and proxy-rating with the normative sample.

Scale	Characteristics	Patient Mean t-score (SD) n = 36	Difference D with the mean t-score of the normative sample	p value	Significant other Mean t-score (SD) n = 20	Difference D with the mean t-score of the normative sample	p value
Syndrome scales	Anxiety and depression	57.03 (9.36)	2.68	0.095	55.00 (5.62)	0.65	0.611
	Withdrawal	58.58 (10.23)	4.48	0.013*	55.00 (6.95)	0.90	0.569
	Somatic complaints	56.53 (7.69)	2.43	0.066	55.50 (5.41)	1.40	0.261
	Thought problems	54.64 (8.44)	0.49	0.730	54.40 (5.74)	0.25	0.848
	Attention problems	58.17 (8.46)	3.97	0.008**	57.55 (4.99)	3.35	0.007**
	Aggressive behavior	54.22 (6.25)	0.12	0.907	54.15 (4.67)	0.50	0.962
	Rule-breaking behavior	54.75 (6.15)	0.60	0.562	54.20 (4.05)	0.50	0.957
	Intrusive behavior	52.50 (4.65)	1.60	0.046*	53.15 (5.52)	0.95	0.451
Combined scales	Externalizing	49.33 (10.07)	0.72	0.672	52.25 (9.82)	2.05	0.362
	Internalizing	54.83 (12.36)	4.63	0.031*	50.90 (7.45)	0.85	0.616
	Total problems	48.90 (9.24)	1.20	0.568	50.65 (8.36)	0.55	0.772
	Critical items	55.50 (6.05)	1.40	0.314	55.85 (5.28)	1.75	0.155

SD: standard deviation; * significant = $p < 0.05$; ** significant = $p < 0.01$.

TABLE 4: Comparison of self-rating and proxy-rating.

Scale	Characteristics	Patient mean t-score (SD) n = 20	Significant other mean t-score (SD) n = 20	Difference between the mean two-tailed p values	Intraclass correlation (ICC)	p value of ICC	Level of clinical significance
Syndrome scales	Anxiety and depression	55.40 (6.73)	55.00 (5.62)	0.762	0.573	0.003	Fair
	Withdrawal	56.60 (8.57)	55.00 (6.95)	0.376	0.492	0.010	Fair
	Somatic complaints	55.55 (5.35)	55.50 (5.41)	0.948	0.813	<0.001	Excellent
	Thought problems	53.70 (6.34)	54.40 (5.74)	0.654	0.370	0.046	Poor
	Attention problems	56.80 (5.60)	57.55 (4.99)	0.541	0.495	0.010	Fair
	Aggressive behavior	53.45 (5.57)	54.15 (4.67)	0.423	0.727	<0.001	Good
	Rule-breaking behavior	53.10 (3.99)	54.20 (4.05)	0.248	0.464	0.015	Fair
	Intrusive behavior	52.35 (4.34)	53.15 (5.52)	0.405	0.646	0.001	Good
Combined scales	Internalizing	52.90 (10.80)	52.25 (9.82)	0.756	0.617	0.001	Good
	Externalizing	48.15 (8.62)	50.90 (7.45)	0.149	0.461	0.016	Fair
	Total problems	48.90 (9.24)	50.65 (8.36)	0.367	0.541	0.005	Fair
	Critical items	55.50 (6.05)	55.85 (5.28)	0.759	0.624	0.001	Good
	Personal strength	46.35 (10.81)	46.55 (7.20)	0.941	0.103	0.326	Poor

SD: standard deviation.

TABLE 5: Comparison between responder and nonresponders (contacted sample $n = 80$).

Patients characteristic	Mean (SD)	<i>p</i> value
<i>PTA (in days)</i>		
Responding ($n = 35$)	42.8 (29.3)	0.459
Nonresponding ($n = 44$)	43.8 (40.0)	
<i>Age at injury (in years)</i>		
Responding ($n = 36$)	18.0 (1.8)	0.441
Nonresponding ($n = 44$)	17.7 (2.1)	
<i>Age at participation (in years)</i>		
Responding ($n = 36$)	24.1 (4.1)	0.806
Nonresponding ($n = 44$)	24.3 (4.3)	
<i>Gender</i>		
Responding ($n = 36$)	Male 27 (75%) Female 9 (25%)	
Nonresponding ($n = 44$)	Male 36 (79.5%) Female 9 (20.5%)	

PTA: posttraumatic amnesia; SD: standard deviation.

versus nonresponders' level of injury which might influence their ability to reply.

Spearman correlations were carried out, and a significant negative correlation was found only between the time since injury and the subscales of anxiety and depression ($rs = -0.388, p = 0.019$).

We compared duration of PTA and the age and the ratio of male and female in the group of subjects who responded to the participation invitation against those subjects who did not respond to the participation invitation during our follow-up. Our results showed that there was no significant difference between the PTA, age at injury, and age at participation. Only slight differences in the ratio of male and female were found (Table 5). Consequently, there was no indication that the nonresponders had more severe injuries than the group who completed the study material.

5. Discussion

This study investigated problems that are perceived by young individuals with severe TBI and their SOs by using a cross-informant comparison of psychological functioning. Our findings suggest that young patients perceive themselves to have significantly more psychological problems when compared to the normative sample. The comparison between the self-rating and the proxy-rating scores demonstrated good and excellent agreement in overt domains and fair to poor agreement in nonovert domains.

5.1. Psychological Outcome. Significant differences between the self-rating scores and the normative sample were identified. The participants expressed that they experienced withdrawal, attention, and internalizing problems, with means for these domains being significantly higher. Patients also reported a significantly lower mean of intrusive behavior

when compared to the normative sample. The findings also indicate that the young patients perceive more psychological difficulties than their SOs detect because the SOs only reported significantly higher scores in one subscale, attention, when compared to the normative sample. This discrepancy may suggest a risk for the young former patients who experience problems but do not notify their closest relative of the intensity of their experiences. The differences in the ratings could also be due to overestimation of the problems by the young patients, as they might be accustomed to reporting their impairments and difficulties after injury, whereas parents may tend to underestimate and normalize the situation.

5.2. Agreement. An excellent level of agreement between former patients and their SOs in the somatic complaints subscale is not surprising, as physical impairments are more likely to be overt and more noticeable by the SOs. Patients are more likely to communicate somatic problems, since these difficulties can be named specifically, such as pain or physical discomfort. The good agreement in aggressive behavior subscale was also expected, as these issues might directly affect the SOs. A fair level of agreement was found in subscales addressing nonovert and passive behavior of individuals such as withdrawal and attention problems. Poor agreement was found in the subscales of thought problems and personal strength.

The proxy-rating scores for the categories of thought problems and personal strength were high when compared to the patients' corresponding self-rating scores. The lower agreement between SOs and patients supports the conclusion that these two domains are nonovert and therefore less visible to SOs. Consequently, it might be difficult for SOs to estimate the intensity of problems experienced by patients in the two nonovert domains of thought problems and personal strength. These results are also consistent with Hart et al. (2003), who stated that questions about physical abilities tend to yield more agreement than those regarding emotional or cognitive status [24, 33].

Within the combined scales, which consisted of several subscales, internalizing demonstrated a better agreement (good) than externalizing (fair). This was in contrast to our expectations, since internalizing behaviors are attributed to one's self and are often more difficult to observe than externalizing behavior such as aggression or substance abuse [33]. However, the symptoms of internalizing problems, such as depression, are known in society and are therefore more easily recognized when compared to externalizing behavior such as rule-breaking behavior.

Our study's findings also demonstrated a difference between self-reported and proxy reported mean scores in the combined scale of externalizing behavior. The proxy-rating scores showed an overall higher mean value than the patient's self-rating scores for externalizing behaviors. This finding suggests that the SOs identify more problems in this domain than the former patients are aware of.

It was also surprising that our study found a poor agreement between self-rating and proxy-rating results for

the subscale of personal strength. The items used to measure personal strength encompassed the social environment of the former patients in domains such as friends, job, education, spouse, and family. This disagreement may be explained by decreased SO insight within those domains (e.g., job) but also by impaired self-awareness of the patient, which is common in TBI survivors.

An investigation of the agreement between outcome measures, as reported by proxy-rating and self-ratings in the chronic phase after TBI, has previously been studied by Rosema et al. (2014) using the ASEBA measures [23]. Rosema et al. conducted a study on 33 patients after mild, moderate, and severe childhood TBI (mean age 4.70 years, SD = 1.7 years) around 16 years after injury. An overall higher level of agreement was found within our current sample compared to their study. In Rosema et al.'s findings, an excellent agreement between the former patients and their SOs was only found in the scale of substance abuse. A fair agreement was noted in somatic complaints, externalizing, and total problem measurements. Finally, a poor agreement was documented in anxiety and depression, withdrawal, thought problems, attention problems, aggressive behavior, rule-breaking behavior, and internalizing. In conclusion, Rosema et al.'s findings showed a similar poor agreement for the overall internalizing symptoms; however, the difference between our results and Rosema et al. might very well be caused by the severity of injury received by the former patients. During our study, only severe cases were included; therefore, the level of support and the need for caregiving may have been higher. Consequently, the patients in our study might be more attached to their parents and share more of their daily life with them. This closer connection could have led to the parents possessing a better insight into the patient's current situation. Additionally, in Rosema et al.'s study, the research follow-up occurred after a longer period of time following the initial injury. Therefore, the patients may have gained more insight and therapy regarding their difficulties during this extended time following their injury. Finally, another reason for the higher agreement in our study may be explained by an older age at the time of injury. Varni et al. showed a trend toward higher intercorrelations with an increase in age. This phenomenon could possibly be explained by the greater verbal communication skills that are typically manifested with increased developmental age [34].

Using the Sydney Psychosocial Reintegration Scale for Children (SPRS-C) and the Pediatric Quality-of-Life Inventory 13–16 years following injury, Green et al. (2012) found excellent agreements in parent-adolescents ratings regarding the psychosocial outcome and quality of life after childhood TBI. Their sample consisted of 16 pairs of former patients and parents after a mild, moderate, and severe pediatric TBI. The authors concluded that parents could act as potentially accurate substitutes for rating the psychosocial outcome [22]. These results are very consistent with the results of our study, although Green et al.'s participants were significantly younger at the time of injury and the TBI severity was heterogeneous.

Most research on agreement between proxy-reporting and self-reporting systems has addressed adults. Hart et al. (2003) found agreement rates for neurobehavioral

functioning between adult individuals with TBI and their SOs one year after injury to be moderately high. In the domains of aggression and depression, however, there was relatively low agreement between the proxy- and self-reporting systems [35].

The results of Dawson et al. regarding the community integration outcome showed a high level of agreement between proxy- and self-reports with respect to objective subscales, such as frequency of participation. However, a lower level of agreement between the reports was found for the more subjective scales, such as expectation and satisfaction with patient participation. Dawson et al.'s findings suggest that the use of proxy data for research purposes is acceptable, but a twofold assessment, including both patient and proxy evaluations, should be used to create goals and evaluate their outcomes [25].

Dawson et al. also reported lower proxy agreement for adult survivors who have sustained more severe TBIs [25]. This is in contrast to our findings where a sample of exclusively severe TBI patients produced an overall good agreement, compared to a sample of mixed severity (mild, moderate, and severe TBI victims) by Rosema et al. (2014) producing a lower level of agreement.

Overall, the high accordance showed that the perception of the psychological and behavioral functioning was very close in the patients and their SOs. Empirical findings supported an association between higher levels of self-awareness and better outcome [36]. However, an agreement demands not only the high self-awareness on the former patients' side, but also the ability for empathic and objective appraisement on SOs' side.

Not only have personal aspects contributed to the level of agreement, but it should also be noted that more specific survey items tend to elicit higher levels of agreement between patient and family member perceptions [21]. This might have contributed to our study's high level of agreement, since the ARS 18–59 and ABCL 18–59 mainly consist of very specific items.

5.3. Methodological Limitations. The single-center design is an obvious limitation of the present study, along with the relatively small sample size. Small sample sizes are a well-known and common problem in the TBI literature [22, 23, 37].

Since all former patients of the past 13 years who met the inclusion criteria were contacted, the time span after injury varies from one to 13 years. Participants with a longer time gap between the injury and the time of participation had more time to adjust to the new situation, define a new life, and receive more rehabilitation interventions. Hence, patients may perceive less psychological problems if interviewed at a more distant time since the original injury. On the other hand, a longer time since injury could also lead to more problems developing over time. However, after analyzing the data, no differences were found in the psychological outcome in relation to the time since injury, except in the categories of anxiety and depression, where higher scores were found in persons with longer time since injury.

The length of time to complete the follow-up survey might have influenced the response rate. The longer it takes to answer a survey, the more likely the response rate decreases. The ASR 18–59 and the ABCL 18–59 are quite complex and require a certain motivation and time effort for the former patients and their SOs to complete the survey. This could have led some participants to not complete the material. However, the returned questionnaires were filled out in a thorough manner, showing a very low rate of missing values. This fact supports the choice of the instruments for this study.

A further limitation was that no Danish norms for the measures existed, and therefore a comparison with the Danish population was not possible. North American norms were used for the ASR-18–59, with cognizance of existing cultural differences and the different welfare systems. However, the common procedure when using the ASEBA material is to use North American norms.

6. Clinical Implications and Future Studies

Despite the abovementioned limitations, the findings have important clinical implications. In order to support former patients in the chronic phase, it is of prominent importance to fully evaluate individuals' problems and impairments. Objective ratings assessing a patient's scope of psychological functioning are necessary. As mentioned, overt areas of psychological functioning demonstrated high consensus between self-rating and proxy-rating reports, thus indicating that either assessment could be used in isolation. Nonovert areas showed lower consensus, suggesting the importance of considering both self-rating and proxy-rating scores when assessing patient difficulties. Finally, regarding a long-term view, it is of prominent importance to obtain a thorough appraisal of the patients' psychological well-being. Ownsworth and Clare (2006) stated that greater awareness of deficits is associated with better treatment outcomes [36].

Future research should be performed on larger samples and with a repeating measure design to observe changes in agreement over time. More research is also needed to investigate factors that may influence agreement levels. By continuing to understand how factors influence psychological assessment systems, professionals will be able to better choose whether a self-rating or proxy-rating system would be more appropriate for the condition being evaluated. Future studies could also explore and evaluate the effects of using a dyadic perspective throughout rehabilitation. Reaching a high level of agreement could be used as a rehabilitation goal of patients and their families.

7. Conclusion

One purpose of this study was to evaluate the level of agreement between self-rated psychological outcome scores of former adolescent TBI patients, compared to their corresponding SOs' proxy-rating scores. Our findings suggest that the exclusive use of either a self-rating or a proxy-rating system would be appropriate for evaluating overt domains of psychological functioning. However, in the nonovert

domains of psychological functioning, it may be beneficial to obtain both a self-rating score from the patient and a proxy-rating score from a significant other. The combination of the self-rating and proxy-rating scores for the nonovert domains may provide additional information to build a more complete objective assessment. Our results also suggest that extended follow-up after TBI is a positive way to support former patients and their significant others as they struggle with psychological difficulties.

Disclaimer

The authors alone are responsible for the content and writing of the paper.

Conflict of Interests

The authors have no conflict of interests to report.

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Research Article

Life after Adolescent and Adult Moderate and Severe Traumatic Brain Injury: Self-Reported Executive, Emotional, and Behavioural Function 2–5 Years after Injury

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Survivors of moderate-severe Traumatic Brain Injury (TBI) are at risk for long-term cognitive, emotional, and behavioural problems. This prospective cohort study investigated self-reported executive, emotional, and behavioural problems in the late chronic phase of moderate and severe TBI, if demographic characteristics (i.e., age, years of education), injury characteristics (Glasgow Coma Scale score, MRI findings such as traumatic axonal injury (TAI), or duration of posttraumatic amnesia), symptoms of depression, or neuropsychological variables in the first year after injury predicted long-term self-reported function. Self-reported executive, emotional, and behavioural functioning were assessed among individuals with moderate and severe TBI ($N = 67$, age range 15–65 years at time of injury) 2–5 years after TBI, compared to a healthy matched control group ($N = 72$). Results revealed significantly more attentional, emotional regulation, and psychological difficulties in the TBI group than controls. Demographic and early clinical variables were associated with poorer cognitive and emotional outcome. Fewer years of education and depressive symptoms predicted greater executive dysfunction. Younger age at injury predicted more aggressive and rule-breaking behaviour. TAI and depressive symptoms predicted Internalizing problems and greater executive dysfunction. In conclusion, age, education, TAI, and depression appear to elevate risk for poor long-term outcome, emphasising the need for long-term follow-up of patients presenting with risk factors.

1. Introduction

Adolescents and adults surviving moderate and severe Traumatic Brain Injury (TBI) often experience long-lasting cognitive, emotional, and behavioural problems [1–4]. In particular executive dysfunction has been demonstrated to have a profound impact on the ability to resume education, employment, and independent living [5–7]. Further, TBI is associated with an increased risk of developing symptoms of psychiatric disorders such as depression [8], anxiety [9], substance abuse [10], personality problems [3, 11], and behavioural changes such as aggression [12, 13]. All of those symptoms affect reintegration into the community [14], and therefore it is of great importance to identify those at risk for poorer long-term outcomes.

Executive function is a complex, overarching concept that refers to all functions related to goal-directed regulation of thoughts, actions, and emotions, including problem-solving, monitoring ongoing operations, switching between operations, emotion regulation, initiation of behaviour, and inhibition of nonadaptive behaviour [15, 16]. While some components of executive functions such as monitoring and switching cognitive operations may be assessed by standardized neuropsychological tests, other aspects such as regulating emotions and actions which are often more detrimental to adaptive functioning are often not captured by such tests [16, 17] and are better measured by questionnaires [18]. Further, the relationship between self-reported and performance-based executive function after TBI is far from established [19, 20].

Several self-report inventories have been developed aiming to assess not only the goal-directed regulation of thoughts, but also regulation of actions and emotions. Studies have demonstrated significant changes in self-reported executive function after TBI related to the individuals overall ability to regulate thoughts, emotions, and behaviour [21, 22]. However, there is a further need for studies utilizing more fine-tuned assessment tools providing more detailed profiles of typical executive problems after TBI. Although descriptions of typical profiles of self-reported executive problems have been examined as long as 10 years after childhood TBI [23, 24], there are no previous studies that have investigated such long-term consequences of TBI sustained in adolescence and adulthood.

Previous research has shown that a broad assessment is necessary to capture the variety of emotional and behavioural problems that persons may experience after TBI, including both Internalizing emotional problems such as depression or anxiety as well as Externalizing problems such as aggressive behaviour [1, 9, 13, 25]. In fact, compared with the general population, a substantially larger proportion of individuals with TBI qualify for an Axis I diagnosis according to DSM-IV, with depression, anxiety, and substance abuse most commonly observed [9, 18]. However, people with TBI may also experience a greater degree of subclinical symptoms compared to healthy individuals, which are better captured by questionnaires [18, 26]. Furthermore, while studies have described self-reported symptoms of depression [27],

anxiety [28], and aggression [12] after TBI previously, there is a paucity of studies investigating Internalizing and externalizing simultaneously following TBI sustained in adolescence and adulthood.

Assessing cognitive, emotional, and behavioural changes after TBI using self-report gives access to unobservable, internal experiences to which only the person with TBI is privileged. A number of adult TBI studies have shown reasonable correspondence between self-report and family report [4, 29, 30]. However, it has been suggested that persons with severe injuries may underreport their problems which is hypothesised to be caused by reduced self-awareness or insight [31]. Nevertheless, the appropriateness of using proxy reports from family has been debated in the broad psychology literature, in particular for children and adolescents [32, 33], suggesting the possibility that family report reflects their own distress rather than that of the person with TBI [34, 35]. Further, it has been shown that the persons' own perception of their problems may influence how well they manage to reintegrate into the community [6, 36, 37]. Taken together, these findings warrant a focus on descriptions of typical self-reported problems as it could inform clinicians as to which symptoms should be targeted during rehabilitation and to inform general clinical decision making.

When considering possible predictors of self-reported executive problems after TBI sustained in late adolescence and adulthood, association has been found with length of education [38], lesion localization [29], Glasgow Coma Scale (GCS) score [39, 40], and concurrent emotional status (i.e., depression) [39]. However, to our knowledge reports of an association between long-term self-reported executive problems after a TBI sustained in adolescence and adulthood and duration of PTA and traumatic diffuse axonal injury (TAI) are lacking. Executive functions rely upon network interactions between several cortical, subcortical, and cerebellar brain regions [16, 41, 42], leaving them vulnerable to traumatic axonal injury (TAI) as a consequence of TBI [43–45]. Detecting TAI *in vivo* has been challenging, and it has further been demonstrated that valuable information about the magnitude of TAI may be lost if MRI is not performed in an early phase after injury [46]. While no relationship has been found between white matter integrity and concurrent self-reported executive function in the chronic phase after moderate and severe TBI utilizing diffusion tensor imaging (DTI) [47], better self-reported executive function in the chronic phase after moderate-to-severe TBI has been associated with compensatory brain activations as measured with functional magnetic resonance imaging (fMRI) [48]. However, no previous studies have investigated associations between self-reported executive function in the chronic phase and TAI as detected by clinical MRI in the early phase.

Associations with self-reported emotional and behavioural change after TBI are equally complex. Development of depression and anxiety after TBI has been observed to be associated with low socioeconomic resources (i.e., fewer years of education) [9, 25], while aggression and antisocial personality problems have been found to be associated with age [9, 26]. Evidence of associations between injury severity and

later neuropsychiatric problems has been conflicting [9, 18, 49, 50], with some studies reporting no association at all [51]. Furthermore, the occurrence of mood disorders has been related to dysfunction in neural circuits involving cortical and subcortical structures [52], but only a few of those studies have included magnetic resonance imaging (MRI) findings [53, 54] and reviews in the field are inconclusive [9, 18].

This study addresses the gaps in the previous literature by investigating long-term cognitive, emotional, and behavioural self-reported outcomes after moderate and severe TBI sustained in adolescence and adulthood by utilizing fine-tuned tools assessing a broad range of possible symptoms; providing methodologically sound methods such as prospective recruitment, comparisons to a large, matched control group; and providing high quality imaging methods for assessing the impact of TAI. The aims of this study were to (1) investigate long-term self-reported executive, emotional, and behavioural function after moderate-to-severe TBI sustained in late adolescence and adulthood and (2) to explore the association between demographic, injury-related, psychological, global outcome, and neuropsychological factors, as obtained in the postacute phase and later self-reported problems. We hypothesised that persons with TBI would report more overall problems with executive function as well as more symptoms of emotional and behavioural problems than healthy individuals 2–5 years after the injury. Based on previous literature using fine-tuned tools such as the Behaviour Rating Inventory of Executive Function-Adult version (BRIEF-A) [30, 38], we expected that problems with problem-solving [30] and working memory [38] would be among the most frequently reported executive cognitive problems. Moreover, we hypothesised that symptoms of depression, anxiety, and aggression would be frequently reported 2–5 years after injury. As the literature shows conflicting evidence of the impact of injury-related measures [39, 40, 47, 51, 53, 54], we specifically investigated the predictive value of injury severity measures such as GCS score, length of PTA, and TAI as detected by MRI in the early phase after TBI. While concurrent emotional status has been demonstrated to affect self-report [29, 55], we wished to extend previous findings by examining whether emotional status during the first year after injury could affect self-report as long as 2–5 years after injury. Based on previous findings [39, 40, 53], we hypothesised that measures of injury severity would be negatively associated with long-term self-reported executive, emotional, and behavioural function. Finally, we explored whether age at injury, length of education, performance-based cognitive function, global function as well as emotional status could explain some of the variance in outcome variables.

2. Methods

2.1. Study Design and Participants. From October 2004 to July 2008, 236 consecutive patients with moderate and severe TBI according to the Head Injury Severity Scale (HISS) criteria [56] were admitted to the Department of Neurosurgery at St. Olavs Hospital, Trondheim University Hospital, Norway, and registered in a database. Five did not consent to any follow-up. Participants registered in this database

were contacted between February 2009 and August 2010 if they were more than one year after injury and fulfilled the inclusion criteria: (1) 15–65 years of age at the time of injury; (2) fluency in Norwegian; and (3) Glasgow Outcome Score Extended (GOSE) ≥ 5 at time of assessment (follow-up). Exclusion criteria were ongoing or preinjury substance abuse, neurological or psychiatric conditions, or previous moderate-to-severe TBI.

Of the 231 patients in the database, 51 died, and 40 were outside the age range. Forty-five were excluded because of premorbid or ongoing illness endorsed in the unstructured clinical interview during the hospital stay after the injury ($n = 28$), being not fluent in the Norwegian language ($n = 4$), and GOSE scores < 5 ($n = 13$). This left 95 patients eligible for this study, of which 74 (78%) consented to a single follow-up assessment between 2 and 5 years after injury. Seven were excluded from analysis owing to invalid questionnaire completion. This left 67 TBI survivors for the full analysis. There were no differences in the distribution of age, gender, education, or injury severity between participants and nonparticipants. Description of patient selection and nonparticipants as well as timeline is described in the flowchart in Figure 1.

Forty-nine patients (injured October 2004–October 2007) consented to participate in a study on longitudinal cognitive outcome with neuropsychological assessment and screening for depressive symptoms 3 and 12 months after injury, as well as participating in the follow-up study 2–5 years after injury. Eighteen participants (injured October 2004–October 2008) consented to participate in the 2–5 years after injury follow-up study, but not to participate in the assessments at 3 and 12 months after injury. There were no differences in the distribution of age, gender, education, or injury severity between the persons participating in the neuropsychological assessment + follow-up compared to those participating only in the follow-up, except that a larger proportion of participants in the first group had PTA durations of > 1 week (Pearson's Chi-square, $p = 0.042$). There were no differences between the participants as a whole group compared to the nonparticipants.

Sex-, age-, and education-matched healthy control participants were recruited from the family and friends of the patients with TBI, hospital employees, and through advertisement. Six of 78 recruited controls were excluded because of previously diagnosed psychiatric or neurological conditions (discovered on the day of testing, $n = 3$) or invalid completion of the forms ($n = 3$). As a result, 72 control participants were included.

2.2. Material and Procedures. Figure 2 describes the timeline for the various measures.

2.2.1. Long-Term Outcome Measures (2–5 Years after Injury). Participants completed questionnaires that assessed self-reported executive, emotional, and behavioural problems at follow-up (mean 2.9 ± 0.9 years after injury, range: 2–5 years after injury). A few participants were unable to complete all questionnaires. While 17 (25%) of the participants were between 15 and 18 years of age at the time of injury

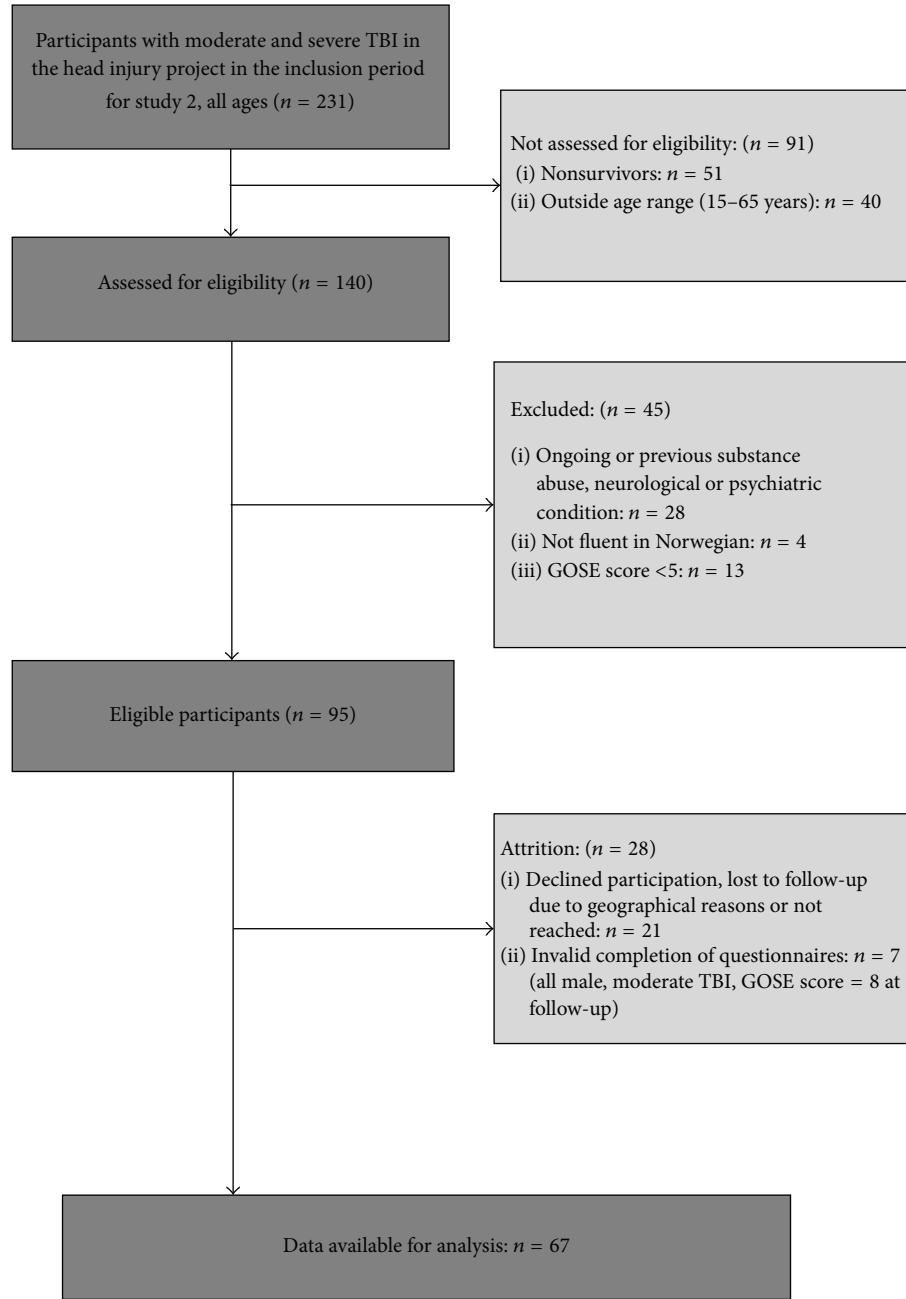


FIGURE 1: Flowchart illustrating sample selection and description of nonparticipants.

(adolescents), all but one participant were ≥ 18 years of age when completing the questionnaires at follow-up 2–5 years after injury and one was 17 years old. We used a self-report form and an interview to estimate the number of years of education completed at the time of follow-up.

2.2.2. Self-Reported Executive Function. Self-reported executive function was assessed with the BRIEF-A questionnaire, which consists of 75 items that measure behavioural, emotional, and cognitive aspects of executive function. It features sound psychometric properties [57, 58], good reliability, and large-scale norms [17, 58]. Each item is rated on a three-point

frequency scale (0 = never; 1 = sometimes; 2 = often). Five items are designed to detect invalid response styles (inconsistencies or negativity). Seventy items generate three composite index scores and nine subscale scores. The subscales Inhibit, Shift, Emotional Control, and Self-Monitor generate the Behaviour Regulation Index (BRI), while the subscales Initiate, Working Memory, Plan/Organize, Task Monitor, and Organization of Materials constitute the Metacognitive Index (MI). In addition, a Global Executive Composite (GEC) is calculated from all 70 items. The BRIEF-A reference manual classifies the clinical range as T -score ≥ 65 , with higher scores indicative of poorer function. The technical manual classifies

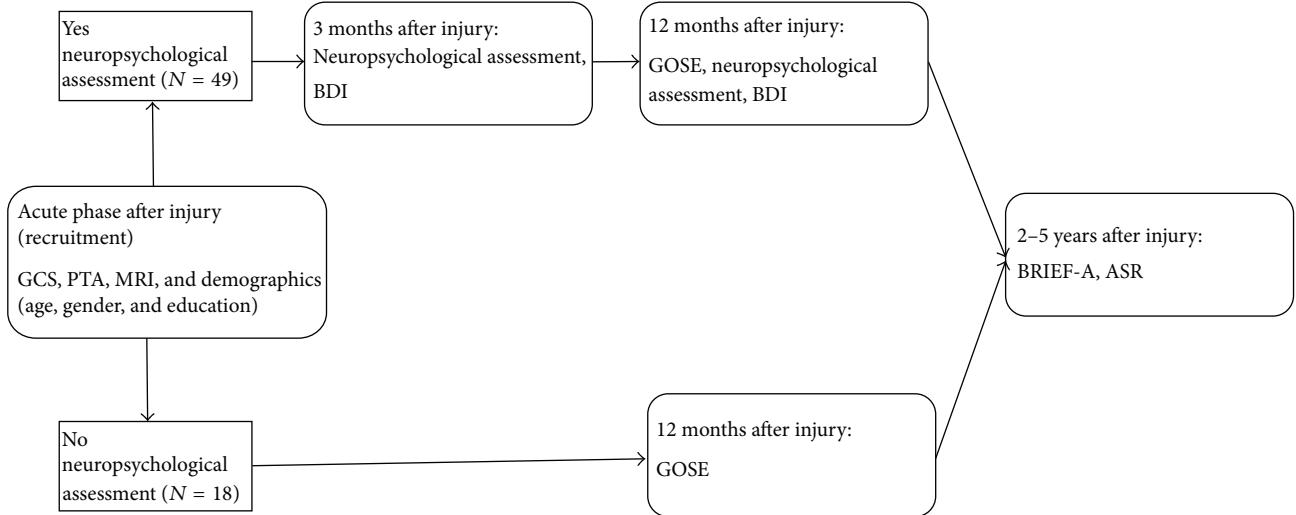


FIGURE 2: Timeline displaying the time points during data collection and the assessments for this study.

a score on the negativity scale of >4 and a score on the inconsistency scale as >7 as an invalid report. Any reports that were classified as invalid according to these criteria were excluded from further analysis.

2.2.3. Self-Reported Emotional and Behavioural Problems. Self-reported emotional and behavioural problems were assessed with the ASEBA: Adult Self-Report (ASR) Form [59]. The ASR consists of one section that measures adaptive functioning (38 items) and one section that measures emotional and behavioural problems (126 items) on a three-point scale (0 = statement not true; 1 = statement sometimes true; 2 = statement very true). Eight syndrome scales are generated: anxious/depressed, withdrawn, somatic complaints, thought problems, attention problems, aggressive behaviour, rule-breaking behaviour, and intrusive behaviour. The form yields three composite scores: Total problems, Internalizing problems (sum of the scales anxious/depressed, withdrawn, and somatic complaints), and Externalizing problems (sum of the scales aggressive, rule-breaking, and intrusive behaviour). The form also yields six DSM-IV-oriented scales: depressive, anxiety, somatic, avoidant personality, attention deficit hyperactivity disorder (ADHD), and antisocial personality problems. Items considered critical to diagnostic categories in the DSM-IV constitute the critical items scale. The ASEBA reference manual [59] recommends using raw scores when presenting descriptive data and borderline range using T -scores as the threshold in research (clinical cut-off) with higher scores indicative of poorer function. The clinical range is classified as T -score ≥ 70 and the borderline range is classified as T -score ≥ 65 for the syndrome scales; the respective ranges are classified as T -score ≥ 63 and ≥ 60 for the composite scales [59]. The subscales inattention and hyperactivity/impulsive are set at ≥ 97 th percentile and ≥ 93 rd percentile, respectively.

2.3. Measures of Predictors of Long-Term Outcome (at Injury and 12 Months after Injury)

2.3.1. Injury-Related Variables: GCS Score, PTA, and Presence of TAI on Early MRI. GCS score was recorded at or after admittance if the patient deteriorated or before intubation in cases of prehospital intubation. GCS scores of 9–13 were classified as moderate TBI and scores ≤ 8 were considered severe TBI [56, 60]. Duration of PTA was categorized as ≤ 1 week or >1 week. The presence of TAI was assessed from the earliest MRI (1.5 Tesla) examination performed at median 10 days after injury (range = 1–120 days). The scan protocol included T1- and T2-weighted sequences, a $T2^*$ -weighted gradient echo sequence, fluid-attenuated inversion recovery (FLAIR) sequences, and diffusion-weighted imaging. MRI parameters and the evaluation procedure have been reported in previous studies [61, 62].

2.3.2. Global Function 12 Months after Injury. Global TBI related outcome was assessed with the Glasgow Outcome Scale Extended (GOSE) [63] structured interview at 12 months after injury for all participants recruited from the initial data base ($n = 66$).

2.3.3. Subgroup Analyses: Neuropsychological and Emotional Assessment. The subgroup was assessed at 3 months after injury, with performance-based neuropsychological tests grouped into cognitive domains covering processing speed [64, 65], attention [66], memory [67–69], and executive function [65, 70]. Table 1 displays the cognitive domains and neuropsychological tests used. Raw scores were converted to T -scores applying normative data provided by the test manufacturers, except for the Symbol Digit Modality test in which a normative sample quoted by Lezak et al. [71] was used. Standardized scores on the individual neuropsychological tests were grouped into composite scores for each

TABLE 1: Overview of performance-based neuropsychological tests assessing cognitive function in the subsample grouped into cognitive domains 3 months after TBI.

Neuropsychological tests		Reference
<i>Motor function</i>		
Grooved Pegboard	Dominant hand	[63]
<i>Information processing speed</i>		
Delis Kaplan Executive Function System	(D-KEFS)	
Trail Making Test	Condition 2 (number sequencing) Condition 3 (letter sequencing)	(TMT) [65]
Color-Word Interference Test	Condition 1 (color naming) Condition 2 (word reading)	(CWIT)
Symbol Digit Modality Test	Oral version Written version	(SDMT) [64]
<i>Attention</i>		
Conners' Continuous Performance Test II		(CPT-II) [66]
<i>Visual memory</i>		
Continuous Visual Memory Test		(CVMT) [69]
Rey-Osterrieth Complex Figure Test		(ROCF) [68]
<i>Verbal memory</i>		
California Verbal Learning Test-II		(CVLT-II) [67]
<i>Executive function</i>		
Wisconsin Card Sorting Test computer version		(WCST) [70]
Verbal Fluency Test (D-KEFS)	Condition 1 (letter fluency), Condition 3 (category change)	
TMT (D-KEFS)	Condition 4 (number-letter sequencing)	[65]
CWIT (D-KEFS)	Condition 3 (inhibition) Condition 4 (inhibition/switching)	
Tower Test (D-KEFS)		

cognitive domain. *T*-scores were used in the analysis. These tests have demonstrated adequate validity and reliability [71]. The Vocabulary and Matrix Reasoning subtests of the Wechsler Abbreviated Scale of Intelligence (WASI) were used to estimate IQ [72]. Depressive symptoms were assessed with the Beck Depression Inventory (BDI) at both 3 months ($n = 47$) and 12 months ($n = 44$) after injury [73].

2.4. Ethics. The Regional Committee for Medical Research Ethics approved the study protocol. Written consent was obtained from patients aged ≥ 16 years at injury and from both participants and their parents if patients were aged < 16 years at injury.

2.5. Statistical Methods. Demographic characteristics, injury severity characteristics, and the different cognitive domains are presented as mean (\pm standard deviation, SD) for normally distributed data, and otherwise as median with interquartile range (IQR; 25th to 75th percentile). For missing data, we used available case analysis, utilizing all cases for which the variables were present. We reported 95% confidence intervals (CIs) where relevant, and two-sided *p* values < 0.05 were considered statistically significant. *p* values between 0.01 and 0.05 should be interpreted with caution owing to multiple

hypotheses. Statistical analyses were performed with SPSS 18.0.

To describe differences in function between persons with TBI and controls, independent samples *t*-tests based on 2000 bootstrap samples were used. The Kruskal-Wallis test and Mann-Whitney *U* test were used for nonnormally distributed data. Effect sizes were calculated as Cohen's *d* based on pooled variance (d_{pooled}) [74]. Cohen defined *d* of 0.8 as large, 0.5 as medium, and 0.2 as small effect sizes [75]. Differences in proportions were compared using the Chi-squared test, the unconditional *z*-pooled test [76], and the Newcombe confidence interval [77, 78].

To test associations between outcome measures and predictors, linear regression analyses were performed with composite scores from BRIEF-A and ASR as dependent variables; preinjury variables, injury-related variables, and GOSE scores were employed as covariates. In the subgroup analyses, neuropsychological test scores at 3 months after injury and BDI were employed as covariates. These covariates were included separately and then adjusted for age at injury and length of education at follow-up. An additional linear regression analysis was performed with main indexes and composite scores from BRIEF-A and ASR as dependent variables and the presence of TAI employed as a covariate

TABLE 2: Description of participants: demographics, injury severity characteristics, and clinical observations at 1 and 2–5 years after moderate and severe TBI: global outcome and employment.

Variable	n	Persons with TBI	n	Controls	p value
<i>Demographics at injury</i>					
Male sex (n, %)	67	48 (72)	72	55 (76)	0.593*
Age (mean, range)	67	29 (15–63)			
<i>Injury-related variables</i>					
Mechanisms of injury	67				
Traffic accident (n, %)		33 (49)			
Fall (n, %)		27 (40)			
Ski accident (n, %)		2 (3)			
Other (n, %)		5 (9)			
GCS score (median, IQR)	67	9 (7)			
HISI grade; moderate TBI (n, %)	67	39 (58)			
PTA <1 week (n, %)	66	37 (55)			
Early MRI findings	65				
EDH only (n, %)		1 (2)			
Pure TAI (n, %)		17 (25)			
Cortical contusions (n, %)		16 (24)			
Cortical contusions/TAI (n, %)		30 (45)			
<i>Global outcome 12 months after injury</i>					
GOSE score (median, IQR)	66	7.0 (2)			
<i>Demographics at follow-up</i>					
Age (mean, range)	67	32 (17–65)	72	33 (13)	0.683†
Years after injury (mean, SD)	67	2.9 0.8			
Years education (mean, range)	67	12 (9–18)	72	12 (2)	0.979†
Occupation	67		72		0.025‡
Unemployed/no school (n, %)		12 (18)		4 (6)	
Employed or at school (n, %)		55 (82)		68 (94)	

GCS: Glasgow Coma Scale; GOSE: Glasgow Outcome Scale Extended; IQR: interquartile range; PTA: posttraumatic amnesia; SD: standard deviation; TAI: traumatic axonal injury; TBI: Traumatic Brain Injury.

* Pearson's Chi-squared test.

† Independent samples t-test.

‡ Unconditional z-pooled test.

with adjustment for BDI. Pearson's correlation coefficient (r) was used to analyse associations between the main indexes on BRIEF-A and the symptom scales on ASR.

3. Results

Participant characteristics are presented in Table 2 for the full sample and in Table 7 for the subsample. Individuals with TBI and healthy controls did not differ regarding distribution of sex, age at testing, or years of education. Participants with TBI assessed at 3 months after injury exhibited significantly lower estimated IQ and reduced processing speed, memory, and executive function compared with controls. At 2–5 years after injury a higher proportion of individuals with TBI neither worked nor attended school (18%) compared with controls (6%, difference in proportions: 12%; $p = 0.03$).

3.1. Self-Reported Executive Function 2–5 Years after Injury.

Individuals with TBI reported more problems on all three composite indexes of BRIEF-A (GEC, BRI, and MI) than

healthy controls (Table 3). Effect sizes were in the moderate range (0.38–0.66). More respondents with TBI (18%) reported symptoms in the clinical range on the GEC (difference in proportions: 17%, $p < 0.001$), BRI (8%; difference in proportions, 7%; $p = 0.02$), and MI (20%; difference in proportions, 18%; $p < 0.001$). On the BRI subscales, participants with TBI also reported more difficulties with inhibition, set-shifting, emotional regulation, and self-monitoring, with effect sizes in the medium range. On the MI subscales, individuals with TBI reported more problems with working memory than healthy controls, with 37% reporting working memory problems in the clinical range (difference in proportions, 32%; $p < 0.001$).

3.2. Emotional and Behavioural Outcome 2–5 Years after TBI. On the ASR adaptive scales, respondents with TBI reported significantly fewer personal strengths than healthy controls. They did not differ from controls with regard to problems in their family relationships or friendships. On the composite scales Total problems, Internalizing problems, and

TABLE 3: Self-reported executive function on BRIEF-A at 2–5 years after moderate and severe Traumatic Brain Injury compared to healthy controls*.

BRIEF-A (T-scores)	Persons with TBI n = 67		Controls n = 72		Mann-Whitney test <i>p</i> value	Effect size <i>d</i> [†]
	Mean	SD	Mean	SD		
Global scales						
Global Executive Composite (GEC)	51.40	(11.94)	46.19	(7.28)	0.003	0.53
Behaviour regulation Index (BRI)	50.69	(11.13)	44.51	(7.28)	<0.001	0.66
Metacognitive Index (MI)	51.81	(11.90)	48.02	(7.57)	0.029	0.38
Behavioural and emotional regulation scales						
Inhibit	51.84	(10.57)	47.72	(8.87)	0.014	0.42
Shift	49.52	(11.04)	44.64	(7.01)	0.003	0.53
Emotional regulation	51.61	(11.45)	44.88	(7.81)	<0.001	0.69
Self-Monitor	47.87	(10.70)	44.54	(7.74)	0.039	0.36
Metacognitive Index Scales						
Initiate	51.87	(11.68)	48.61	(9.86)	0.079	0.30
Working Memory	57.48	(13.01)	47.89	(7.91)	<0.001	0.89
Plan/Organize	50.54	(11.00)	47.61	(7.45)	0.071	0.31
Task Monitoring	50.97	(11.90)	48.88	(7.27)	0.217	0.21
Organization of Materials	46.60	(11.54)	48.49	(8.35)	0.268	-0.19

Higher *T*-scores indicate more problems.

*Central tendency and variance given as mean and SD.

[†]Cohen's *d*.

SD: standard deviation.

Externalizing problems, persons with TBI reported significantly more problems compared with controls (Table 4). Effect sizes were in the medium range (0.40–0.68). A greater proportion of individuals with TBI (20%) reported problems in the clinical range on the scales Total problems (difference in proportions, 18%; *p* = 0.002), Internalizing problems (24%; difference in proportions, 16%; *p* = 0.05), and Externalizing problems (14%; difference in proportions, 12%; *p* = 0.016). On the syndrome scales, individuals with TBI also reported more problems with anxiousness/depression, somatic complaints, thought problems, attention problems, and aggressive behaviour than healthy controls. Among the DSM-IV-oriented scales, respondents with TBI reported higher scores for depression, anxiety, somatic problems, and attention problems. They also reported higher scores than controls on critical items (*d*: 0.84).

3.3. Factors Associated with Executive, Emotional, and Behavioural Problems at Follow-Up. Fewer years of education predicted endorsement of greater problems on the GEC and BRI, but not on the MI (Table 5). TAI on MRI during the early phase predicted more problems on GEC and BRI, while GCS score and duration of PTA did not. However, the association between TAI and the GEC and BRI did not reach statistical significance when adjusted for age and education. Neuropsychological test performance at 3 months after injury was not associated with any of the BRIEF-A scales (β ranging from -0.187 to 0.137, *p* > 0.05 for all; see Table 8 for full overview). Depressive symptoms at 3 months after injury predicted metacognitive problems (MI) at follow-up,

while depressive symptoms 1 year after injury predicted later executive problems on all the main indexes. Lower GOSE score at 12 months after injury predicted more problems on all main indexes at follow-up.

Younger age at injury predicted more emotional and behavioural problems at follow-up, particularly regarding Externalizing problems (Table 6). Presence of TAI on early MRI predicted higher scores on ASR Total problems and Internalizing problems. Only the association with Internalizing problems persisted after adjusting for age at injury and length of education. However, the presence of TAI still predicted higher scores on ASR Total problems and Internalizing problems, when adjusting for depressive symptoms 3 months after injury. More depressive symptoms at both 3 and 12 months after injury predicted later high scores on ASR Total problems, and depressive symptoms 12 months after injury predicted both Internalizing and Externalizing problems at follow-up.

Lower GOSE score at 12 months after injury predicted later high scores on both ASR Total problems and Internalizing problems when adjusted for age and education. Neuropsychological test performance at 3 months after injury was not associated with any of the ASR scales (β ranging from -0.086 to 0.588, *p* > 0.05 for all; see Table 8 for full overview).

Concurrent status of employment was not associated with any main BRIEF-A index or ASR composite score (β : -5.151 to 2.954, *p* > 0.05 for all). Patients that reported more problems on the ASR symptom scales also reported more problems on the GEC, with correlation coefficients ranging from 0.327 (thought problems) to 0.823 (attention problems; *p* < 0.001

TABLE 4: Self-reported adaptive function, personal strengths, and psychological problems on ASR at 2–5 years after moderate and severe Traumatic Brain Injury compared to healthy controls.

Adult Self-Report	Persons with TBI <i>n</i> = 66		Controls <i>n</i> = 71		Mean difference (95 % CI) [†]		<i>t</i> -test	Effect size <i>d</i> [‡]
	Mean	SD	Mean	SD	Lower	Upper		
Adaptive scores*								
Personal strengths	16.18	(3.18)	17.39	(3.09)	-2.26	-0.15	0.025	0.39
Mean adaptive	49.61	(5.44)	50.15	(4.32)	-2.21	1.13	0.523	0.11
Relation to friends	9.82	(2.00)	10.00	(1.82)	-0.82	0.46	0.580	0.09
Relation to family	1.57	(0.44)	1.49	(0.37)	-0.06	0.22	0.246	-0.20
Composite scales								
Total problems	39.17	(26.08)	26.13	(16.67)	5.57	20.51	0.001	0.60
Internalizing problems	12.44	(9.81)	7.08	(5.42)	2.64	8.07	<0.001	0.68
Externalizing problems	9.05	(8.59)	6.24	(5.05)	0.40	5.22	0.023	0.40
Critical items	4.95	(3.64)	2.46	(2.22)	1.46	3.52	<0.001	0.83
Syndrome scales								
Anxious/depressed	6.48	(6.29)	3.34	(3.26)	1.43	4.87	<0.001	0.63
Withdrawn	2.27	(2.22)	1.75	(1.93)	-0.17	1.27	0.139	.25
Somatic complaints	3.68	(2.81)	2.00	(2.08)	0.84	2.52	<0.001	0.68
Thought problems	2.09	(2.26)	1.01	(2.25)	0.31	1.84	0.006	0.48
Attention problems	7.73	(5.37)	4.96	(3.72)	1.19	4.32	0.001	0.60
Aggressive behaviour	4.76	(4.55)	2.01	(2.46)	1.49	4.00	<0.001	0.75
Rule-breaking behaviour	2.70	(3.49)	2.21	(2.12)	-0.50	1.47	0.331	0.17
Intrusive behaviour	1.59	(1.96)	2.01	(1.89)	-1.07	0.23	0.200	-0.22
DSM-IV oriented scales								
Depression	5.02	(4.52)	2.70	(2.47)	1.06	3.56	<0.001	0.64
Anxiety	3.12	(2.67)	2.00	(2.00)	0.32	1.92	0.007	0.47
Somatic	2.21	(2.17)	1.30	(1.57)	0.28	1.55	0.005	0.48
Avoidant personality problems	2.32	(2.02)	2.11	(1.88)	-0.45	0.86	0.538	0.11
ADHD problems	7.20	(4.86)	4.85	(3.69)	0.88	3.82	0.002	0.54
Inattention	3.88	(2.81)	2.37	(2.10)	0.67	2.36	0.001	0.61
Hyperactivity/impulsivity	3.32	(2.53)	2.48	(2.21)	0.04	1.64	0.040	0.35
Antisocial personality problems	3.50	(4.44)	2.66	(2.73)	-0.41	2.11	0.182	0.23

Central tendency and variance measured in mean and SD (raw scores). Higher scores indicate more problems.

*Higher scores indicate better function

[†]Results from *t*-test based on 2000 bootstrap samples.

[‡]Cohen's *d*.

ADHD: attention deficit and hyperactivity disorder, CI: confidence interval, DSM-IV: Diagnostic and Statistical Manual of Mental Disorders, 4th edition, and SD: standard deviation.

for all). This pattern held true also for the indexes BRI (*r*: from 0.242 to 0.716, *p* < 0.01 for all) and MI (*r*: 0.283 to 0.816, *p* < 0.001 for all). An exception was ASR intrusive behaviour, which was associated only with BRI (*r*: 0.27, *p* = 0.027), and not with GEC (*r*: 0.20, *p* = 0.112) or MI (*r*: 0.12, *p* = 0.319; see Table 9 for full overview).

4. Discussion

In this large, prospective longitudinal study, our main aim was to delineate the magnitude and profile of chronic problems with executive, emotional, and behavioural function experienced by individuals with moderate-to-severe TBI 2–5

years after injury. As we hypothesised, greater overall self-reported executive problems were found among persons with TBI compared with healthy controls. This was evident both in terms of group differences and the frequency of individuals reporting problems in the clinical range. Further, persons with TBI significantly more often reported feeling sad or depressed compared with healthy controls. However, group differences in emotional and behavioural problems did not always indicate symptoms above the clinical cut-off, supporting emerging findings within the paediatric TBI population [79]. This observation suggests that subclinical executive problems are commonly experienced within the group as a whole, which may add to the total symptom burden for individuals with TBI.

TABLE 5: Demographic and clinical factors during 1st year after injury associated with self-reported executive function (BRIEF-A) 2–5 years after moderate and severe TBI.

	Regression coefficient for worse outcome, unadjusted						Dependent variable		
	Independent variables			Regression coefficient for worse outcome, adjusted*			Estimate	95% CI	<i>p</i> value
	N	R ²	Estimate	95% CI	<i>p</i> value	R ²			
Global Executive Composite									
Age at injury	67	0.049	-0.405	-0.850 to 0.040	0.074				
Years of education at injury	67	0.067	-3.076	-5.934 to -0.219	0.035				
PTA duration (1 week)	66	0.000	-1.103	-11.832 to 14.038	0.856	0.114	-1.273	-14.425 to 11.880	0.847
GCS score	67	0.003	-0.421	-2.279 to 1.437	0.652	0.098	-0.011	-1.861 to 1.838	0.990
Presence of TAI	65	0.063	14.140	0.279 to 28.002	0.046	0.150	10.616	-3.164 to 24.396	0.129
Presence of TAI adjusted for BDI 3 months after injury	48	0.048	12.012	-2.957 to 26.980	0.113				
BDI 3 months after injury	48	0.066	1.442	-0.192 to 3.075	0.082	0.117	1.579	-0.010 to 3.167	0.051
BDI 1 year after injury	45	0.277	2.224	1.105 to 3.343	<0.001	0.337	2.070	0.941 to 3.199	0.001
GOS-E score 1 year after injury	67	0.087	-6.720	-12.161 to -1.279	0.016	0.231	-9.280	-14.945 to -3.615	0.002
Behaviour Regulation Index									
Age at injury	67	0.040	-0.159	-0.352 to 0.033	0.103				
Years of education	67	0.063	-1.277	-2.496 to -0.059	0.040				
PTA duration (1 week)	66	0.003	-1.148	-6.691 to 4.396	0.680	0.109	-1.806	-7.351 to 3.738	0.517
GCS score	67	0.005	-0.229	-1.030 to 0.572	0.570	0.089	-0.069	-0.870 to 0.733	0.864
Presence of TAI	65	0.059	6.677	0.721 to 12.633	0.029	0.143	5.313	-0.648 to 11.275	0.080
Presence of TAI adjusted for BDI 3 months after injury	49	0.129	6.314	0.286 to 12.343	0.040				
BDI 3 months after injury	49	0.043	0.478	-0.195 to 1.152	0.159	0.160	0.546	-0.108 to 1.200	0.099
BDI 1 year after injury	45	0.326	1.046	0.583 to 1.509	<0.001	0.381	0.979	0.513 to 1.443	<0.001
GOS-E score 1 year after injury	67	0.087	-2.910	-5.241 to -0.578	0.015	0.216	-3.954	-6.417 to -1.490	0.002
Metacognitive Index									
Age at injury	67	0.048	-0.247	-0.520 to 0.026	0.075				
Years of education	67	0.053	-1.665	-3.410 to 0.080	0.061				
PTA duration (1 week)	66	0.000	0.242	-7.670 to 8.1559	0.951	0.099	-0.796	-8.740 to 7.148	0.842
GCS score	67	0.002	-0.192	-1.335 to 0.950	0.737	0.086	0.063	-1.080 to 1.206	0.913
Presence of TAI	65	0.047	7.501	-1.036 to 16.038	0.084	0.130	5.475	-2.964 to 13.961	0.202
Presence of TAI adjusted for BDI 3 months after injury	49	0.107	5.825	-3.438 to 15.088	0.212				
BDI 3 months after injury	49	0.055	0.968	-0.037 to 1.972	0.059	0.169	1.027	0.041 to 2.014	0.042
BDI 1 year after injury	45	0.200	1.136	0.437 to 1.834	0.002	0.248	1.029	0.318 to 1.741	0.006
GOS-E score 1 year after injury	67	0.068	-3.653	-7.009 to -0.298	0.033	0.197	-5.244	-8.796 to -1.692	0.004

* Adjusted for age at injury and years of education prior to the injury.

BDI: Beck Depression Inventory; BRIEF-A: Behavioural Rating Inventory for Executive Function-Adult version; CI: confidence interval; GCS: Glasgow Coma Scale; GOS-E: Glasgow Outcome Scale Extended; PTA: posttraumatic amnesia; TAI: traumatic axonal injury; TBI: Traumatic Brain Injury.

TABLE 6: Demographic and clinical factors during 1st year after injury associated with self-reported emotional and behavioural problems (ASR) 2–5 years after moderate and severe Traumatic Brain Injury (TBI).

	N	R^2	Estimate	95% CI	Dependent variable			
					Regression coefficient for worse outcome, unadjusted		Independent variables	Regression coefficient for worse outcome, adjusted*
					p value	R^2		
ASR Total problems								
Age at injury	66	0.116	-0.640	-1.081 to -0.199	0.005			
Years of education at injury	66	0.032	-2.157	-5.143 to 0.828	0.154			
PTA duration (1 week)	64	0.000	-0.796	-14.013 to 12.420	0.905	0.155	4.782	-8.259 to 17.823 0.466
GCS score	66	0.000	0.085	-1.823 to 1.993	0.929	0.141	0.761	-1.090 to 2.613 0.414
Presence of TAI	64	0.076	16.085	1.822 to 30.347	0.028	0.185	12.728	-1.276 to 26.733 0.074
Presence of TAI adjusted for BDI 3 months after injury	46	0.315	15.524	1.772 to 29.277	0.028			
BDI 3 months after injury	46	0.235	2.845	1.303 to 4.388	0.001	0.331	2.868	1.375 to 4.362 <0.001
BDI 1 year after injury	43	0.401	2.683	1.662 to 3.705	<0.001	0.440	2.518	1.481 to 3.554 <0.001
GOSE score 1 year after injury	66	0.020	-3.308	-9.087 to 2.471	0.257	0.210	-7.371	-13.303 to -1.440 0.016
ASR Internalizing problems								
Age at injury	66	0.023	-0.106	-0.281 to 0.068	0.228			
Years of education	66	0.006	-0.343	-1.481 to 0.795	0.550			
PTA duration (1 week)	64	0.001	0.495	-4.416 to 5.405	0.841	0.041	1.380	-3.783 to 6.544 0.595
GCS score	66	0.000	0.006	-0.712 to 0.724	0.986	0.027	0.118	-0.623 to 0.859 0.752
Presence of TAI	64	0.075	5.986	0.668 to 11.303	0.028	0.097	5.548	0.055 to 11.041 0.048
Presence of TAI adjusted for BDI 3 months after injury	46	0.200	6.714	0.641 to 12.787	0.031			
BDI 3 months after injury	46	0.110	0.794	0.114 to 1.474	0.023	0.137	0.803	0.110 to 1.496 0.024
BDI 1 year after injury	43	0.306	0.922	0.490 to 1.354	<0.001	0.316	0.886	0.436 to 1.337 <0.001
GOSE score 1 year after injury	66	0.040	-1.764	-3.916 to 0.387	0.106	0.104	-2.768	-5.145 to -0.392 0.023
ASR Externalizing problems								
Age at injury	66	0.128	-0.221	-0.365 to -0.077	0.003			
Years of education	66	0.042	-0.819	-1.797 to 0.159	0.099			
PTA duration (1 week)	64	0.000	0.001	-4.373 to 4.375	1.000	0.174	2.029	-2.239 to 6.297 0.345
GCS score	66	0.001	-0.058	-0.686 to 0.570	0.853	0.157	0.171	-0.434 to 0.776 0.574
Presence of TAI	64	0.023	2.915	-1.859 to 7.689	0.227	0.146	1.630	-3.037 to 6.297 0.488
Presence of TAI adjusted for BDI 3 months after injury	46	0.298	3.525	0.485 to 1.414	0.106			
BDI 3 months after injury	46	0.255	0.917	0.446 to 1.388	<0.001	0.369	0.934	0.485 to 1.383 <0.001
BDI 1 year after injury	43	0.403	0.761	0.472 to 1.049	<0.001	0.446	0.718	0.426 to 1.010 <0.001
GOSE score 1 year after injury	66	0.002	-0.307	-2.228 to 1.613	0.750	0.178	-1.450	-3.442 to 0.542 0.151

* Adjusted for age at injury and years of education prior to the injury.

ASR: Adult Self Report (ASEBA); BDI: Beck Depression Inventory; CI: confidence interval; GCS: Glasgow Coma Scale; GOSE: Glasgow Outcome Scale Extended; PTA: posttraumatic amnesia; TAI: traumatic axonal injury; TBI: Traumatic Brain Injury.

TABLE 7: Description of participants in the subgroup analysis: demographics, injury severity characteristics, and clinical observations at 3 months, 1 year, and 2–5 years after moderate and severe TBI: cognitive function, emotional function, global outcome, and employment.

Variable	n	Persons with TBI	n	Controls	p value
<i>Demographics</i>					
Male sex (n, %)	49	35 (71)	28	24 (86)	0.593*
Age at injury (mean, range)	49	30 (14–63)			
<i>Injury-related variables</i>					
GCS score (median, IQR)	49	9 (6)			
HISS grade; moderate TBI (n, %)	49	28 (57)			
PTA <1 week (n, %)	48	23 (47)			
<i>Early MRI findings</i>					
EDH only (n, %)		1 (2)			
Pure TAI (n, %)		10 (20)			
Cortical contusions (n, %)		14 (29)			
Cortical contusions/TAI (n, %)		23 (48)			
<i>Neuropsychological assessment (3 months after injury)</i>					
Days after injury (mean, SD)	49	99 (10)			
Estimated IQ (mean, SD)	47	106 (16)	26	119 (12)	0.001†
Processing speed (mean, SD)	46	44.5 (10.2)	26	53.0 (4.8)	<0.001†
Attention (mean, SD)	46	49.9 (4.9)	26	51.6 (4.3)	0.124†
Memory (mean, SD)	46	42.6 (10.0)	26	48.2 (8.3)	0.016†
Executive function (mean, SD)	47	47.3 (7.6)	26	53.1 (4.8)	0.001†
<i>Depressive symptoms and global outcome 1st year after injury</i>					
BDI 3 months after injury (mean, SD)	47	5.5 (4.4)			
BDI 12 months after injury (mean, SD)	44	6.7 (6.4)			
GOSE score 12 months after injury (median, IQR)	49	7.0 (2)			
<i>Demographics at follow-up</i>					
Years after injury (mean, SD)	49	3.2 (1.0)			
Age (mean, range)	49	34 (17–65)	28	34 (19–64)	0.895†
Years education (mean, range)	49	12 (9–18)	28	12 (9–18)	0.630†
<i>Occupation</i>					
Unemployed/no school (n, %)		10 (20)		1 (4)	
Employed or at school (n, %)		55 (82)		26 (96)	

GCS: Glasgow Coma Scale; GOSE: Glasgow Outcome Scale Extended; IQ: Intelligence Quotient; IQR: interquartile range; PTA: posttraumatic amnesia; SD: standard deviation; TAI: traumatic axonal injury; TBI: Traumatic Brain Injury.

* Pearson's Chi-squared test.

† Independent samples t-test.

Our study demonstrated that self-reported problems with working memory, attentional control, and monitoring ongoing operations were frequently reported among persons sustaining TBI in adolescence and adulthood, which adds to the findings in studies utilizing similar tools in populations with other neurological deficits [29, 80, 81]. We also observed that participants with TBI experienced significantly more problems with inhibition, mental flexibility, and emotional regulation, which adds to existing literature on adult/adolescent TBI populations applying the same assessment tools and has not been reported in previous studies. Contrary to our expectations, problem-solving, initiation, and task monitoring were not perceived as problematic among individuals with TBI in our study, which is in contrast to a study comprising moderate and severe TBI survivors, where these functions were perceived as most problematic [30]. However, the few studies that have employed

the BRIEF-A as an outcome measure after TBI sustained in late adolescence and adulthood have had relatively small sample sizes [29, 30, 82], been retrospective in design [29, 83], and lacked comparisons with large demographically matched healthy control groups. We may speculate that by addressing these methodological issues our study revealed significant differences in self-reported problems within several areas of executive function after TBI previously not highlighted as problematic for this population.

While the presence of aggressive behaviour across the entire TBI group is in line with the literature reviewing long-term psychiatric outcome after TBI [13, 25], in our study, they did not report more rule-breaking behaviour (lack of empathy, substance abuse, and law-breaking behaviour) or intrusive behaviour. The aggression scale on ASR consists of several items related to behavioural control, and we speculate that executive problems (e.g., impaired inhibition

TABLE 8: Associations between main composite scores on BRIEF-A and ASR 2–5 years after moderate and severe TBI and neuropsychological test performance 3 months after injury*.

	N	R^2	Dependent variable		
			Estimate	Regression coefficient for worse outcome	
				Independent variable	95% confidence interval
BRIEF-A GEC					
Processing speed	47	0.015	-0.143	-0.492 to 0.205	0.413
Attention	47	0.001	-0.077	-0.831 to 0.678	0.839
Memory	46	0.008	0.112	-0.268 to 0.491	0.556
Executive function	48	0.012	-0.167	-0.626 to 0.291	0.467
BRIEF-A BRI					
Processing speed	47	0.015	-0.138	-0.470 to 0.194	0.408
Attention	47	0.006	-0.187	-0.887 to 0.513	0.594
Memory	46	0.004	0.074	-0.285 to 0.433	0.679
Executive function	48	0.011	-0.155	-0.592 to 0.281	0.478
BRIEF-A MI					
Processing speed	47	0.010	-0.115	-0.454 to 0.224	0.497
Attention	47	0.000	0.011	-0.723 to 0.745	0.976
Memory	46	0.013	0.137	-0.225 to 0.500	0.449
Executive function	48	0.009	-0.146	-0.591 to 0.299	0.513
ASR Total problems					
Processing speed	46	0.000	0.059	-0.753 to 0.872	0.883
Attention	46	0.000	0.065	-1.627 to 1.756	0.939
Memory	46	0.046	0.588	-0.229 to 1.405	0.154
Executive function	47	0.002	0.145	-0.933 to 1.223	0.788
ASR Internalizing problems					
Processing speed	46	0.010	0.106	-0.209 to 0.421	0.501
Attention	46	0.000	0.043	-0.620 to 0.705	0.897
Memory	46	0.060	0.260	-0.054 to 0.575	0.102
Executive function	47	0.008	0.126	-0.291 to 0.543	0.545
ASR Externalizing problems					
Processing speed	46	0.001	-0.033	-0.291 to 0.225	0.798
Attention	46	0.002	-0.086	-0.628 to 0.456	0.750
Memory	46	0.020	0.125	-0.138 to 0.388	0.344
Executive function	47	0.000	0.024	-0.318 to 0.367	0.887

* Given in T-scores.

BRI: Behaviour Regulation Index, GEC: Global Executive Composite, MI: Metacognitive Index, and TBI: Traumatic Brain Injury.

TABLE 9: Associations between main indexes on BRIEF-A and symptom scales on ASR at 2–5 years after moderate and severe TBI.

ASR symptom scales	BRIEF-A		BRIEF-A		BRIEF-A	
	Global Executive Composite (GEC)	Behaviour Regulation Index (BRI)	Behaviour Regulation Index (BRI)	Metacognitive Index (MI)	r	p value
Anxious/depressed	0.75	<0.001	0.70	<0.001	0.72	<0.001
Withdrawn	0.59	<0.001	0.55	<0.001	0.57	<0.001
Somatic complaints	0.51	<0.001	0.50	<0.001	0.47	<0.001
Thought problems	0.44	<0.001	0.43	<0.001	0.41	0.001
Attention problems	0.86	<0.001	0.77	<0.001	0.83	<0.001
Aggressive behaviour	0.62	<0.001	0.72	<0.001	0.49	<0.001
Rule-breaking behaviour	0.44	<0.001	0.40	0.001	0.43	<0.001
Intrusive behaviour	0.20	0.112	0.27	0.027	0.12	0.319

ASR: Adult Self-Report; BRIEF-A: Behaviour Rating Inventory of Executive Function-Adult version.

and reduced task monitoring/switching) [15] may mediate the behavioural and emotional problems experienced by individuals after TBI [25]. Further, excessive mood swings were commonly reported, which may indicate an increased risk of psychiatric diagnoses [59]. Controlling emotional and behavioural expression is also important for social and occupational functioning [84]. However, our respondents with TBI did not report more social withdrawal or problems with social relations, which is in contrast to previous studies [9, 85]. It could be argued that the persons with TBI may have underestimated their social problems, but the substantial proportion of moderate TBI in our study may reduce the risk of underreporting problems due to problems with self-awareness [86]. Another possibility is that this measure may not be sensitive enough to pick up underlying relationship problems. However, the health care system in Norway provides early access to treatment and rehabilitation services, including family support interventions. Whether such access to early intervention may contribute to participants reporting less social problems compared to findings from previous studies should be investigated further in future research. Nevertheless, our finding illustrates that the persons with TBI were less concerned about relationship problems compared to problems with regulating their emotions and behaviour, which suggests that this area is an important target in post-TBI rehabilitation.

4.1. Factors Associated with Self-Reported Executive, Behavioural, and Emotional Problems. Our second aim was to explore the effects of demographic, injury-related, psychological, neuropsychological, and global outcome factors, as obtained in the postacute phase, on later self-reported problems. Firstly, we hypothesised that the measures of injury severity were associated with later long-term outcome. Extending previous studies, our results suggest that TAI plays a contributing role in the development of self-reported Internalizing problems (e.g., anxiety and depression) and behaviour regulation. This association persisted even after adjusting for early self-reported depressive symptoms. TAI is a microscopic strain injury of axons and blood vessels in different predilection locations of the brain, typically causing widespread damage often localized in frontotemporal and subcortical structures [87], also affecting subcortical structures with frontal projections [3, 88]. The same neuropathological changes may also affect the development of mood disorders [52]. In combination with the unexpected findings that other measures of injury severity were not associated with later self-reported problems [39], this suggests that the pathophysiological processes associated with TAI may have a distinct effect on later perceived problems with emotional and behavioural regulation as long as 2–5 years after injury. No previous study has investigated associations between long-term self-reported executive, emotional and behavioural function, and presence of TAI detected by clinical MRI in the early phase, and our findings suggest that neurological imaging in the early phase after TBI may aid in identifying persons at risk of poorer long-term outcome.

As hypothesised, we found that self-reported symptoms of depression within the first year after injury predicted

later perceived overall problems with goal-directed cognitive and behavioural regulation, in addition to Externalizing and Internalizing problems. These findings support previous studies showing that emotional distress affects the extent of self-reported cognitive problems [29, 55]. However, adaptive problems in every-day life due to impairments after TBI in combination with the negative thinking typically experienced during depression [89] may contribute to the long-term self-reported depressive symptoms found in our study. This illustrates the importance of identifying, monitoring, and possibly treating depressive symptoms early in the course after TBI.

Further, younger age at injury predicted more self-reported Externalizing problems in the longer-term post-TBI, which is in accordance with previous studies that employed methods of retrospective assessment [12] or cluster analysis [26]. While we found that fewer years of education were associated with more self-reported problems with goal-directed cognitive and behavioural regulation, no association was found with self-reported aggressive behaviour. This is in contrast to other reports which have indicated that more years of education and higher socioeconomic status are associated with lesser endorsement of behavioural problems [26]. The aggressive behaviour in participants who were younger at the time of injury could be explained by the increased vulnerability to injury in rapidly developing brain areas [90]. The frontal lobe is still maturing during adolescence and young adulthood, rendering functions located therein (e.g., emotional and behavioural regulation) at increased risk following injury [91]. Furthermore, age was not associated with symptoms of depression, anxiety, or somatic complaints among individuals with TBI. Some have suggested the presence of distinct pathways and risk factors in the development of depression and anxiety as opposed to aggression [26], and we speculate that our findings might be in line with this. Our results indicate a need for future research to examine the possible differences in long-term outcome for persons injured in adolescence compared to those sustaining a TBI in adulthood.

We hypothesised that both global function and neuropsychological performance within the first year after injury would be associated with outcome 2–5 years after TBI. As expected, reduced global outcome one year after injury was associated with more reported executive and Internalizing problems. Experiencing reduced global function, including less ability to resume social relationships or leisure activities, may lead to a negative self-image and the increased endorsement of problems. However, the reported executive problems may also reflect cognitive impairment caused by the injury. Contrary to what we hypothesised, we observed no association between performance-based measures of cognitive function three months after injury and later self-reported executive, emotional, and behavioural function. This is in contrast to other studies demonstrating associations between performance-based and self-reported measures of task monitoring and switching [29, 30]. The lack of convergence among the data may be explained by different modes of measurement [92]. Our findings support the notion that self-reported cognitive complaints are affected by emotional symptoms

[21, 29, 93], compared to performance-based measures of executive function which as previous studies suggest are more closely linked to neural damage after TBI [21, 29, 47]. Taken together, this may suggest that performance-based executive function may better reflect the efficacy of processing (optimal performance) as supported by the underlying brain structure [19], whereas self-reported executive function is rather related to adaptive functional changes in the brain [47, 48], possibly developing over time as a consequence of the initial injury and/or cognitive problems. Given the multifaceted and complex nature of executive dysfunction after TBI, further validation of both performance-based and self-report measures of executive function is needed.

4.2. Clinical Implications. By assessing self-reported executive, emotional, and behavioural long-term outcome, our study revealed that the persons with TBI experienced subjective problems that were not detected with, for instance, neuropsychological tests, illustrating the importance of including self-evaluation inventories in addition to tests. Our results indicate that detection of DAI on early MRI and assessment of self-reported symptoms of depression within the first year after injury can aid in identifying persons at risk of experiencing poorer executive, emotional, and behavioural long-term outcome. This can be used for more targeted and cost efficient rehabilitation. Furthermore, psychological and/or pharmaceutical interventions, with a focus on depressive symptomatology, may be helpful in reducing the long-term problems experienced by persons sustaining a TBI and lessen their overall symptom burden. In addition, the results suggest that age is a notable risk factor for development of aggressive behaviour, and initiating interventions targeting this should be part of the rehabilitation of adolescence sustaining TBI.

4.3. Study Limitations. Our main aim was to explore long-term change in self-reported executive, emotional, and behavioural function after moderate and severe TBI sustained in adolescence as well as in adulthood, which also guided the development of the study design. The reliance on self-report forms may limit transferral to studies applying performance-based neuropsychological tests or diagnostic interviews and makes our study less optimal for exploring the validity of the BRIEF-A and ASR as proxies for cognitive function and psychiatric diagnoses. Performance-based measures were available for only the subgroup that consented to participate in both the neuropsychological study and the long-term follow-up study. Due to this design, the findings should be interpreted with caution.

5. Conclusion

Persons with moderate and severe TBI reported significantly more pronounced difficulties in aspects of executive functions related to attentional control, working memory, and emotional regulation, as well as emotional and behavioural problems related to symptoms of depression, anxiety, and aggressive behaviour 2–5 years after injury compared to healthy controls. Both the presence of TAI on early MRI and reported symptoms of depression during the first year after

injury were important predictors of later self-reported executive, emotional, and behavioural problems. Our findings indicate that demographic, neuropathological, and psychological factors all influence the development of self-reported executive, emotional, and behavioural problems for years after TBI. Our study highlights that early radiological and broad psychological evaluations may give clues as to which patients may be at risk for poorer long-term outcome. In summary, this study yields new information to guide the clinical management of TBI survivors and provides groundwork for additional clinical research regarding the long-term consequences of TBI.

Appendix

See Figures 1 and 2 and Tables 7, 8, and 9.

Ethical Approval

The work has been conducted in accordance with the Declaration of Helsinki (1964).

Consent

Consent has been obtained from persons named in Acknowledgments and from the participants in this study.

Conflict of Interests

The authors declare that there is no conflict of interests regarding the publication of this paper. There are no financial or other relationships that might lead to a conflict of interests.

Authors' Contribution

The paper has been approved by all the coauthors.

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Review Article

Traumatic Brain Injury Rehabilitation in Hong Kong: A Review of Practice and Research

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Background. The rising public health concern regarding traumatic brain injury (TBI) implies a growing need for rehabilitation services for patients surviving TBI. **Methods.** To this end, this paper reviews the practices and research on TBI rehabilitation in Hong Kong so as to inform future developments in this area. This paper begins by introducing the general situation of TBI patients in Hong Kong and the need for rehabilitation. Next, the trauma system in Hong Kong is introduced. Following that is a detailed description of the rehabilitation services for TBI patients in Hong Kong, as exemplified by a rehabilitation hospital in Hong Kong. This paper will also review intervention studies on rehabilitating brain-injured populations in Hong Kong with respect to various rehabilitation goals. Lastly, the implications of culture-related issues will be discussed in relation to TBI. **Results/Conclusions.** The intervention studies conducted in Hong Kong are generally successful in achieving various rehabilitative outcomes. Additionally, certain cultural-related issues, such as the stigma associated with TBI, may impede the rehabilitative process and lead to various psychosocial problems.

1. Introduction

Traumatic brain injury (TBI) is a condition involving brain damage caused by external forces, such as acceleration and deceleration, impact, blast waves, or penetrating injury. Its pathophysiology is characterized by shearing of white matter tracts, intra- and extracerebral hematomas, focal contusions, and diffuse swelling [1]. This condition has affected many people around the world; every year at least 42 million people sustain a TBI [2]. These survivors of TBI are likely to suffer from many possible long-term consequences in emotional, cognitive, and daily functioning [3–5].

Similar to findings from studies conducted in Western populations [6], survivors of TBI in Hong Kong also report similar consequences following their brain injury such as having a low quality of life. Specifically, they are unsatisfied with their material well-being, their place in the community, and their productivity at work [7]. This dissatisfaction may very likely be due to their reduced ability to work to support themselves and thereby contribute to the community. In fact,

the postinjury employment rate of brain-injured individuals in Hong Kong ranges from 10% to 47% [7, 8], which is relatively low compared to their Western counterparts [9]. Another possible reason for their low quality of life may revolve around interpersonal issues commonly affecting survivors of TBI. Those who had been living with brain injuries for an extended period of time (≥ 5 years) reported low satisfaction in the domain of intimacy [7], suggesting that they have experienced some strained relationships with others. The aging population in Hong Kong [10] further complicates the local TBI context in two ways. First, the elderly population is highly prone to falls [11] and falls are the most common cause of trauma-related injuries within the Hong Kong context [12]. Hence, as the population grows, we would expect the incidence of TBI to increase correspondingly. Second, relative to younger brain-injured patients, elderly patients require longer hospitalizations and have poorer functional outcomes [13, 14].

According to Yeung et al. [15], in Hong Kong approximately a fifth of all emergency cases received by hospitals

were trauma related, and more than half of these cases were diagnosed with TBI [12]. The increasing incidence of TBI is paired with a growing need and importance for rehabilitative services catered to those afflicted with TBI. TBI patients, even those who suffer from mild but repetitive TBI, may suffer long-term consequences, such as progressive brain atrophy and increased vulnerability to neurodegenerative disorders [16]. Within the cognitive domain, those with moderate to severe TBI are likely to be impaired in attention, memory, executive functions, and insight relating to their deficits [4, 17]; these impairments will in turn have an adverse impact on functional outcomes [18]. Those with mild TBI are not spared from cognitive impairments either; they may still report clusters of attentional impairments and deficits in verbal fluency [19] despite sustaining the injury years ago [20]. They also experience difficulties in the psychosocial domain—often as a result of a combination of injury-related, psychological, and social factors [21, 22], which predisposes them to a range of psychosocial and emotional problems [5]. Taken together, these consequences also hinder their reintegration into the community [23]. Fortunately, some of these consequences are at least amenable to rehabilitation. In a review of randomized controlled trials (RCTs) targeting various rehabilitation goals in patients with moderate to severe TBI, 36 out of 45 RCTs reported significant positive gains in the cognitive, functional, and/or psychosocial domains [24]. The need for rehabilitative efforts to better the lives of TBI patients cannot be understated; rehabilitation for TBI is a key area to direct research and intervention efforts so as to better patients' outcomes in Hong Kong. While there has been extensive work in the literature on the rehabilitation of TBI patients, most of this research has been conducted with Western populations and in managed care settings; research in the Asian contexts is lacking. Moreover, Asian cultural factors in TBI rehabilitation have often been overlooked in the literature. Given that health care infrastructure and culture are major factors in shaping rehabilitative efforts [25, 26], there might be issues with translating these findings into practice in Hong Kong—a society with a predominantly Chinese population where healthcare services are typically financed by government subsidies and out-of-pocket payments (by the patients and/or their families), instead of relying on social or private insurance. Hence, whenever possible, it may be more useful to look at the practice and research in the local context, so as to inform local TBI rehabilitation efforts. To this end, the current report aims to review the practice and research of rehabilitating TBI patients in Hong Kong as well as explore the implications of TBI in the local cultural context. The present review is focused only on the rehabilitation of the adult TBI population (i.e., aged 18 years and above) in Hong Kong.

2. Description of TBI Practices/Health Care Services/Rehabilitation in Hong Kong

2.1. Trauma System. Patients who sustain trauma-related injuries are served by the trauma system as managed by the Hospital Authority (HA). The current trauma system,

comprising five regional trauma centers—namely, Prince of Wales Hospital, Princess Margaret Hospital, Queen Elizabeth Hospital, Queen Mary Hospital, and Tuen Mun Hospital—was set up gradually in 2003 to provide trauma care services to various hospital clusters. For instance, Queen Elizabeth Hospital, which is based in central Kowloon, serves one such cluster by extending its trauma services to three other hospitals within its close proximity [27]. These five trauma centers had met the criteria for a Level I trauma center and were well equipped to handle trauma cases [28]; a Level I trauma center has to be able to admit at least 1,200 trauma patients or receive 240 admissions of severe injuries in a year [28]. In the past, trauma casualties were brought to the nearest public hospital regardless of the severity of their injuries. With the pilot implementation of the Primary Trauma Diversion Policy in 2003, trauma casualties are transported from the scene to these trauma centers directly if necessary, as determined by the ambulance crew according to a standardized protocol [29]. Alternatively, the crew may decide to transport the casualty to a regional hospital for initial resuscitation before transferring to a trauma center, that is, a Secondary Trauma Diversion [30]. Prehospital trauma care is provided by the ambulance services; the paramedics were trained and equipped to provide such care on the way to the hospital [31]. Subsequently, a trauma team consisting of an emergency physician, trauma surgeon, and other specialists [32] is called upon to attend to the case received at the trauma center [33]. These trauma centers provide a variety of services for the acute care and rehabilitation of TBI patients. On top of that, there are a few convalescent hospitals that specifically cater to their rehabilitative needs, such as Tung Wah Eastern Hospital, MacLehose Medical Rehabilitation Centre, Rehabid Centre, Rotary Rehabid Centre for Children, and The Duchess of Kent Children's Hospital. These rehabilitation units provide a range of services for neurological patients in general. However, due to limited resources, some patients with TBI may also receive rehabilitation services from other hospitals. Figure 1 depicts the flow of trauma case management.

2.2. Rehabilitation. For the purpose of describing the rehabilitation of TBI patients in Hong Kong, we shall examine a rehabilitation hospital in Hong Kong: the MacLehose Medical Rehabilitation Centre (MMRC) [34]. This example was selected due to its significance of being the first and only rehabilitation hospital opened on Hong Kong Island. In this hospital, rehabilitation regimes are tailored according to each patient's assessment findings and are delivered by a multidisciplinary team. For TBI cases, this team would usually include clinical psychologists, occupational therapists, physiotherapists, and speech therapists, in addition to other medical professionals. Cognitive rehabilitation is conducted by the clinical psychologists. Based on the concept of neuroplasticity, well-structured cognitive training programs, targeting attention, memory, visual-spatial, and executive functions, are delivered to TBI patients. The occupational therapists assist the patients to work on their self-care skills and household management and modification, as well as

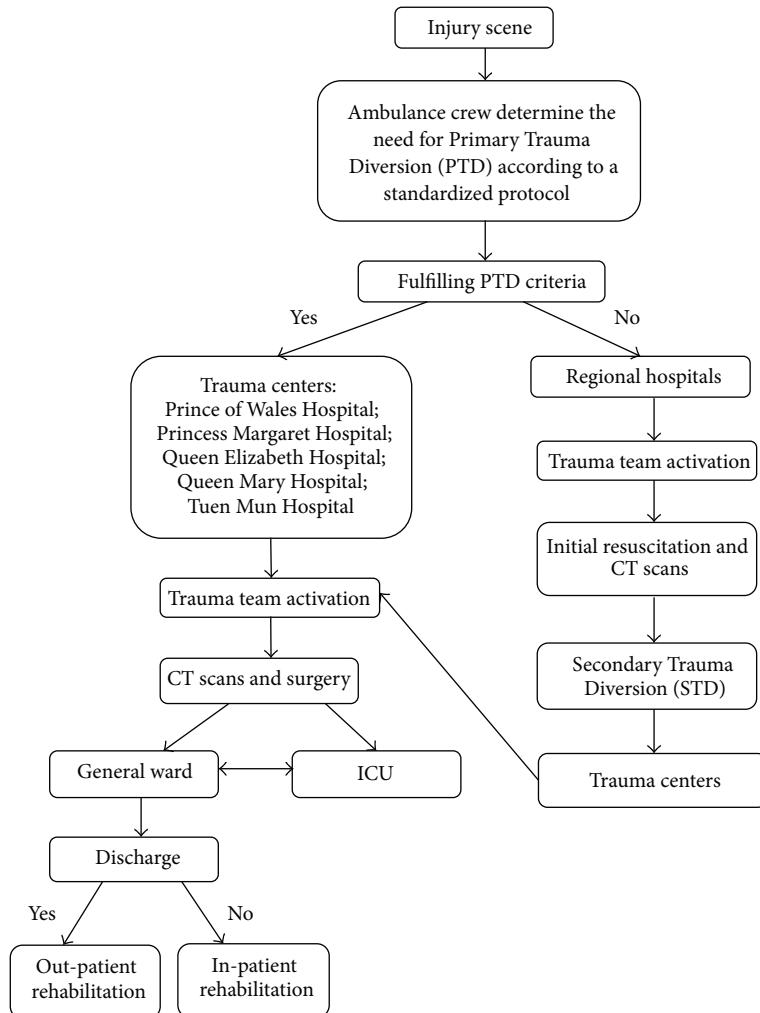


FIGURE 1: Flow diagram illustrating trauma patient management.

community integration. The physiotherapy team implements a rehabilitation program to maximize the patients' existing physical abilities and to regain functional independence. For this purpose, they are equipped with a neurological room, a standard sized gymnasium, and a hydrotherapy room. The speech therapists attend to patients who have issues with swallowing and/or verbal communication. These different specialists work closely with each other to contribute to the rehabilitation process and to carry out interventions tailored to each patient. They also meet up in weekly case rounds to discuss the progress of each patient. After a patient has completed his/her assigned rehabilitation regime, predischarge arrangements are made by the same team.

Patients usually receive short-term rehabilitation services in hospital settings. They may however, with an appropriate referral, turn to various nongovernmental organizations (NGOs) in Hong Kong for long-term care and rehabilitation. These NGO rehabilitation centers provide various outpatient services for discharged neurological patients and also facilitate the patient's reintegration into the community.

3. Review of TBI Rehabilitation Research in Hong Kong

At the time of this writing, there have not been any published trials on the rehabilitation of, specifically, TBI patients in Hong Kong. Given the paucity of TBI research in Hong Kong, it might be worthwhile to broaden the scope to other brain-injured populations, such as that of stroke. Stroke and TBI are highly similar in terms of pathophysiology. Hence, rehabilitation strategies beneficial to patients with stroke are likely to be beneficial to those with TBI as well [35]. For the present review, literature search was conducted using PubMed and Scopus with the following search terms in the title or abstract of the article: traumatic brain injury, TBI, close head injury, stroke, intervention, RCT, trial, training, remediation, rehabilitation, and Hong Kong. The exclusion criteria were (1) nonintervention studies, (2) studies that were not conducted in the postacute phase of the brain injury, (3) studies that did not include brain-injured participants, (4) studies that included participants below the age of 18 years, (5) studies that were conducted outside Hong Kong, and (6)

studies that did not focus on functional related outcomes or had focused on narrow areas of physical functioning (i.e., hemiparetic upper extremity). A total of 7 studies were retrieved with the above criteria.

These studies have achieved various significant rehabilitative outcomes among brain-injured patients in Hong Kong via different modalities and objectives. For instance, improving the daily functioning of these patients is one such objective; these patients are likely to be impaired in many aspects of their daily functioning [36, 37]. To remediate such impairments, two interventions utilized relearning protocols to enhance competency on tasks with which patients had difficulty with following stroke. In the first, the intervention utilized mental imagery to achieve patients' goals [38]. Patients ($n = 49$) were randomly assigned to the mental imagery group or functional retraining group for three weeks (5 h/wk). In the mental imagery group, patients were taught to use mental imagery to analyze and identify their difficulties and practice certain tasks. The functional retraining group practiced similar tasks; however, unlike the mental imagery group, the entire process was more instructional and didactic and did not involve mental imagery. At the end of the intervention, the mental imagery group had significantly higher levels of task performance on both trained and untrained tasks.

The other relearning intervention focused on the relearning of motor skills [39]. A total of 66 patients were randomly assigned to a motor-relearning program or conventional therapy program for six weeks (6 h/wk). The motor-relearning program involved a step-by-step process of first identifying one's motor task-related deficit, remediating this deficit by practicing on selected tasks related to the deficit, and transferring the skills acquired to functional tasks. The conventional therapy program was similar, except that the task selection was based on the patients' physical status rather than their deficits and patients were not trained to identify their deficits. At the end of six weeks, group \times time interaction effects suggested that the motor-relearning program had produced better outcomes relative to the conventional therapy program on measures of functional balance, self-care ability, daily living tasks, and community integration.

Stroke and TBI patients may both experience problems related to mobility [3, 40]; hence, it is important for community-based interventions to reach out to these people, who may have difficulties accessing rehabilitative facilities far away from home. There were three studies that specifically tackled such issues. The first study [41] made use of home visits within a nurse-led transitional care RCT. Stroke patients ($N = 108$) were randomly distributed between the intervention and control groups. The intervention group was administered a holistic care package that was delivered via weekly home visits that involved motivational interviewing and follow-up telephone calls for four weeks. Subsequently, the intervention group reported better physical functioning relative to controls immediately after the intervention and at a follow-up assessment four weeks later.

The second study [42] had video conferencing apparatus sited at various community venues in a district to reach out to their participants. Stroke patients ($N = 21$) took part in

an eight-week intervention (1.5 h/wk) that consisted of stroke education and physical exercise components, both of which were delivered via video conferencing to all participants. At the end of eight weeks, there were significant increases, relative to baseline, in measures of physical balance ability, self-esteem, quality of life, and knowledge of stroke. It should be noted that these results should be interpreted conservatively since there were no comparisons to a control group.

The third study [43] examined the option of having a short-term residential care program to eliminate the need for patients to travel. In this study, 188 stroke patients were assigned either to the residential care program or to a usual care program (as similarly described in the previous section) in a public hospital (both 12 h/wk). The residential care program had similar rehabilitation provisions as the usual care program, though their rehabilitation regime was spread out across more days of the week. Additionally, in the former, participants stayed in a home-like environment instead of hospitals and received round-the-clock residential and nursing care. At the end of four months, both groups had similar levels of improvements in general cognition, daily functioning, caregiver burden, depression, and self-esteem.

Brain injuries can also result in a variety of cognitive deficits as mentioned earlier. Memory impairments are one of these deficits that was of key interest in Tam and Man's [44] intervention study. In their study, 34 brain-injured patients with impairments in semantic memory were assigned to four different computerized training groups for two weeks (2.5 h/wk) and a no-treatment control group. Those in the training groups were trained to remember similar contents across groups, such as faces and names, things to do, something that was said, and where to place an item. However, the training strategy differed across groups: The first group was allowed to work at their own pace; the second group was given clear, consistent, and nonjudgmental feedback at every instance; the third group made use of actual stimuli that the participants had seen or known before; and the last group utilized attractive and bright stimuli. Even though all four training groups showed significant performance improvements across time on the computerized tasks within their training programs, none of the training groups reported significant improvements across time on a standardized memory assessment (i.e., Rivermead Behavioural Memory Test).

Attention is another cognitive domain where intervention work could be targeted. In one such experiment [45], 10 patients with closed head injury (CHI) were compared with 10 healthy controls on jigsaw puzzle tasks. All participants completed two different jigsaw puzzles while being recorded on video. In one of the puzzle tasks, they were instructed to verbalize their actions, and in the other no such instructions were given. Also, in the course of completing a puzzle, distractors (such as someone dropping a book or playing on the computer) were introduced. The authors divided the recorded videos into fifteen-second clips in which they coded for the presence of a distractor and the presence of off-task behaviors (e.g., head and eyes oriented away from the puzzle). The numbers of correct and incorrect placements of

the puzzle pieces were also recorded. The results indicated that verbalization did have a significant effect on reducing the number of off-task behaviors in the presence of distractors in both CHI patients and controls. It was also reported that there were significantly more correct placements in the verbalization condition than the nonverbalization condition in both groups. In both outcome measures, the differences attributed to verbalization were larger for CHI patients than for controls. The authors, while noting possible ceiling effects on the controls, suggested that CHI patients, relative to controls, can benefit more from such verbalization techniques.

The results of these intervention studies in Hong Kong are generally consistent with previous research in showing that functional outcomes among the brain-injured, such as those within the physical, psychosocial, and cognitive domains, can be improved via various rehabilitative approaches [24]. However it should also be noted that most of these studies do not meet Cicerone et al.'s [46] criteria of a well-designed "Class I" study for their findings to be translated into practice standards and guidelines.

4. Cultural Implications of TBI in the Local Hong Kong Context

The disabilities or dysfunctions associated with TBI may not be the only concerns of TBI patients. TBI patients may experience certain psychosocial problems, which have less to do with the severity of the injury but perhaps more so to do with societal perceptions [47]. These societal perceptions or stigma may also have major implications for TBI patients' rehabilitation. The discussion of stigma has a special relevance here in Hong Kong, given the cultural context and the nature of the public health system.

One cannot easily identify a TBI patient just from his/her appearance because TBIs are usually not associated with any physically obvious abnormalities unlike patients with physical disabilities. Hence, individuals with TBI can choose whether to conceal their disabilities or disclose them to others. In either scenario, there will be undesirable consequences. If they disclose their condition to others, they might risk being stigmatized by the society as being mentally ill [47]. This is due to a number of reasons: (1) similar to those afflicted with mental illness, TBI patients do sometimes exhibit deviant behaviors and mental disabilities/impairments as well [48], and as a result, the layperson may not be able to distinguish between neurological conditions and mental illnesses [49]; (2) TBI patients are often diagnosed with mental illness following TBI [50]; and (3) the label of "brain-injured," like "mentally ill," is equally reductionistic and carries similar negative connotations for the individual [47]. Furthermore, this stigma can be particularly unpleasant in Hong Kong because of the traditional Chinese belief that mental illness reflects the inferiority of one's family, the failure of one's parents, and the misdoings of one's ancestors [51]. In essence, having a mentally ill relative is something to be ashamed of in the Chinese context. This stigma or shame adds further stress to the family, who are already burdened by the need to provide and care for their brain-injured relatives.

Within Chinese contexts, families assumed the primary role in the management, coordination, and provision of care for TBI patients. However, these families were generally not adequately equipped in terms of resources and information to deal with the challenges of caring for their brain-injured relatives. As a result of undertaking these responsibilities, most of these families are already overwhelmed with shock, negative emotions, and uncertainty and consequently compromised their own physical and psychological well-being in the process [52, 53].

As a result, it is likely that TBI patients, like those diagnosed with mental illness, would choose to conceal their conditions from others to avoid the stigma or even hide their condition from their family members to avoid implicating them [54]. In fact, this tendency to cover up has been documented among TBI patients from a similar cultural background in a qualitative study. In this study, Vietnamese respondents reported attempting to cover up or not draw attention to their TBI by avoiding friends and telling lies because they were worried it might bring shame to their families [26]. This culture of concealing one's condition makes it difficult for people with TBI to seek social support, access rehabilitative services, and receive social welfare benefits. In Hong Kong, TBI is considered as a form of disability and TBI patients—like those who are physically disabled—may apply to receive social welfare assistance to cope with their disability. However, in order to obtain these benefits, one has to be certified "severely disabled" by the authorities [55], and this label may deter TBI patients from applying for these benefits especially if they would prefer to not draw attention to their conditions or disabilities. Furthermore, by concealing their disabilities, TBI patients receive less sympathy and empathetic understanding for their inappropriate actions and deficits, and as a result, unrealistic expectations are often placed upon them at the workplace based on the failure to compensate for their disabilities [56]. Even among family members who are well aware of the patient's condition, their lack of understanding of the residual impairments of TBI will similarly result in such unrealistic expectations. For instance, family members and caregivers would assume a hospital discharge implies that the patient will be able to revert back to his normal life, such as by returning to work, especially since the patient does not present with any obvious physical abnormalities that might indicate functional impairments. These unrealistic expectations set upon individuals with TBI will further complicate their interpersonal relationships and occupational functioning. The failure to satisfy such expectations will adversely affect the patient's self-concept as well. This is especially so in the Chinese culture whereby having a job symbolizes good health [8], and work itself is a major aspect of one's self-concept [57].

Taken together, the stigma encountered by TBI patients can hinder their rehabilitation in more than one way. This is a major concern that has yet to be adequately addressed in the current practices and research on rehabilitating TBI patients in Hong Kong. Certainly, more effort should be devoted to tackling such stigma. One effective way in which this can be accomplished is to promote more interpersonal contact with and exposure to this group of people. This method was

found to be more effective than education alone in reducing various aspects of the stigma and can be implemented widely via school-based programs [58].

5. Future Directions

The current rehabilitation practices for TBI patients in Hong Kong have generally satisfied the guidelines for the rehabilitation following acquired brain injury as laid out by the Royal College of Physicians and British Society of Rehabilitation Medicine [59]. TBI patients in Hong Kong were also generally satisfied with the rehabilitative services provided [7]. In particular, they were most satisfied with the services catering to their physical well-being and functioning (such as medical services, occupational therapy, and physiotherapy); these services were also rated as highly important. On the other hand, while vocational counseling was ranked as one of the most important needs, it was also one of the least satisfactory services provided to them [7]. This, taken together with the economic, psychological, and cultural implications of returning to work discussed previously, suggests a critical need to improve rehabilitative efforts geared towards the reemployment of TBI patients. Certainly, more research and resources can be directed towards enabling TBI patients to recover their preinjury and maximize their postinjury occupational ability.

Additionally, given that the patients' main caregivers are their families, it is crucial to involve them in the rehabilitation process prior to the patient's hospital discharge. However, such family involvements remain somewhat low, and perhaps this explains their unpreparedness and lack of the know-how in caring for their brain-injured relatives [52, 53]. The fact that TBI patients' disabilities may not be reflected in any atypical physical features (as discussed previously) makes this worse; these families may sometimes have unrealistic expectations of their brain-injured relatives upon discharge simply because they "look fine." As a result, tensions between the patient and his/her family members may arise, making it more difficult to care for the patient. Hence, to minimize such problems, prior to the patient's discharge, it would be helpful to inform and educate these families on the patient's impairments and the appropriate way to handle these impairments and care for the patient.

The few reported researches on interventions for brain-injured populations conducted in Hong Kong have generally been effective in achieving certain specific goals such as the remediation of skills compromised by the injury and community integration. Despite the lack of local research on specifically rehabilitating TBI patients, these researches on other brain-injured populations do suggest that there are adequate resources, both in the community and in the health care infrastructure, to carry out similar rehabilitative efforts on TBI patients.

Certainly, future research on TBI rehabilitation in Hong Kong will be useful in informing and guiding the current practices and ultimately to better the lives of TBI patients. Intervention efforts utilizing cognitive-based rehabilitative approaches on brain-injured populations in Hong Kong have been scarce. In light of the possible impairments

in various cognitive domains [18] and the fact that these impairments are a major concern among discharged brain-injured patients in Hong Kong [53], there is huge potential for intervention work in this area. Additionally, with advances in neuroimaging, it will be useful for future interventions to track neuroplastic changes in the brain as a function of the intervention progress, so as to gain a better understanding of the brain mediators/mechanisms of such improvements in cognition, especially within the context of a neurological condition like TBI.

6. Conclusions

The present paper has reviewed the practice and research of TBI rehabilitation in Hong Kong. TBI rehabilitation in Hong Kong is carried out by a multidisciplinary team of health care professionals primarily within hospitals, as consistent with international guidelines. Despite limited resources, these rehabilitation services have generally satisfied most of the TBI patients' needs. However, there is room for improvement in rehabilitative efforts aimed at enabling them to return to work. While stigma is a major concern for these patients and their rehabilitation, it is hardly addressed in the current practices. Finally, research on TBI rehabilitation in Hong Kong is lacking; there is a need for more local research in this area to inform the current practice of TBI rehabilitation and more importantly to benefit TBI patients in Hong Kong.

Conflict of Interests

The authors declare that there is no conflict of interests regarding the publication of this paper.

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Research Article

Neurophysiological Indicators of Residual Cognitive Capacity in the Minimally Conscious State

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Background. The diagnostic usefulness of electrophysiological methods in assessing disorders of consciousness (DoC) remains to be established on an individual patient level, and there is need to determine what constitutes robust experimental paradigm to elicit electrophysiological indices of covert cognitive capacity. **Objectives.** Two tasks encompassing active and passive conditions were explored in an event-related potentials (ERP) study. The task robustness was studied in healthy controls, and their utility to detect covert signs of command-following on an individual patient level was investigated in patients in a minimally conscious state (MCS). **Methods.** Twenty healthy controls and 20 MCS patients participated. The active tasks included (1) listening for a change of pitch in the subject's own name (SON) and (2) counting SON, both contrasted to passive conditions. Midline ERPs are reported. **Results.** A larger P3 response was detected in the counting task compared to active listening to pitch change in the healthy controls. On an individual level, the counting task revealed a higher rate of responders among both healthy subjects and MCS patients. **Conclusion.** ERP paradigms involving actively counting SON represent a robust paradigm in probing for volitional cognition in minimally conscious patients and add important diagnostic information in some patients.

1. Introduction

A minority of patients with severe acquired brain injury remain in a state of disordered consciousness (DoC) after awakening from coma [1, 2], and some experience prolonged DoC [3, 4]. Following coma, most patients transition to either a vegetative state (VS), also referred to as the “unresponsive wakefulness syndrome (UWS)” [5], or a minimally conscious state (MCS). While VS is characterized by intermittent wakefulness in the absence of any behavioral signs of awareness, MCS is characterized by the presence of inconsistent, but

clearly discernible behavioral evidence of awareness of self or the environment (i.e., visual pursuit, localization to pain, or reproducible command-following) [6]. It has recently been suggested that MCS can be subcategorized into MCS+ and MCS-, based on the presence or absence of language function. MCS+ is defined by the presence of command-following, intelligible verbalization, or gestural or verbal yes/no responses. In contrast, MCS- is characterized by nonlinguistic signs of conscious awareness such as visual pursuit and localization of noxious stimuli or other behaviors that selectively occur in response to specific stimuli

(e.g., appropriate smiling or crying to a picture of a family member) [7].

Adequate assessment of level of consciousness is challenging, but crucial, in establishment of an appropriate plan of care and provision of an accurate prognosis to caregivers and may affect end-of-life decisions [8]. Importantly, patient, examiner, and environmental factors have been recognized as sources of inaccurate diagnosis in DoC patients [9], and rates of misdiagnosis have been reported to be up to ~40% [10, 11]. Even experienced clinicians can be mistaken when differentiation between volitional and reflexive behavior is based on unstructured bedside examinations instead of standardized assessment procedures [12–14]. Standardized behavioral assessment is the most common diagnostic method, and the Coma Recovery Scale-Revised (CRS-R) has been recommended as the preferred assessment scale [13]. Standardized measures depend on the patient's ability to move and communicate; however, conscious awareness may be masked as the result of severe sensory and motor deficits [15]. The diagnostic validity of behavioral assessment may be compromised by these issues.

Over the last two decades, neurodiagnostic techniques have been explored that do not rely on overt behavioral responses. Included among these are techniques designed to detect patterns of brain activity such as event-related brain potentials (ERPs) and functional magnetic resonance imaging (fMRI). Functional imaging and neurophysiological studies have shown that when using standardized diagnostic scales, like the CRS-R, volitional behaviors such as command-following may go undetected in a minority of patients [16–19], suggesting a key role for fMRI and electrophysiological studies in detecting covert cognition in patients with DoC.

ERP is a promising, low-cost, noninvasive technique that can be conducted repeatedly at bedside [20, 21]. Event-related potentials (ERPs) are extracted from continuous electroencephalography (EEG) that is recorded from the skull while participants are exposed to repeated stimulus presentations in cognitive tasks. Signal averaging is used to eliminate the background EEG activity to derive an averaged measure of stimulus-related processing [21]. Thus, ERPs represent time-locked EEG activity elicited by external events, providing a neurophysiological correlate of cognitive processing at the millisecond level, from early and largely sensory components, that is, the N1 component, to later and cognitively mediated waveforms, such as the P3. The well-established P3 component has attracted particular interest in the DoC population, as it reflects allocation of attentional resources [22, 23], and presence of the P3 wave is a reliable predictor of awakening from coma [24]. In a clinical context, it is essential to understand to what degree ERPs may add valuable clinical information on an individual level and, furthermore, under what experimental conditions this can be best done. It has been argued that ERP experiments need to include subjectively meaningful stimuli, as the probability of electrophysiological responses in DoC patient increases with salient self-referential stimuli [25]. The salient value of the person's own name (SON) has proven promising in eliciting the P3 response [26–29], even when repeated extensively [30]. SON

also seems to result in enhanced responses in healthy and awake subjects [31–33] and during sleep [33, 34], implying that SON is a robust salient stimulus. However, the inference of consciousness based on passive ERP paradigms is insufficient, as passive tasks without demand of volitional mental effort can elicit a P3 response in comatose or VS patients [26, 28] and in healthy subjects under anaesthesia [35]. Therefore, a second argument concerns the necessity to include "active" experimental paradigms requiring volitional cognitive effort, allowing detection of covert command-following by comparing P3 response in passive versus active tasks [30, 36–38].

In their ERP study, Schnakers et al. [38] presented a list of eight randomized names, including SON. When instructed to actively count a target name (either SON or an unfamiliar name (UN)), the MCS, but not VS group, showed an increase in P3 amplitude. The study reported that 9/14 individual MCS patients had enhanced P3 amplitudes in one out of two active counting conditions, but 2/8 patients showing command-following at bedside did not show the suspected ERP (false negatives). Also, covert command-following was detected in two MCS patients with absence of externally observable signs of command-following. In a more recent study, the Schnakers et al. [38] paradigm was developed into a single-stimuli paradigm, presenting SON in a passive listening condition along with an active condition, instructing patients to listen for a change of pitch in the voice saying their name. They found that 5/8 MCS+ patients and 3/8 MCS- patients versus only 1/10 VS patients displayed enhanced P3 amplitude in the active versus passive condition [30]. Other studies using active ERP paradigms have also demonstrated signs of covert volitional mental effort in DoC [36, 37]. Despite increased knowledge of ERP responses typical for DoC patients at a group level, the literature is still sparse, and little is known about what type of cognitive task constitutes the most robust paradigm in order to elicit electrophysiological indices of covert cognitive capacity. Some studies report only group level findings or lack sufficient reports of false negative rates [36, 37, 39]. Thus, the potential clinical utility of electrophysiological methods on an individual patient level remains largely unknown. An important step forward is therefore establishing paradigms that are recognized as robust in healthy individuals. Further, the efficacy of these paradigms in revealing covert voluntary cognition on an individual patient level needs to be explored. This is paramount in order to establish the diagnostic utility of the ERP method in clinical practice, where correct assessment of a DoC patient's level of consciousness is crucial. Thus, reproducing the results from active paradigms is necessary in order to recognize their value and limitations.

The present study aims to replicate and expand upon previous ERP study designs [30, 38]. We specifically wished to explore the robustness of a paradigm involving both passive and active conditions using SON. The aim of the study was twofold. The first aim was to investigate the robustness of two separate active tasks with varying stimulus type and cognitive load in healthy controls. It was expected that the salient value of SON would elicit more pronounced responses compared to an unfamiliar name (UN). It was furthermore anticipated that SON would elicit a larger P3

TABLE 1: Patients' diagnosis, etiology, gender, age, time since injury, and CRS-R scores.

Patients	Etiology	Sex	Age	TSI months	CRS-R total	AF	VF	MF	OF	C	Ar
MCS- 1	TBI	M	34	115,9	10	1	3	2	2	0	2
MCS- 2	TBI	M	34	57,7	15	2	4	5	2	0	2
MCS- 3	TBI	M	19	63,6	7	1	3	1	1	0	1
MCS- 4	TBI	F	66	6,0	10	2	3	2	2	0	1
MCS- 5	TBI	F	19	5,3	13	1	3	5	2	0	2
MCS- 6	Anoxia	F	29	6,5	10	2	3	2	1	0	2
MCS- 7	TBI	M	27	40,2	11	2	3	2	2	0	2
MCS- 8	TBI	M	29	39,0	8	0	0	4	2	0	2
MCS- 9	Anoxia	M	54	9,5	8	1	3	2	1	0	1
MCS- 10	Encephalitis	M	49	4,3	11	2	3	2	2	0	2
MCS- 11	TBI	M	47	4,8	13	2	3	5	2	0	1
MCS+ 1	SAH	F	49	56,1	11	3	3	2	2	0	1
MCS+ 2	TBI	F	24	47,0	14	3	3	2	2	1	2
MCS+ 3	TBI	F	35	117,0	12	3	3	2	2	0	2
MCS+ 4	TBI	M	60	29,1	18	4	4	5	2	1	2
MCS+ 5	Anoxia	M	50	3,6	15	3	3	5	2	0	2
MCS+ 6	TBI	M	35	4,3	18	3	5	5	2	1	2
MCS+ 7	Encephalitis	F	27	6,8	9	3	1	2	1	0	2
MCS+ 8	TBI	F	58	8,8	13	3	5	2	1	1	1
MCS+ 9	SAH	F	49	29,0	8	3	0	2	1	0	2

MCS-: minimally conscious state minus; MCS+: minimally conscious state plus; TBI: traumatic brain injury; SAH: subarachnoidal hemorrhage; M/F: male/female; TSI: time since injury (months after injury); CRS-R: Coma Recovery Scale-Revised; AF: auditory function; VF: visual function; MF: motor function; OF: oromotor function; C: communication; and Ar: arousal.

in active compared to passive tasks. It was also an aim to explore the rate of healthy controls with enhanced P3 in the two active compared to passive conditions. The second aim was to compare the MCS+ and MCS- patients with regard to the amplitude of the P3 in the active versus passive conditions. It was expected that more patients in the MCS+ group would demonstrate an enhanced P3 in the active conditions than in the MCS- group. We also anticipated that electrophysiological indications of command-following would be observed in a minority of MCS- patients and that some MCS+ patients would fail to display P3 in the active conditions.

2. Materials and Methods

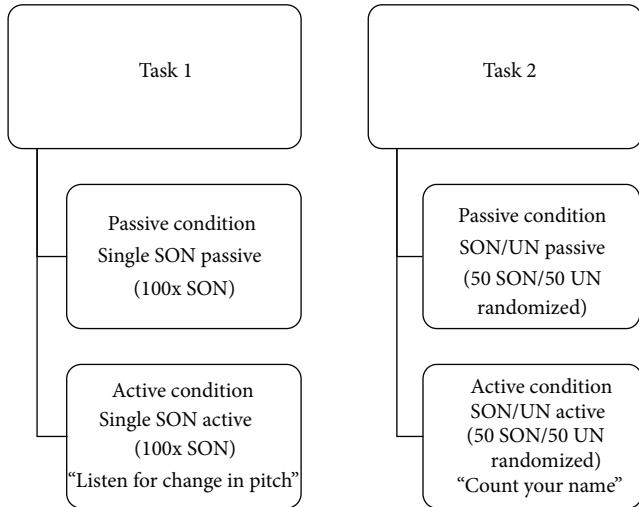
2.1. Participants. Twenty-two healthy controls aged 18–65 years were enrolled in the study. All were native Norwegian speakers with no previous history of brain injury, neurological or psychiatric illness, premorbid hearing impairments, or cognitive deficits. Health personnel at Sunnaas Rehabilitation Hospital were recruited as healthy controls. Twenty-two patients were enrolled from the Brain Injury Unit at Sunnaas Rehabilitation Hospital in Oslo, Norway, and two patients from St. Olavs Hospital in Trondheim. All were above 18 years of age and were fluent Norwegian speakers prior to their injury. Patients were assessed with the CRS-R and met the diagnostic criteria for MCS [6]. ERP recordings were performed at least 90 days after injury. All patients had a documented presence of the auditory startle (i.e., CRS-R auditory

subscale score ≥ 1) or the auditory N1 ERP component, indicating intact hearing. None had a documented history of prior brain injury or premorbid hearing impairments, and no sedation was given within 24 hours prior to the recording.

Two controls and four patients were excluded due to low quality EEG recordings (i.e., ocular, muscle, and/or noise artifacts that could not be adequately corrected for by the preprocessing procedures). Hence, 20 controls (mean age = 38, range 25–61 years; 10 males) and 20 patients (mean age = 40, range 19–66 years; 11 males) were included in the ERP analysis. The control group was comparable to the patients with regard to gender and age distribution. Nine patients were classified as MCS+ and eleven were MCS- according to the CRS-R scores obtained by an experienced rater on the day of EEG recordings (Table 1). MCS+ was defined as presence of reproducible response to command (CRS-R auditory subscale score ≥ 3) and MCS- as no reproducible response to command (CRS-R auditory subscale score ≤ 3 [40]). Diagnostic distinction between MCS+ and MCS- was hence derived from the complexity of present behavior on the auditory subscale.

The study was conducted in agreement with the Helsinki Declaration and was approved by the Regional Committee for Medical Research Ethics in South East Norway. Written informed consent was obtained from healthy controls and the patients' next of kin.

2.2. Experimental Procedures. The ERP paradigm consisted of two tasks, both containing a passive and an active condition



SON: subject's own name
UN: unfamiliar name

FIGURE 1: Experimental ERP design.

(Figure 1). All four conditions were presented in the same hierarchical order (each condition containing four sets of consecutive blocks of 25 stimuli, 100 in total). Task 1 consisted of single SON passive and active conditions, identical to the design used in Schnakers et al.'s latest study [30]. The single SON passive condition contained SON repeated 100 times, with the instruction to do nothing but to stay awake. Thereafter, the subjects were presented with the single SON active condition, with the instruction to listen very carefully for a change in the pitch of the voice saying their name. There was no actual change in the voice, rendering the physical stimulus characteristics identical, and the demanded level of mental effort was the only difference between conditions. Task 2 included two-stimuli SON/UN passive and active conditions, where SON ($n = 50$) was randomly interspersed in between an unfamiliar name (UN—confirmed unfamiliar by family or the healthy controls themselves, $n = 50$). In the passive condition, the subjects were instructed to do nothing but to stay awake. In the active condition, subjects were instructed to count the number of times they heard SON, requiring sustained attention and working memory effort. Hence, the active conditions in tasks 1 and 2 differed with regard to cognitive load. Instructions were repeated between each block of 25 stimuli for all conditions. EEG recordings were performed while participants were in a wakeful state. For the patients, a short break and, if needed, brief auditory or deep pressure stimulation according to CRS-R protocol were applied between conditions in order to ensure adequate arousal levels. All names were digitally recorded from a female, middle-aged native Norwegian speaker (stimulus duration range: approximately 500–600 ms), and a stimulus onset asynchrony of 2000 ms was used.

2.3. EEG Acquisition. Data were acquired at the patients' bedside with a 32-electrode cap (Quik-Cap; Compumedics Neuroscan) connected to a portable digital NuAmp EEG

amplifier (Compumedics Neuroscan). Electrooculogram was recorded using the electrodes located above and below the left eye and at the outer canthi of the two eyes. The ground electrode was placed near Fz and a nasal reference was applied. The EEG signals were acquired using the NeuroScan Inc. acquisition unit with an analog band-pass filter of 0.1 to 200 Hz and a sampling frequency of 500 Hz. The impedance was kept below 10 k Ω . Auditory stimuli were presented binaurally through earphones with a maximum 90 dB sound pressure level. The whole procedure lasted approximately 25–30 minutes including breaks.

2.4. Behavioral Assessment of DoC Patients. The Coma Recovery Scale-Revised (CRS-R) is comprised of six subscales addressing auditory, visual, motor, oromotor/verbal, communication, and arousal functions [41]. Items are hierarchically arranged, from reflexive to cognitively mediated responses. The lowest item score on each subscale represents reflexive activity, whereas the highest scores reflect cognitively mediated behaviors. The scale has good psychometric properties and is sensitive for behavioral assessment of DoC [13, 41, 42]. The authorized Norwegian version was used on the day of the EEG recording. A validation study of the authorized Norwegian version has confirmed acceptable psychometric properties comparable to the original CRS-R [43].

2.5. ERP Analysis. EEG data were analyzed with custom-made MATLAB (The MathWorks, Inc., Natick, MA, USA) scripts built on the open source EEGLAB environment (<http://sccn.ucsd.edu/eeglab/>) [44] and the study function in EEGLAB. Data were high-pass-filtered above 1 Hz. Artifact correction was performed on epoched data (−500 to 1500 ms) by excluding independent components (ICs) characteristic of nonbrain artifact (e.g., eye, muscle, or line noise) identified by inspection of topographies, time courses, and activity spectra. Following artifact removal, data were low-pass-filtered below 20 Hz. Bad channels were interpolated and trials with amplitude values exceeding $\pm 75 \mu\text{V}$ were rejected at the midline electrodes Fz, Cz, and Pz. Average activity between −200 and 0 ms was defined as baseline.

In order to investigate the robustness of a design comparing stimulus type and two different active conditions in healthy controls, grand-averaged ERPs were computed for SON and UN as well as for the active and passive condition in both tasks. Peak and mean amplitudes over specified time windows were exported for statistical analyses. Peak amplitudes for the N1 component were derived from the 80–150 ms time window at Cz, corresponding to the expected latency and distribution for the auditory N1 wave [45, 46]. Based on grand average group ERPs, a temporal window between 500 and 680 ms after stimulus was determined for extracting peak and mean P3 amplitudes for SON in the active and the passive conditions in task 1 and correspondingly between 300 and 500 ms for SON and UN in task 2.

The second aim was to investigate P3 responses in the MCS+ and MCS− patient groups with regard to active mental tasks on an individual level and also to explore the robustness of the tasks on an individual level in

the control group. The P3 component was considered present on an individual level when detected in the expected time window at all three midline electrodes (Fz, Cz, and Pz), by means of visual inspection by three of the authors (Solveig L. Hauger, Marianne Løvstad, and Stein Andersson). Subjects with consensus-based identification of larger P3 amplitude values in the active versus passive condition at minimally one electrode were defined as “responders.” One of the authors was blinded to the CRS-R results, while the other two were involved in both CRS-R scoring and ERP analyses.

2.6. Statistical Analyses. In the healthy control group, averaged ERP amplitudes were subject to statistical analysis, using SPSS version 22 for Macintosh (SPSS, Inc., Chicago, IL). Repeated measures analysis of variance (ANOVAs) was used to examine differences in mean or peak amplitude between stimulus types or conditions in the healthy control group. Either SON versus UN or active versus passive condition was contrasted, with stimulus type (SON-UN) or condition (passive-active) as within-subjects factors and electrode location along the midline (Fz, Cz, and Pz) as the second within-subject factor. Extreme values were identified using boxplots. Analyses including extreme values were repeated without these, and any resulting changes in results are reported. Greenhouse-Geisser epsilon corrected p values are reported for computations involving more than two levels of a repeated measures factor. When indicated by the ANOVA, post hoc tests with Bonferroni correction were run. Partial eta squared (partial η^2) was used to calculate the sample effect size based on within-subjects factor variability. Effect size values of .01, .06, and .14 have been suggested to represent small, medium, and large effect sizes, respectively, but larger values will often be expected in nonsocial experimental research, such as physiology [47–49].

To investigate if each visually identified responder could be confirmed statistically, an unpaired t -test was performed in the EEGLAB study function [44]. Amplitude differences between passive and active conditions were tested on an individual level on a trial-by-trial basis for each sampling point, with Bonferroni correction for multiple comparisons. Rate of responders is described by actual numbers of subjects, percentage, and 95% confidence interval (CI). Statistical significance was set to $p < .05$. Despite the small sample and thus a need for caution in interpreting results, sensitivity and specificity of the ERP tasks were calculated with CRS-R as the reference standard and MCS– as the disorder of interest.

3. Results

3.1. The Effect of SON versus UN and Active versus Passive Experimental Conditions in Healthy Controls. Grand average ERPs for SON versus UN in a passive listening task as well as passive versus active conditions in tasks 1 and 2 are presented in Figures 2, 3, and 4. Visual inspection suggested that SON generally elicits a larger P3 compared to UN (Figure 2). The active conditions in both tasks elicited a larger P3 for SON compared to the passive conditions, but with larger amplitude differences in the counting condition of task 2

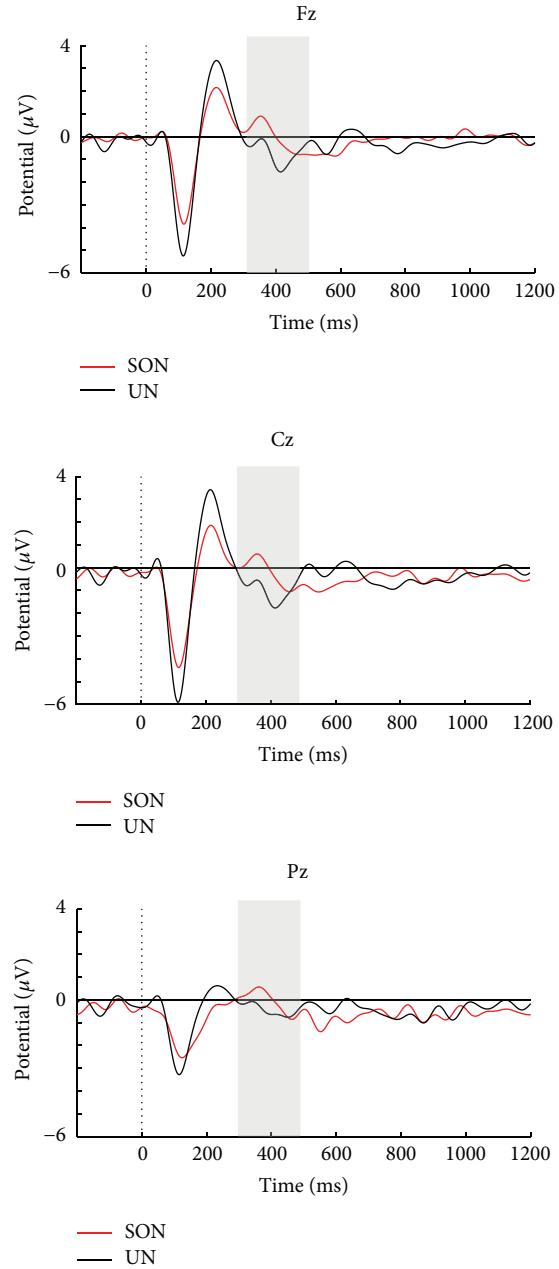


FIGURE 2: Stimuli SON and UN in passive listening task for the healthy controls.

(Figures 3 and 4). Moreover, visual inspection suggested that the counting condition in task 2 elicited larger N1 amplitudes compared to task 1.

3.1.1. Effects of SON and UN on N1 and P3. A main effect of stimulus type in task 2 reflected that the control group had a larger N1 peak amplitude at Cz for UN compared to SON $F(1, 19 = 6.42, p = .02$, and partial $\eta^2 = .25$).

We also found that the type of name presented had significant effects on P3 amplitude in the control group, with larger amplitudes to SON compared to UN in the passive condition of task 2 for both peak ($F(1, 19 = 4.45, p = .048$,

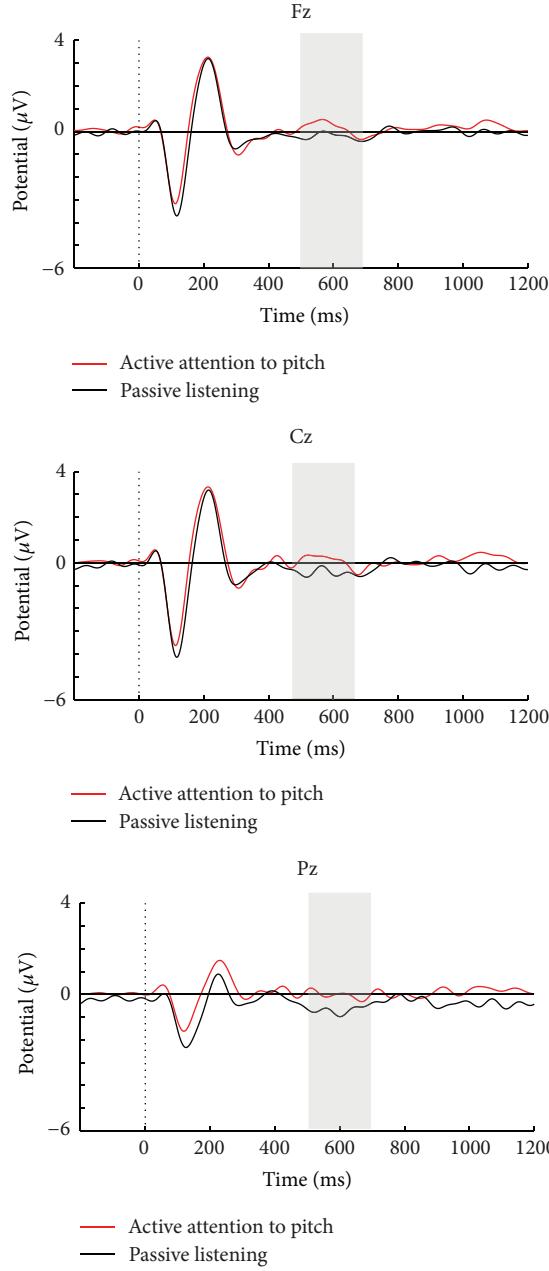


FIGURE 3: Passive and active conditions in task 1 for the healthy controls.

and partial $\eta^2 = .19$) and mean amplitudes ($F(1, 19 = 5.56, p = .03$, and partial $\eta^2 = .23$). A significant effect of electrode location was found for the mean amplitude analysis ($F(1.45, 27.58) = 8.51, p = .003$, and partial $\eta^2 = .31$), due to a larger P3 at Pz compared to Fz ($p < .001$).

3.1.2. Effects of Active Task Instructions on N1. The auditory N1 component elicited by the passive and active conditions in task 1 did not differ in peak amplitude at Cz. However, as Figure 4 shows, enhancement of N1 was detected at Cz in the active counting compared to passive listening in task 2 ($F(1, 19) = 6.85, p = .02$, and partial $\eta^2 = .27$). Moreover,

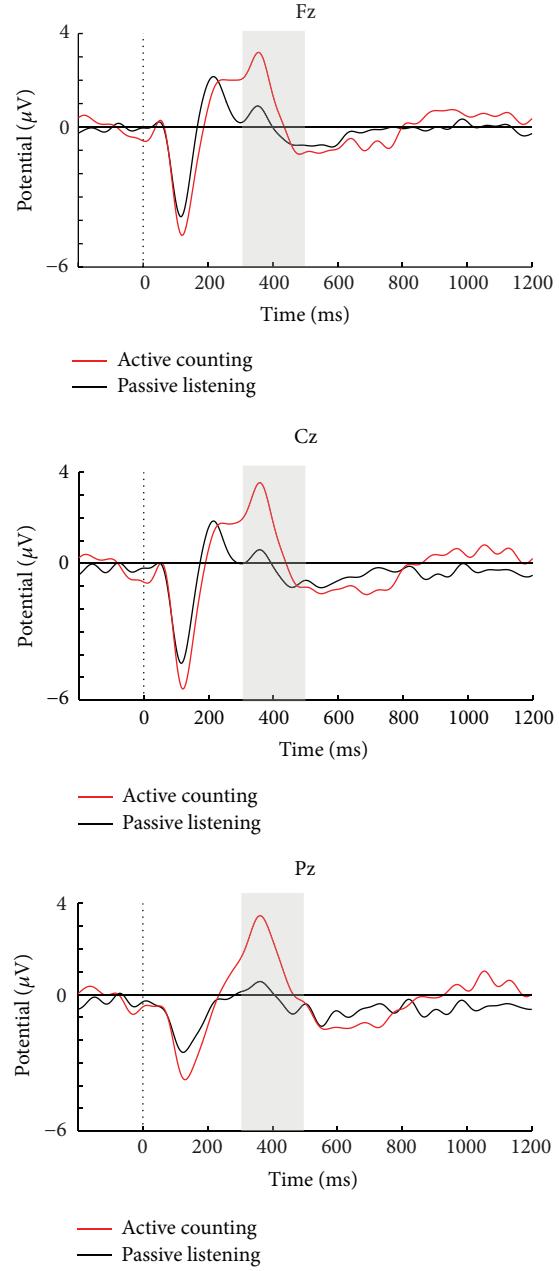


FIGURE 4: Passive and active conditions in task 2 for the healthy controls.

a significant difference was found when comparing the active conditions in tasks 1 and 2, with a larger N1 in the counting task ($F(1, 19) = 15.68, p < .001$, and partial $\eta^2 = .45$).

3.1.3. Effects of Active Task Instructions on P3. The active condition in task 1 elicited a significantly larger mean P3 amplitude ($F(1, 19) = 6.03, p = .02$, and partial $\eta^2 = .24$), compared to the passive condition (see Figure 3). This was however not significant in the peak analysis. A significant main effect of electrode location was evident for mean amplitudes ($F(1.35, 25.67) = 10.52, p = .002$, and partial

TABLE 2: Controls and patients classified as responders in tasks 1 and 2.

Group	Task 1			Task 2		
	Yes*	No**		Yes	No	
CTR (<i>N</i> = 20)	15	75% (CI = ±19.0)	5	25%	19	95% (CI = ±9.6)
MCS (<i>N</i> = 20)	4	20% (CI = ±17.5)	16	80%	9	45% (CI = ±21.8)
MCS+ (<i>N</i> = 9)	3	33% (CI = ±30.7)	6	67%	4	44% (CI = 32.4)
MCS- (<i>N</i> = 11)	1	9% (CI = ±16.9)	10	91%	5	45% (CI = 29.4)

*Yes = subjects identified as responders in active condition.

**No = subjects identified as nonresponders in active condition.

CI = 95% confidence interval.

$\eta^2 = .36$), due to a larger amplitude at Fz compared to both Cz ($p = .04$) and Pz ($p = .01$).

In task 2, the instruction to count SON resulted in a significant main effect of condition, with a larger P3 compared to passive listening to SON for both peak ($F(1, 19) = 44.83, p < .001$, and partial $\eta^2 = .78$) and mean amplitudes ($F(1, 19) = 24.44, p < .001$, and partial $\eta^2 = .56$). No significant main effect of electrode location in peak was found, but there was for mean amplitude ($F(1.22, 23.12) = 5.32, p = .03$, and partial $\eta^2 = .22$), due to a maximum effect at Pz compared to both Fz ($p = .03$) and Cz ($p = .02$). Likewise, P3 to SON in the counting condition was also significantly larger than that to SON in the passive condition in task 1 ($F(1, 19) = 32.12, p < .001$, and partial $\eta^2 = .63$), with a main effect of electrode location ($F(1.16, 22.01) = 7.15, p = .01$, and partial $\eta^2 = .27$), due to a maximum effect at Pz compared to Fz ($p = .03$).

3.2. Individual Responders among Controls and Patients in Active Tasks

3.2.1. Individual P3 Effects in Controls. A main objective was to identify the rate of individual responders, that is, subjects with elevated P3 amplitudes in active compared to passive conditions. As noted in Table 2, 15/20 controls showed an enhanced P3 in the active compared to the passive condition of task 1. On a trial-by-trial basis, 11 of these could be confirmed statistically. On the other hand, all controls, except one, displayed larger P3 amplitudes in the active counting condition of task 2 (see Table 2). Here, enhanced P3 curves in the counting relative to the passive listening condition was confirmed statistically on an individual level in 17/20 controls.

3.2.2. Individual P3 Effects in MCS Patients. The criterion for a patient being identified as a responder was the same as for the healthy controls, namely, identification of the P3 component at all midline electrodes and a larger P3 at minimally one midline electrode in the active condition compared to the passive. On visual inspection, only four patients (three MCS+/one MCS-) showed a larger P3 component in the active compared to the passive condition of task 1

(see Figure 1), whereas three (all MCS+) could be confirmed statistically. Also, six MCS+ patients who demonstrated command-following behaviorally failed to be detected in task 1, rendering a false negativity rate of 67%, while one MCS- patient with absence of behavioral command-following was considered a responder in this task. On the other hand, 9/20 patients (four MCS+/five MCS-) showed higher P3 amplitudes in the active counting condition compared to the passive listening in task 2. Here, five MCS+ patients who showed behavioral command-following did not display elevated P3 responses in the counting condition, yielding a false negative rate of 56%. Yet, five MCS- patients with absence of behavioral command-following were considered responders in this task. Seven of these identified responders (four MCS+/three MCS-) could be confirmed statistically in a trial-by-trial basis analysis. The MCS responders in the counting task are shown in Figure 5, where ERPs are illustrated at the midline electrode with the most pronounced P3 response. Notably, only two patients (patient MCS+ 1 and MCS- 10) were responders across both active tasks, and therefore a total of 11/20 MCS patients had enhanced P3 amplitude in one of the two active counting conditions, or both. All in all, 5 patients showed elevated P3 in active mental tasks (in one or both tasks), but no behavioral command-following. Sensitivity of the ERP assessment was 67% (95% CI ±30.7), and as six MCS- patients also lacked a P3 effect in the active tasks, specificity was 55% (95% CI ±29.4). In addition, of the nine patients that showed command-following in the CRS-R assessment session, three failed to demonstrate enhancement of P3 in either active condition.

3.2.3. P3 Effects in the Active Counting versus Passive Condition of Task 2 in MCS Responders. The patient responders' grand average ERPs in task 2 were investigated with the same procedure as the healthy control group data (temporal window for analysis of P3 mean amplitude in patient responders was examined at both 300–500 and 800–1000 ms after stimulus). As can be seen in Figure 5, there was a prominent heterogeneity in P3 latency across the individual patient responders, rendering a lack P3 effect of the active counting condition on a group level.

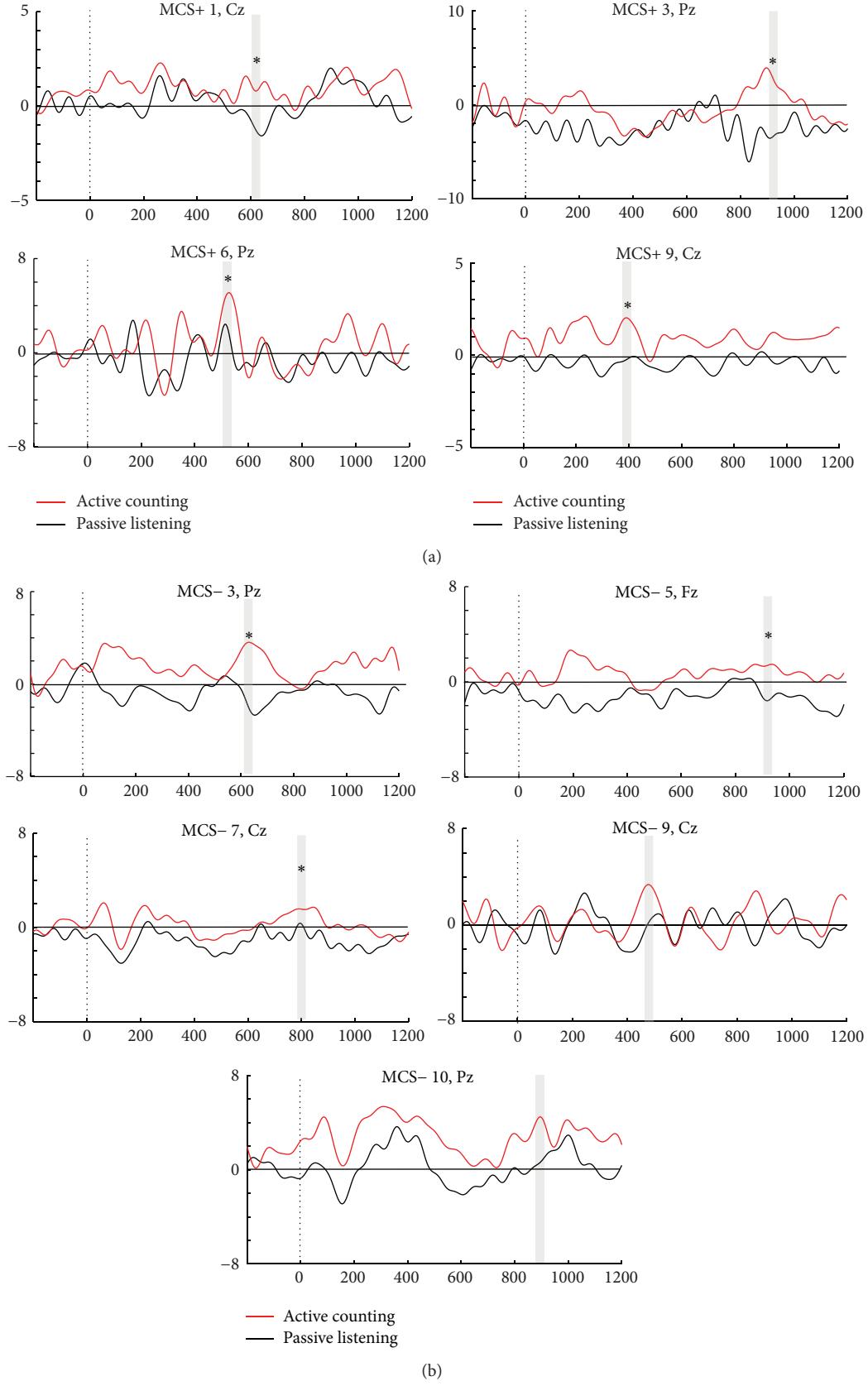


FIGURE 5: Individual patients considered responders in the active counting condition of task 2. (a) Illustrates ERPs in individual MCS+ responders in task 2, while (b) provides ERPs in individual MCS- responders. The averaged ERPs in the active counting (red) versus passive (black) condition (y -axis, amplitude in μ V; x -axis, time in ms) are illustrated. Observed significant differences of P3 amplitude between conditions (p values $< .05$ to $.001$) are marked with a star above the P3 curve marked with grey line.

There was no significant difference in time since injury between patients classified as responders in task 1 or 2 and nonresponders.

4. Discussion

The aim of this study was to explore the robustness of two active ERP tasks that differed in stimulus type and cognitive load. Tasks were first administered to healthy subjects and then to a group of MCS patients to investigate their utility in detecting covert command-following on an individual level.

To probe for covert cognitive resources in DoC patients with electrophysiological methods requires specially tailored stimuli with an established probability of eliciting P3 responses. This study used the subjects' own name (SON) contrasted with an unfamiliar name (UN) and revealed a larger P3 to SON compared to UN in the control group, confirming earlier findings showing increased probability of enhanced responses with salient self-referential stimuli [25–27, 29, 38]. A larger N1 was in contrast found to UN. N1 is recognized to be affected by stimuli change and attention [45, 50]. At the time point control subjects are introduced to UN, they have already been exposed to SON repeatedly. Herein, the addition of UN to SON represents a novelty of UN, and attention allocation towards novel stimuli may thus have affected the early N1 component in controls.

In the inquiry of which of the two ERP tasks constitutes the most robust paradigm among healthy controls, both a markedly larger N1 and P3 potential were found for the active task requesting counting of SON compared to active listening to pitch in the control group. The robustness of the counting task was furthermore confirmed when exploring the rate of individual responders across the two tasks among the healthy subjects, revealing a 95% responder rate in the counting task. In contrast, only 75% of the healthy controls could be identified as responders in the task where listening for a change in pitch constituted the active task. This is in line with the previous study of Schnakers and colleagues using the same pitch paradigm, where a 78% responder rate was seen in the control group [30]. Taken together, the results suggest greater robustness of the counting task in eliciting a P3 effect in active tasks. The robustness of tasks requiring counting of a target stimulus has also been demonstrated in earlier DoC-related ERP studies, showing a 100% responder rate amongst individual healthy controls [37, 38]. The robustness of the counting task was also reflected in the patient group, with more responders in the counting task (9/20) compared to actively listening for change in pitch (4/20). Although it is established that P3 amplitude is affected by level of attentional task load [22, 23], it is not the actual P3 amplitude, but the fact that a difference between active and passive tasks can be identified indicates the presence of consciousness on an individual patient level. Instruction to actively listen for change in pitch in task 1 elicited a more pronounced frontal P3 effect in the control group. This result is comparable with the frontal P3 effect found in the previous study of Schnakers et al. [30], using the same pitch paradigm. In contrast, the counting task

elicited a larger parietal P3 effect. The differentiation in P3 topography elicited in the control group between the two active task instructions most likely reflects divergence in the attentional demands of the task. Actively listening for change in pitch represents a low cognitive load but requires focused attention, while the counting task demands working memory and selective attention towards SON. The results are in line with previous ERP studies that have also found a parietal P3 effect in healthy controls and MCS patients when instructed to count a specific target stimulus [39, 51], and a parietal activation is furthermore described as the typical scalp distribution of a target P3 response with working memory load [22].

With regard to the ability of ERP to distinguish between MCS+ and MCS-, sensitivity was 67%, with three patients with definite behavioral signs of consciousness not displaying clear electrophysiological evidence of command-following. Previous studies have also revealed false negatives, although these numbers are not always reported. The lack of responses in ERP tasks could be explained by a number of cognitive factors, such as variability in vigilance and arousal, fatigue, habituation, and limited attention span. However, lack of enhanced P3 response in active tasks in the current study cannot solely be explained by fatigue, habituation, or decreased arousal levels over time, as there were more responders in the last condition. However, fluctuations in vigilance throughout the session cannot be ruled out. Additionally, of the MCS+ patients, only 6/9 showed command-following both in ERP and CRS-R, demonstrating inconsistency between the behavioral and neurophysiological measures. This could either be explained by fluctuation of functioning or the fact that one could argue that the ERP experiments of active listening to pitch or counting represent a higher cognitive demand compared to the command-following instructions of the CRS-R, for example, to move a limb, or look at a target stimuli. The ERP tasks require the patient not only to be awake and conscious during the recording, but also to understand the instructions, be able to keep perceptual representations in working memory, and continuously perform the task. In other words, a DoC patient with cognitive impairments in any of the listed processes may miss the task but do not lack consciousness. Furthermore, the response is assessed over a shorter number of sequences in the CRS-R compared to ERP. In summary, also MCS+ patients are likely to suffer from underlying severe cognitive deficits, and the probability of revealing their residual cognitive resources in ERP assessment is dependent upon the complexity of the tasks. Hence, as previous fMRI studies have emphasized, negative findings in this patient group cannot be interpreted as evidence that the patients lack awareness or cognitive abilities [19, 52, 53]. A goal is to establish ERP tasks that are demanding enough to elicit cognitively mediated responses, but simple enough to not exceed the cognitive capacity of severely brain damaged individuals.

On the other hand, a specificity of only 54% was due to 5 MCS- patients displaying electrophysiological, but not behavioral signs of command-following. As there is no established veridical benchmark of level of consciousness [8, 54–56], the relatively low specificity numbers can be

explained by the small sample or might actually be due to the fact that behavioral measures such as the CRS-R in some cases do not detect the true level of functioning in the patient. The results are in line with previous ERP studies using SON to detect covert cognitive resources in DoC patients. In Schnakers and colleagues' recent study [30], 3/8 MCS- and 1/10 VS displayed electrophysiological signs of higher cognitive functioning, undetected by standardized behavioral assessment. Also, in their earlier study, covert signs of command-following were detected in 2/6 MCS patients [38]. Signs of covert residual cognition were also detected in Lulé et al.'s study, but instead of using a salient stimulus, they instructed participants to count a target "yes" or "no" [36]. Of the 13 MCS patients included, only one, also lacking behavioral signs of command-following, could do the ERP task, but none of the three VS patients. Taken together, these studies suggest that functional neurophysiological methods may aid in detecting volitional cognition in a minority of patients where this is not accomplished with behavioral scales such as the CRS-R. Thus, this study provides further evidence that the absence of behavioral signs of cognition in severely brain-injured patients does not always indicate the true absence of such abilities and that counting the salient stimuli SON as an active ERP task may facilitate detection of covert residual cognition in DoC.

The P3 component is thought to be produced by either multiple, relatively independent generators or reflection of a central integrated system with widespread connections and impact throughout the brain. Preserved parts of this complex cortical and subcortical system may thus still enable the capacity to generate P3 [20]. However, there is debate as to whether the recordings of P3 amplitude could be affected according to different etiologies of brain injury. Cruse et al. [57] investigated the difference between TBI and non-TBI etiology regarding both overt and covert cognitive capacity in a group of MCS patients. In their EEG study, 3/4 TBI MCS patients who could not follow commands behaviorally demonstrated evidence of cognitive processing on an active imagery task, compared with none of the four non-TBI MCS patients. The authors argued that patients who progress to the MCS after a non-TBI are significantly less likely to produce evidence of high-level cognitive functioning than traumatically injured MCS patients. We did not observe a difference in detectable covert cognition based on injury mechanism in the present study. Among the 11 MCS patients showing enhanced P3 amplitude in one or both of the active counting conditions, five had TBI and six non-TBI. Of the five patients showing elevated P3 in active mental tasks, but no behavioral command-following, two were non-TBI. Additionally, no link was found between responders and nonresponders with regard to time since injury.

In order to incorporate new functional neurophysiological techniques in addition to standardized behavioral assessment in the clinical setting, establishment of robust electrophysiological measures of brain activity is required. In accordance with the results of this study, the robustness of counting SON contrasted to a passive condition increases the detection of residual covert cognitive resources on an individual level in patients with disordered consciousness and thus

may provide valuable complementary clinical information in a subset of patients. A P3 response in healthy persons typically peaks between 300 and 600 ms [22]; however, prolonged latency in brain injured patients relative to healthy subjects has been demonstrated [58], also when using the persons' own name [26, 30, 38]. The results show that P3 latency varies prominently between individual patients, resulting in an inconsistent P3 effect for the active counting condition on the MCS group level. Thus, in order for this ERP paradigm to be a robust and sensitive measure of covert command-following in MCS patient groups, analysis procedures must adapt to individual, and often prolonged, P3 latencies.

Study Limitations. This study illustrates several challenges concerning ERP studies in patients with DoC. Inherent to the DoC diagnosis, nonsedated DoC patients cannot reliably follow simple instructions. This includes difficulty following instructions not to move the eyes and body during EEG recordings, often leading to excessive motor artifacts that need to be addressed carefully in the preprocessing analysis. Thus, one would expect the signal-to-noise ratio to be lower than in healthy controls, further confirming the need for robust experimental paradigms. Furthermore, the high false negative rate we observed may be due, in part, to the fact that only one ERP recording was performed per patient. The importance of conducting serial reassessments with standardized behavioral scales [9, 59] also applies to other methodologies, including ERP. Thus, multiple ERP assessments performed on the same day or on different days would potentially reduce false negative ERP findings, but this is time-consuming and may not be realistic in a clinical setting. In future research there is a need to investigate retest reliability of ERP responses to counting SON. Also, while the ERP method has a great advantage in bypassing requirements for coordinated motor output, DoC patients may have underlying cognitive difficulties in understanding instructions limiting their capacity to engage in active ERP tasks. It has been suggested that when assessing DoC patients, one should take into account potential language deficits and provide adaptive accommodations such as presenting written or gestural instructions [60]. Further effort is required in developing robust test procedures that are not restricted by language comprehension. While neurophysiologic studies are subject to many of the same constraints as neuroimaging and behavioral studies [55], ERP may detect conscious awareness in patients who would otherwise be missed by alternate assessment modalities. Finally, the restricted sample size calls for interpretive caution regarding the exact specificity and sensitivity estimates.

5. Conclusion

To date, neurophysiological studies of residual cognitive capacity in DoC patients have been conducted with limited knowledge about which type of cognitive tasks constitutes the most robust paradigm when it comes to eliciting electrophysiological indices of covert cognitive capacity on an individual patient level. This study confirms that the use of an active task of counting the subjects' own name contrasted to a passive

listening task is robust in probing for volitional cognitive capacity in MCS patients. In spite of the fact that clinical ERP assessment on an individual level in DoC patients is challenging, it offers supplementary information about covert cognitive resources in some patients.

Disclaimer

The authors alone are responsible for the content and writing of the paper.

Conflict of Interests

The authors report no conflict of interests.

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Research Article

Exploring Vocational Evaluation Practices following Traumatic Brain Injury

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Background. Individuals with traumatic brain injury (TBI) face many challenges when attempting to return to work (RTW). Vocational evaluation (VE) is a systematic process that involves assessment and appraisal of an individual's current work-related characteristics and abilities. **Objective.** The aims of this study are to (1) examine demographic and employment characteristics of vocational rehabilitation providers (VRPs), (2) identify the specific evaluation methods that are used in the VE of individuals with TBI, and (3) examine the differences in assessment method practices based upon evaluator assessment preferences. **Methods.** This exploratory case study used a forty-six-item online survey which was distributed to VRPs. **Results.** One hundred and nine VRPs accessed the survey. Of these, 74 completed the survey. A majority of respondents were female (79.7%), Caucasian (71.6%), and holding a master's degree (74.3%), and more than half (56.8%) were employed as state vocational rehabilitation counselors (VRCs). In addition, over two-thirds (67.6%) were certified rehabilitation counselors (CRCs). Respondents reported using several specific tools and assessments during the VE process. **Conclusions.** Study findings reveal differences in use of and rationales for specific assessments amongst VRPs. Understanding VRP assessment practices and use of an evidence-based framework for VE following TBI may inform and improve VE practice.

1. Introduction

Traumatic brain injury (TBI) is a common injury with a unique incidence, prevalence, and consequence [1–4]. By definition, brain injury is “an insult to the skull, brain, or its covering, resulting from external trauma, which produces an altered state of consciousness or anatomic, motor, sensory, cognitive, or behavioral deficits” [5]. Individuals reporting any level of TBI severity, whether mild, moderate, or severe, have significantly higher percentages of activity limitations and lower satisfaction with life [6]. To determine the severity

of TBI requires an assessment of patient function and observable structural properties of the affected brain [4, 7–9]. Some 3 to 5 million individuals in the United States currently live with the long-term effects of a TBI [4, 10, 11]. In Florida, where this study is located, over 210,000 people have a TBI-related disability and these numbers are expected to rise [12, 13].

TBI may affect any or all aspects of daily living, including the ability to work [2, 4, 14–26]. The national estimates of the costs of medical care, rehabilitation, and loss of productivity for persons with TBI approximate \$76.5 billion annually [27–29]. Unemployment is higher among individuals with TBI,

who often have significant problems working after injury [15, 30–42]. Approximately 60% of patients with TBI are unable to return to work and approximately 35% of individuals with TBI are able to find only part-time work (35%) [43]. Due to the consequential nature of the injury, returning to work for individuals with TBI is challenging [15, 17, 19–21, 27, 30–34, 40, 44–50]. Even individuals with mild traumatic brain injuries may experience limitations in employment and social functioning [39, 51].

Rates of unemployment are even higher (60–90%) for individuals with TBI who do not receive specialized rehabilitation or interventions [21]. In Florida, employment rates for individuals with TBI receiving state vocational rehabilitation services range between 8.6% and 10% [53, 54]. Underemployment and unemployment following TBI can have detrimental effects for individuals, their support systems, and their communities [55–57]. These include diminished life satisfaction and psychological well-being, as well as poor community reintegration in the areas of home, social, and leisure activities [2, 36, 58–60].

Conversely, there are many benefits in returning to work following a TBI. Individuals report improved quality of life and fewer symptoms of depression and anxiety [26, 34, 50, 58, 61]. Work also provides a sense of structure and purpose, has economic rewards, and helps maintain respect from peers [32, 49]. Essentially, work provides a sense of normalcy, allowing the individual to feel socially involved and connected after sustaining an injury [32, 49]. Thus, determining effective evaluations to help the person return to work is an important part of the treatment and rehabilitation of individuals with TBI.

Rehabilitation counselors and vocational rehabilitation professionals use a number of counseling and rehabilitative approaches to help persons with TBI make positive psychological adjustments to life in the community [16, 30, 32, 59, 62, 63]. Rigorous, comprehensive, and consistent vocational assessment and evaluation practices are essential for facilitating successful return to work for individuals with TBI [32, 59, 64]. Vocational assessments identify an individual's characteristics, education, training, and placement needs; serve as the basis for planning an individual's educational program; and provide insight into his or her vocational potential [65, 66].

There are three levels within a vocational assessment [65, 67, 68]. Level one screens for additional services and captures necessary, relevant, and appropriate information. Level two is the clinical phase and involves detailed case study, interviews, in-depth vocational counseling, and psychometric testing. It also may include a transferrable skills analysis. Level three is the final and most comprehensive level, which includes the vocational evaluation process. Level three is an extension of level two and may include additional strategies, such as job analysis, work samples, situational and community based-assessments, and observation of real and simulated work behavior [65, 67, 68].

Specifically, vocational evaluation is defined as a comprehensive, collaborative, interprofessional process of evaluating an individual's current work abilities and work functions, limitations, and tolerances in order to (a) gain an understanding

of an individual's work-related strengths and deficits, (b) determine whether the occupation or job being evaluated is consistent with the individual's interests and abilities, and (c) make recommendations as to the supports necessary to achieve the identified occupational or job goal (e.g., training, education, job coaching, additional services, and supports) [65, 68]. A review of the literature reveals that no evaluative or randomized controlled trials examining the effectiveness of specific vocational assessment or evaluation practices following TBI currently exist [17, 32]. However, empirically validated neuropsychologically based vocational batteries, such as the McCarron-Dial System (MDS) [69–72], do exist.

Until recently, there were no specific detailed guidelines for VE of cases involving TBI [31, 32, 64, 67]. However, Stergiou-Kita and colleagues [64] identify seven process domains, with key factors integrated in each domain, evaluators should utilize when they conduct VE with individuals with TBI. The process domains are (1) identification of the evaluation purpose and rationale; (2) intake process; (3) assessment of person; (4) assessment of the environment; (5) assessment of occupation/job requirements; (6) analysis and synthesis of assessment results; and (7) development of evaluation recommendations. Key personal, environmental, and occupational factors also are considered within the context of their effects on an individual's work performance. These domain processes and factors are integrated into an evidence-based framework (EBF), which was utilized to develop the clinical practice guideline (CPG) for VE following TBI. The purpose of the EBF following TBI is to outline what important information vocational evaluators should consider, discuss, and recommend during and after completion of VE. Figure 1 illustrates the EBF for VE following TBI [52, 64].

Considering the increase in TBI nationally and in Florida, and the development of a VE clinical practice guideline specific to TBI, there is little in the literature that examines the daily practice of VE for TBI. With that in mind, we conducted a case study to gain a fuller understanding of how vocational rehabilitation professionals make sense of the VE process when evaluating a person with TBI. Hence, the purpose of this paper is threefold. First, the study describes demographic and employment characteristics of a small cohort of vocational rehabilitation providers (VRPs) who evaluate individual work abilities following TBI. Second, the study broadly identifies the evaluation methods reported as important when conducting vocational evaluations with individuals with TBI after injury. Finally, it examines differences in preferred tools and assessments used by evaluators.

2. Methods

This case study explores the processes and factors relevant to the practice of VE following TBI in the state of Florida with the intent to (1) inform current vocational evaluation practices and (2) improve the understanding of vocational assessment and evaluation of individuals with TBI.

2.1. Ethics Statement. The Institutional Review Board (IRB) determined that this research study (eIRB 00013147) met the University of South Florida (USF) requirements and Federal

Exemption criteria as outlined in 45 CFR §46.101(b)(2): “research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior; unless (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects’ responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects’ financial standing, employability, or reputation.” Before responding to any study questions, participants completed an electronic online informed consent form.

2.2. Design. Case study designs focus on providing a detailed account of one or more cases with an interest in both their uniqueness and commonality. Since the intent of a case study is to be descriptive, exploratory, and explanatory, case studies are preferred when we want to make sense of a situation or how an individual understands something that is not readily apparent to an external viewer. Understanding the “how” or “why” things are done addresses a “phenomenon” within a real-life context and can be used as a sense-making tool that can help change practice and inform policy. Case study designs are often used when conducting exploratory or pilot studies of a particular population.

The target population was vocational rehabilitation providers (VRPs) in Florida who conduct and/or review vocational evaluations of individuals with TBI who reside in Florida. The VRP included public and private rehabilitation counselors and independent vocational evaluators and vendors in Florida. This one-year exploratory study distributed a cross-sectional online survey to VRP. A web-based survey format was chosen to provide a “snapshot” of the target population and to establish a baseline of their perceptions [73]. The survey was anonymous and self-administered online and contained forty-six (46) items. Survey questions were a mix of yes/no, single and/or multiple answer selections, Likert scales, and open-ended questions. Many of the yes/no questions included an option for further comments or explanations.

Survey items were developed based on an empirically validated framework for vocational evaluation following TBI [52, 64]. Survey items captured basic demographic information about VRP, including age, sex, race/ethnicity, level of education, and history of employment. Items further surveyed evaluation processes perceived to be most valuable and identified the tools evaluators used to conduct or review assessments. Continuous and categorical scales were used to measure items on the survey instrument. Stratification was not used before selecting the sample.

The anonymous survey function in the Qualtrics Survey Research Suite ensured that all responses were anonymous. Further, since Qualtrics uses cookies to save the respondents’ progress, if the respondents start the survey, leave, and come back to the same browser, they will resume where they left off [74]. Settings in Qualtrics that were selected did not allow respondents to go back and change answers, but they were allowed to skip questions. Participants could complete the

survey from their computer. The survey could be accessed from other computers and locations.

The initial survey was sent to two experts in vocational evaluation and survey design for review, to solicit feedback and to provide an estimate of survey completion time. Minor suggestions for reorganization and editing were provided by the experts. As a result, minor modifications and improvements were made prior to distributing the survey to VRPs in Florida. Due to the length of the survey, it is not included in the appendix. The corresponding author will provide a copy of the survey upon email request.

2.3. Participants. Participants in the current study were Florida VRPs who were invited (via email) to participate in an online survey to assess factors related to vocational evaluations (VEs) of individuals with TBI. The invitational email included a description of the study and provided a link to an electronic online informed consent form. The electronic consent form, approved by the USF IRB, ensured that participants would have appropriate information on the scope and aims of the study, as well as the procedures the researchers would use to ensure confidentiality and privacy of the respondents.

Email addresses were obtained from the Florida Division of Vocational Rehabilitation (FL-DVR), the Commission on Certification of Rehabilitation Counselors (CRCC), and the International Association of Rehabilitation Professionals (IARP). To be included in the study, VRP must currently conduct or review vocational evaluations of individuals with TBI residing in the state of Florida or must have conducted or reviewed vocational VEs within the past five years.

VRP respondents were excluded from the study if they (1) had their certification or licensure revoked; (2) were not currently conducting or reviewing VEs of individuals with TBI in Florida; (3) had not conducted or reviewed VEs with individuals within the previous five years; (4) had medical or psychiatric conditions precluding comprehension/completion of the study; (5) were students without appropriate certification and licensure; or (6) were unable to provide informed consent.

Preapproval to distribute the survey to vocational rehabilitation professionals was obtained from the Director of the Division of Vocational Rehabilitation in Florida. A total of 653 emails were sent to public and private VRPs in Florida. Of the possible number of total respondents, 109 respondents accessed the survey and 80 (73.3%) respondents completed the online survey. Six individuals did not currently work with individuals with TBI or they had not worked with this population within the past five years. Since these 6 individuals were not eligible to complete the study, no demographic information was collected on them. The final sample used for the present study was 74 respondents. There were no differences in sociodemographic variables between those who did ($N = 74$) and did not complete the survey ($N = 29$). All respondents (including those who did not meet the inclusion criteria) were linked to a separate survey to request a copy of the survey report and enter the drawing for a chance to win the gift card.

There are many potential influences on response rates in e-mail surveys, including respondent contacts, length of surveys, design issues, research and academic affiliations, and compensation [75]. Kaplowitz et al., for example, determined that there was a 10 percentage point discrepancy in the number of responses to an email survey (21%), compared to a postal survey (31%) [76]. Since our intent was to confirm that the sampling process acquired a representative collection of respondents for purposes of a case study and as a pilot study, the 17% response rate was low but deemed acceptable. The average survey completion time was 20 minutes, which was five minutes longer than the time estimated by both of our expert survey reviewers. This discrepancy may be due to the experts' familiarity with the subject matter and the Qualtrics survey research program.

2.4. Procedure. Participants who responded to the invitational email completed a 15-minute online survey administered through the Qualtrics software program, which administers surveys and stores confidential survey responses. Qualtrics data are stored in SSAE 16 certified facilities that meet the privacy standards imposed on health care records by the Health Insurance Portability and Accountability Act and the Health Information Technology for Economic and Clinical Health Act [77].

The online survey consisted of 46 yes/no, multiple choice, and open-ended questions. In addition to the collection of basic demographic information, items asked about specific evaluation processes, tools used when conducting VEs, and the review of client vocational reports. Survey items were developed based upon the existing clinical practice guideline entitled *Evidence-Based Framework for Vocational Evaluation following TBI* (EBF). Survey items were aligned with the seven processes in the EBF [52, 64]: (1) identification of the evaluation purpose and rationale; (2) intake (gathering information); (3) person domains (assessment); (4) environmental elements (assessment); (5) occupation and job requirements (assessment); (6) analysis and synthesis; and (7) evaluation recommendations. Figure 1 illustrates the evidence-based framework for VE following TBI [52, 64].

As a recruitment strategy, participants had the option to sign up for a chance to win a \$100 gift card after they completed the survey. If they were interested in entering the drawing, respondents were redirected to a separate survey to provide their contact information. To ensure confidentiality, the separate survey was not linked to the main survey.

2.5. Data Analysis. All data responses were downloaded from the Qualtrics website into an SPSS 22.0 dataset file. Data included demographic responses, tools and assessments used in VE, specific characteristics of VRP, and responses to the open-ended questions. Demographic responses were coded and grouped based on the level of education, certification, and training of the respondent. Respondents reported their highest level of education (bachelor's, master's, or doctorate degree) and what type of certifications they currently hold (respondents were able to select more than one certification or credential). In addition, respondents reported how many

years of experience they had conducting VE by selecting the appropriate range of years of experience in the survey.

Qualitative data were gathered through open-ended survey questions. The questions were used to (1) clarify the choice of predefined responses and (2) gather additional qualitative data on the purpose of the VE. The questions included the purpose and rationale of the VE; the intake process; issues surrounding assessment, data analysis, and synthesis; and evaluation recommendations. Respondents also were asked to consider characteristics of best TBI evaluators and list characteristics that set them apart from other TBI evaluators. The qualitative comments were coded, and responses were grouped into thematic categories identified in the EBF: evaluation purpose and rationale, gathering information, assessment, analysis and synthesis, and evaluation recommendations.

One question in particular, characteristics of the best TBI evaluators, was subjected to a more granular analysis based upon researcher consensus that these characteristics may be indicative of model VRP practice. This question was subjected to a second thematic analysis of eight categories: use of detailed reports, knowledge/experience with TBI population, client interaction, individualized assessment, job search information, quick evaluations, understanding the purpose of the evaluation, and creativity/honesty.

3. Results

3.1. Descriptive Information

3.1.1. Demographic Data. The majority of the participants were female (79.7), white (71.6%), and holding a master's degree (74.3%). Additionally, the majority were certified rehabilitation counselors (CRCs) (67.6%); over half (56.8%) were employed as state vocational rehabilitation counselors (VRCs). Tables 1 and 2 display the demographic data.

3.1.2. Tools, Assessments, and Techniques Considered and Used When Conducting VE. Table 3 shows the variety of tools, assessments, and techniques used when conducting VE. The most prevalent tools used were vocational interest inventories (86.5%), achievement tests (85.1%), and behavioral observations (81.1%). All other prevalence estimates are reported in Table 3.

3.1.3. Important Characteristics of TBI Vocational Evaluators. Respondents qualitatively described characteristics of best TBI evaluators and listed characteristics that set them apart from other TBI evaluators. Participant responses were grouped into eight categories. Over a quarter (27.0%) of the respondents believed that having knowledge of TBI and having experience working with this population were important (27.0%); 24.3% believed that including detailed evaluation reports of the client in the evaluation was important. Additionally, 21.6% believed it was equally important to have positive interactions with the client and also to provide individualized assessments. A smaller proportion of respondents believed that providing the client with job search information (5.4%), being creative and honest when

TABLE 1: Demographic information ($N = 74$).

Variable	<i>N (%)</i>
Gender	
Female	59 (79.7)
Male	14 (18.9)
Did not answer	1 (1.4)
Age group	
18–30	13 (17.6)
31–40	19 (25.7)
41–50	14 (18.9)
51–60	16 (21.6)
>61	9 (12.1)
Did not provide a response	3 (4.1)
Race	
White	53 (71.6)
Black/African American	9 (12.2)
Hispanic	7 (9.5)
Other*	5 (6.7)
Highest education	
Bachelor's degree	13 (17.6)
Master's degree	55 (74.3)
Doctoral degree	6 (8.1)

Note. * Other includes respondents that were either biracial (2), Asian/Pacific Islander (1), or Native American (2).

considering job prospects (5.4%), and providing abbreviated (4–6 hours versus 8 hours) evaluations (4.1%) were important characteristics of a VRP. However, understanding the purpose of the evaluation (1.4%) was noted as the least important characteristic to consider during the vocational evaluation of individuals with TBI (Table 4).

4. Discussion

In this study, an evidence-based framework for VE following TBI guided the development of a survey that explored the current practice of the vocational evaluation of individuals with TBI in Florida. Consistent with previous research, the data in this study suggest that VRPs vary in their preference for and use of tools, assessments, and techniques during the vocational evaluation process [32, 52, 64, 78]. Survey data further elucidates how these variations can affect VE practice.

4.1. General Survey Feedback. In this section, we examine the open-ended comments provided by the respondents, using selected elements of the framework from the *Evidence-Based Framework for Vocational Evaluation following TBI*, as shown in Figure 1: evaluation purpose and rationale, gathering information, assessment, analysis and synthesis, and evaluation recommendations [52]. Incorporated into this analysis are data describing important characteristics of TBI vocational evaluators.

TABLE 2: Employment information: credentials, years of experience, and occupation ($N = 74$).

Variable	<i>N (%)</i>
Credentials*	
CAP	3 (4.1)
CCM	4 (5.4)
CDMS	1 (1.4)
CLCP	2 (2.7)
CRC	50 (67.6)
CVE	14 (18.9)
LMFT	2 (2.7)
LMHC	7 (9.5)
ABVE	3 (4.1)
PVE	6 (8.1)
Other**	9 (12.2)
Years of vocational rehabilitation experience	
<1 years	3 (4.1)
1–5 years	16 (21.6)
5–10 years	23 (31.1)
10+ years	32 (43.2)
Occupation*	
State VR counselor	42 (56.8)
Rehabilitation educator	3 (4.1)
Independent rehabilitation Provider, public sector	3 (4.1)
Independent rehabilitation Provider, private sector	11 (14.9)
Rehabilitation service provider, nonprofit	6 (8.1)
Rehabilitation service provider, for profit	3 (4.1)
Other***	21 (28.4)

Note. * Respondents may choose more than one category. ** Other examples include Florida Certified Workforce Professional, Mental Health Counseling Intern, National Certified Counselor, Certified Brain Injury Specialist, Certified Work Adjustment Specialist, Certified Psychiatric Rehabilitation Practitioner, Certified Multisystemic Therapist, and Certified Clinical Mental Health Counselor. *** Other includes VR area supervisor, VR field supervisor, Division of Blind Services supervisor, veteran rehabilitation counselor, consultant, forensic vocational expert, and vocational evaluator not otherwise specified.

4.2. Evaluation Purpose and Rationale

4.2.1. Defining Evaluation Purpose. Stergiou-Kita and colleagues [52, 64] suggest that an essential domain for VE was the identification of the evaluation purpose and rationale. Although only four respondents (1.4%) explicitly stated this was an important characteristic for persons performing VE, the open-ended comments suggest otherwise. Respondents provided a wide range of definitions, such as “the purpose of a vocational evaluation is to learn about the customer’s interests, strengths, and aptitudes.” We also get an idea of the person’s functional limitations and strengths. In this way we are able to develop a mutually agreeable vocational goal based upon a person’s unique needs and strengths. They also delved into elements that may play a factor in VE,

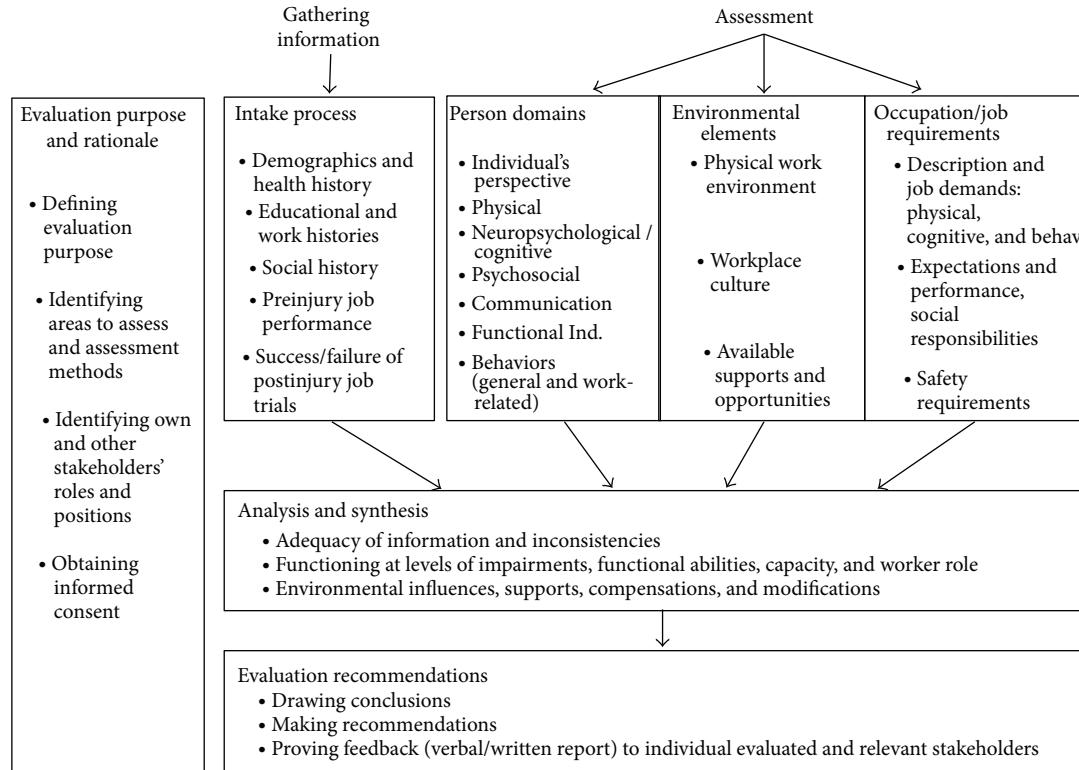


FIGURE 1: Evidence-based framework for vocational evaluation following TBI. This figure was reprinted with kind permission from Springer Science and Business Media. Note: reprinted with permission CCO license number 3697230252812. The figure was originally published in [52].

TABLE 3: Tools/assessments/techniques used in vocational evaluation.

Variable*	N (%)
Learning style preferences	30 (40.5)
Vocational interest inventories	64 (86.5)
Work values	53 (71.6)
Evaluator knowledge of TBI	54 (73.0)
Behavioral observations	60 (81.1)
McCarron-Dial System	4 (5.4)
Achievement tests	63 (85.1)
Aptitude tests, general abilities	45 (60.8)
Work samples	46 (62.2)
Neuropsychological evaluation reports	39 (52.7)
Aptitude tests, intelligence	52 (70.3)
Computer software/training aids**	15 (20.3)
Other***	13 (17.6)

Note. * Respondents may choose more than one tool/assessment/technique.

Brain Train was specifically mentioned by respondents. * Other = situational assessment, job site analysis, customized employment (e.g., Discovery), on-the-job training, volunteering, personality assessments, input from past employers and family members, and Veteran TBI Clinical Assessment.

including identification of discrete items, such as hard and soft work skills; additional accommodations, services, and supports; and “transferable” skills, abilities, and/or interests. These items, which come from the evaluation, assist in

TABLE 4: Important characteristics of successful TBI vocational evaluators.

Variable*	N (%)
(1) Detailed reports	18 (24.3)
(2) Knowledge of TBI/experience	20 (27.0)
(3) Interaction with client	16 (21.6)
(4) Individualized assessment	16 (21.6)
(5) Job search	4 (5.4)
(6) Quick evaluations	3 (4.1)
(7) Understanding the purpose of the evaluation	1 (1.4)
(8) Creative/honest	4 (5.4)

Note. * (1) Providing detailed reports, (2) having knowledge and experience working with the TBI population, (3) having positive interactions with the client, (4) providing individualized assessments, (5) providing the client with job search information, (6) conducting quick yet thorough evaluations (4-5 hours in duration), (7) having a good understanding of the purpose of the evaluation, (8) and being honest, open-minded, and having creative ideas to help accommodate the client.

determining “achievable and appropriate employment” for the client, which is central to VE.

4.3. Identifying Own and Other Stakeholder's Roles and Positions. Our finding that VRPs (27.0%) value the importance of experience and knowledge working when evaluating persons with TBI mirrors findings in the literature [30, 52, 79].

Naturally, experience may benefit vocational evaluators in all areas. However, experience and knowledge particularly contribute to a VRP's understanding of the complexity of TBI in helping their clients return to work. One respondent offered, "My clinical background and knowledge regarding the medical aspects of disability give me a unique perspective regarding the vocational impact of TBI." Additionally, it is important for evaluators to be familiar with challenges and obstacles that clients may face following a TBI. Another respondent stated that knowledge of individuals with disabilities helped clients identify their positive attributes and strengths, which tend to be harder for clients to identify than weaknesses. By being knowledgeable in these areas, VRP may be able to better support client/community reintegration and affect the likelihood of employment [80].

4.4. Identifying Areas to Assess and Assessment Methods. Respondents expressed the importance of providing detailed reports. The more detailed vocational evaluation reports are, the better they may assist counselors in determining the type and intensity of vocational services needed for their clients [68]. Respondents further highlighted the importance of evaluators having positive interactions with clients (21.6%) and conducting individualized assessments (21.6%). By providing individualized assessments, individuals with TBI may feel that they have established rapport with evaluators who are genuinely vested in their interests. Respondents agreed that "a client's personal strengths, preferences, and family considerations" were central in individualized assessments. Respondents were less likely to view abbreviated evaluations as helpful. "Tailored," "appropriate," "practical," and "realistic" were terms consistently used to describe both vocational and other client's evaluations. This may be due to a preference to spend more time discussing the purpose of the evaluation with the client and to gather detailed background information (e.g., health, social, and work histories) during the evaluation to better meet client- and VRP-generated goals [52, 57, 59, 80].

4.5. Assessment (Person, Environment, and Occupation/Job). In the literature, rehabilitation counselors consider the assessment of physical, cognitive, and psychosocial abilities, work interests, and work behaviors to be extremely important [62, 66, 68]. Almost a quarter of our respondents concurred (24.3%). Respondents indicated that they most frequently assess individuals through behavioral observation, interest inventories, work values inventories, and achievement tests. As one respondent noted, VE should "have and use a wide variety of instruments" and be able "to explain WHY they used the testing instruments that they did." However, respondents placed less emphasis on assessing communication skills, workplace culture, and social support networks. This is problematic as individuals' communication skills have been found to be relevant to employment outcomes following TBI [81]. However, respondents did identify assistive technologies and compensatory strategies as important components for assessment and augmentation of existing deficits, especially as supports from a workplace perspective. Understanding

workplace culture elements and identifying the supports that are available, to individuals with TBI, both within the workplace and their support networks, can provide the rehabilitation counselor with further valuable information for ensuring successful work transitions [15, 33, 48, 64, 80].

Respondents also reported several types of assessments to be particularly beneficial during conducting and reviewing vocational evaluations following TBI. These included situational assessments, community assessments, cognitive demands analyses, and job shadowing, which parallels findings in other studies [30, 64, 66, 79, 82, 83]. However, we also found that a very small percentage (5.4%) of VRPs use the McCarron-Dial System (MDS). Although only four individuals reported using the MDS, this finding is interesting because research shows the MDS is effective as a vocational evaluation system for persons with neuropsychological disabilities, such as TBI [72, 84]. There are several factors that may contribute to low use of this reliable and valid assessment. One factor may be the lack of knowledge about the MDS by vocational evaluators. Additional factors may be related to the cost of the system, training requirements (three dedicated days), and the amount of time needed to administer the full battery (1 week) or the abbreviated version (one half day). Further research on the potential usefulness of incorporation of the MDS into vocational rehabilitation counselor (VRC) training and direct service settings may be timely, warranted, and beneficial [85].

Slightly over half (52.7%) of study participants refer to neuropsychological reports. The literature suggests that vocational rehabilitation counselors (VRCs) may have difficulty in understanding how to use and interpret neuropsychological tests or how they apply to vocational preparation and return to work [44, 81, 86–88]. The literature, however, also shows an increase in the number of vocational rehabilitation counselors relying on neuropsychological reports to better assess their clients for job placement [64, 79, 86]. Use of neuropsychological reports by VRP is an area of research that is not yet fully elucidated and deserves further study. Neuropsychological reports may reveal additional information that the counselor is unable to capture during qualitative interviews with the client or through review of traditional vocational evaluation reports [70, 88]. Therefore, a combination of assessment techniques and a synthesis of findings from a variety of reports may be beneficial when assisting individuals with TBI in their return to work.

4.6. Analysis and Synthesis. Overall, respondents concurred that analysis and synthesis of results are two important pieces of VE; however, they are also very difficult. As mentioned above, being able to explain why specific testing instruments were used and how the results are interpreted to the client when making workplace recommendations is essential, but difficult. Reports need to be "thorough and individualized" and analyses need to factor the information necessary to address client concerns. One respondent suggested "bluntness with professional tact in conveying the realities of TBI disabilities upon placement" is a necessary and valuable characteristic for VRP, when analyzing and synthesizing all of the measures and assessments used in VE.

When asked about additional assessments for VE, respondents provided a number of areas they would like to have. Pre- and postinjury functioning were mentioned, as that would provide a 360° perspective on the client's work experience and expectation for VE. "Reality check" questions, health care needs questions, support system questions, and motivation questions were also pointed out as essential for assessment. One recurring theme was the "ability to use all aspects of the evaluation to develop the report."

4.7. Evaluation Recommendations. According to respondents, recommendations should not be just the "examination of abilities and aptitudes, but also include the true feedback of the client." Respondents also were clear that information should be presented in an easy to read manner and, perhaps, most importantly, recommendations should be a working document that "counselor and consumer can agree on and work towards."

Some findings deviated from previous literature in the field. Unlike previous findings which suggest that providing prospect and career advice is an important component of VE [52, 80, 89], only 5.4% of our respondents explicitly emphasized the importance of providing clients with honest, direct, and creative information for job prospects and information on how to improve the job search. However, respondents did identify truthfulness, honest, and accurate assessment, evidence-based vocational recommendations, and knowledge of the local labor market as important characteristics for vocational evaluators. Also, respondents may view the VE as the initial step in the return-to-work process and that the information gathered during the evaluation would contribute to future suggestions and strategies to support successful job searches. Respondents also may believe that they already provide this type of information as part of their daily practice and saw no reason to emphasize this in their responses. In retrospect, the survey should have explicitly asked this question. However, we extrapolate, based on the open-ended responses, that client needs and the information to help clients succeed are very important.

4.8. Limitations. Considerations should be taken when interpreting the results of this study. Limitations of the study include a relatively small sample size, including mostly VRP who work for the state of Florida Division of Vocational Rehabilitation. A larger and more representative sample is needed to contribute to the validity, reliability, and significance associated with these findings. Since the sample consisted predominantly of Caucasian females who hold master's degrees and are CRCs, this sample did not represent diversity in culture and gender of individuals who work as evaluators in the field of vocational rehabilitation. An additional limitation is the survey instrument, which lacks baseline measures.

Future research should include refinement of the survey instrument and consider incorporating more formal measures to examine additional factors, such as alcohol and substance use, cooccurring disorders, use of medications, and personality assessments, and consider salient factors affecting

job satisfaction and job tenure. The Qualtrics survey settings allowed for survey access and completion from different computers. When offering an incentive it is important to prevent participants from taking a survey more than once. Although there is no evidence that this occurred in our study, Qualtrics' "Prevent Ballot Box Stuffing" option will prevent respondents from taking future surveys more than once from the same computer. Future use of the Qualtrics Mailer (which creates a unique, one-time use link for each participant) will also prevent respondents from completing the survey more than once. Finally, the study was sent once via email to VRP in the state of Florida. Future recruitment efforts should include mechanisms to expand access to a more representative sample that is generalizable to a broader population of VRP who work with individuals with TBI outside of Florida.

5. Conclusions

In summary, return to work for individuals with TBI is complex and challenging due to the consequential nature of the injury. Despite the provision of necessary rehabilitation supports, many of these individuals encounter a myriad of barriers that impede successful vocational rehabilitation [62]. Employment rates are lower for persons with TBI compared to those of the general population [43, 68, 77]. Considering the complexity of challenges individuals with TBI face, rehabilitation counselors, and other vocational rehabilitation providers should consider expanding their understanding of TBI and incorporate the use of specific skills, techniques, and tools to provide psychosocial and vocational supports to facilitate return to work [62]. Due to the variability in vocational evaluation of individuals with TBI, vocational rehabilitation counselors (VRCs) and providers need to understand the key processes and relevant factors important for a thorough and rigorous vocational evaluation. VRPs require a clear, clinical knowledge of the skills and abilities that are being measured, technical expertise in test/assessment procedures, and good understanding of and appreciation of the demands of the position and work environment the client may be entering. The introduction, adoption, and successful implementation of new technologies and assessments in vocational evaluation and rehabilitation should be a focal content area in continuing education and professional development activities as well as statewide policy initiatives taking research to practice.

The evidence-based framework for VE following TBI presented may be useful for rehabilitation educators, counselors, vocational evaluators, and other rehabilitation providers. These findings can inform the current practice of vocational evaluation and ultimately improve return-to-work outcomes for individuals with TBI, by guiding and improving the vocational assessment process. Further research is needed to formally examine the success of the framework among a diverse group of vocational rehabilitation providers.

Conflict of Interests

The authors declare that there is no conflict of interests regarding publication of this paper.

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Research Article

Sexual Functioning, Desire, and Satisfaction in Women with TBI and Healthy Controls

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Traumatic brain injury (TBI) can substantially alter many areas of a person's life and there has been little research published regarding sexual functioning in women with TBI. *Methods.* A total of 58 women (29 with TBI and 29 healthy controls) from Neiva, Colombia, participated. There were no statistically significant differences between groups in sociodemographic characteristics. All 58 women completed the Sexual Quality of Life Questionnaire (SQoL), Female Sexual Functioning Index (FSFI), Sexual Desire Inventory (SDI), and the Sexual Satisfaction Index (ISS). *Results.* Women with TBI scored statistically significantly lower on the SQoL ($p < 0.001$), FSFI subscales of desire ($p < 0.05$), arousal ($p < 0.05$), lubrication ($p < 0.05$), orgasm ($p < 0.05$), and satisfaction ($p < 0.05$), and the ISS ($p < 0.001$) than healthy controls. Multiple linear regressions revealed that age was negatively associated with some sexuality measures, while months since the TBI incident were positively associated with these variables. *Conclusion.* These results disclose that women with TBI do not fare as well as controls in these measures of sexual functioning and were less sexually satisfied. Future research is required to further understand the impact of TBI on sexual function and satisfaction to inform for rehabilitation programs.

1. Introduction

Sexuality and sexual functioning are important aspects of one's life experience. Greater sexual dysfunction among women (43%) compared to men (31%) has been reported in the general population [1]. The disruption of brain functioning as a result of a traumatic brain injury may cause changes to the endocrine system [2]. In addition, sexual functioning may also be impacted by the well-documented physical, emotional, cognitive, behavioral, and relationship changes after TBI [3]. Despite the limited research on sexual dysfunction after TBI, the sample percentage reporting of sexual dysfunction has ranged in some studies from 29 to 54%, depending on the assessment time frame [4–7].

Diverse sampling methods, small sample sizes, and time of assessment after injury may contribute to differing reports of sexual dissatisfaction after TBI.

To date, only five studies have conducted a comparative analysis of sexual functioning between persons with TBI and healthy controls [4, 5, 8–10]. Overall, persons with TBI in these studies reported greater sexual dysfunction in comparison to healthy controls. Although some studies on sexual dysfunction after TBI have included women, few studies have specifically researched sexual dysfunction in women [7–9, 11].

One study found that women with TBI, having both an endocrine disorder and depression, were the most sensitive

predictors of sexual difficulties [8]. Also, women with TBI in comparison to women without disability have reported greater sexual dysfunction in areas, such as sexual energy, sexual drive, ability to achieve orgasm, and sexual arousal [8]. However, two studies did not find gender differences in sexuality between men and women [9, 11]. It appeared that men and women identified similar negative changes regarding sexuality and sexual functioning following TBI. Gaudet and colleagues [9] reported that men with TBI had great sexuality concerns compared to women with TBI as well as men and women without TBI; however, their sample size was smaller. Another study made comparisons using community-based norms. Women with TBI at one year following injury reported reduced sexual cognition/fantasy, sexual arousal, sexual behavior/experience, and orgasm [7]. In addition, when compared to men, women with TBI reported significantly lower sexual cognition/fantasy and sexual arousal, which may be due to disruptions in endocrine functioning and emotional functioning [12].

Despite the importance of sexuality after TBI and the unique issues that women with TBI experience in terms of sexual dysfunction, research efforts have utilized nonequivalent control groups, community-based norms, and non-standardized measures of sexual functioning, which are methodological limitations in the assessment of sexuality after TBI. Several demographic and injury-related characteristics related to sexuality have been identified in the TBI literature, such as age [8, 11, 13–15], time after injury [3, 13, 14], and injury severity [3]. However, the impact of these factors on sexual functioning in women with TBI is missing from the literature. As a result, the aims of this study were (1) to compare the sexual functioning, desire, and satisfaction of women with TBI to a comparison group and (2) to investigate the association between age, time after injury, and injury severity and sexual functioning, desire, and satisfaction.

2. Methods

2.1. Participants. Thirty-nine Spanish-speaking Colombian women with a moderate to severe TBI were identified in July of 2013 through a systematic review of all medical records in Hospital Universitario Hernando Moncaleano Perdomo de Neiva from August 2012 to March 2013. All patients had moderate to severe TBI confirmed in these medical records (loss of consciousness, positive computerized tomography, or magnetic resonance imaging). Inclusion criteria required that each participant be between the ages of 18 and 65, and participants were excluded if they had a history of neurological or psychiatric conditions, alcohol or drug abuse, or learning disabilities. All 39 met these inclusion criteria. Between April and December of 2013, these patients were contacted and invited to participate in the study when at least six months had passed since their injury. Ten women could not be contacted and the other 29 consented and completed the study.

The sample of twenty-nine women with TBI had an average age of 36.41 years ($SD = 11.87$), the average years of education were 9.41 ($SD = 3.35$), the mean time since injury

TABLE 1: Participant demographics.

Variable	TBI group (n = 29)	Control group (n = 29)	p value
Age, years, mean (SD)	36.41 (11.87)	36.34 (11.97)	NS
Education, years, mean (SD)	9.41 (3.35)	9.45 (3.33)	NS
Cause of TBI, %			
Motorcycle accident	44.8	—	
Interpersonal violence	13.8	—	
Fall	13.8	—	
Sports accident	10.3	—	
Pedestrian accident	6.9	—	
Car accident	6.9	—	
Other	3.4	—	
Relationship status, %			NS
Married	31.0	31.0	
Cohabiting	34.5	31.0	
Single	24.1	31.0	
Separated	6.9	6.9	
Widowed	3.4	—	
Sexual orientation, %			NS
Heterosexual	96.6	96.6	
Homosexual	3.4	3.4	
Employment status, %			NS
Full-time employment	34.5	31.0	
Unemployed	34.5	37.9	
Student	6.9	10.3	
Part-time employment	6.9	6.9	
Stay at home parent	6.9	3.4	
Other	10.3	6.9	

was 18.03 months ($SD = 10.41$), and the mean Glasgow Coma Scale score at the time of admission to the hospital was 8.07 ($SD = 3.80$). The majority (44%) sustained their TBI in a motorcycle accident, 35% were in cohabiting relationships at the time of participation, 35% were employed full-time, and 97% of the TBI sample were self-identified as heterosexual.

For every female patient who completed the study, a healthy female control matched for age was identified and recruited. All controls approached did not have a history of TBI, neurological or psychiatric conditions, alcohol or drug abuse, or learning disabilities. All consented and completed the study. The healthy control group was comprised of 29 women, with an average age of 36.34 years ($SD = 11.97$). At the time of study participation, 31% were single and employed full-time, and the majority of controls (97%) were self-identified as heterosexual. There were no statistically significant differences based on age, education, marital status, or employment status between the control group and the TBI group (see Table 1).

2.2. Measures

2.2.1. Female Sexual Function Index (FSFI). The FSFI is a self-report measure of female sexual function, which contains 19 items. It has 6 domains: desire (2 questions), arousal (4 questions), lubrication (4 questions), orgasm (3 questions), satisfaction (3 questions), and pain (3 questions) [16]. The full-scale score is obtained by adding the six domain scores, and a score of zero indicates that no sexual activity was reported during the past month. The domain scores and total score can be derived with the following formula. For individual domain scores, items that comprise the domain are added. Then, the sum is multiplied by the domain factor (ranging from 0.3 to 0.6). The total score is the sum of six domains scores, which range from 2 to 36. Higher scores indicate greater sexual function. It has excellent psychometric properties and it supports the clinical utility [17–20]. The Spanish version was used which had been previously validated by Blumel et al. [21].

2.2.2. Index of Sexual Satisfaction (ISS). The ISS is a self-report scale that measures the degree of dissatisfaction in the sexual component of a dyadic relationship [22]. It contains 25 items [22], and scores range from 0 to 100 in which higher scores indicate greater sexual dissatisfaction. The ISS has a clinical cutoff score of 30 such that scores above that value indicate the presence of a clinically significant degree of sexual discord in the relationship. It has been used in clinical samples [23–25] and has shown good psychometric properties; the validated Spanish version was used in this study [26].

2.2.3. Sexual Quality of Life Questionnaire (SQoL). The SQoL has male (SQoL-M) and female (SQoL-F) forms. It evaluates the impact of sexual dysfunction on quality of life, including sexual confidence, emotional well-being, and relationship issues. The SQoL-M has 18 items and the SQoL-F has 18 items, each with a 6-point response scale (“completely agree” to “completely disagree”), and standardized total scores range from 0 to 100. Higher scores indicate better sexual quality of life. It has good psychometric properties [27–29]. The SQoL had been validated in Spanish and this version was utilized [30].

2.2.4. Sexual Desire Inventory (SDI-2). The SDI-2 is an 11-item self-report measure of sexual desire that assesses dyadic and solitary sexual desire as two subscales [31]. Participants rate how strong their desire would be in a variety of sexual situations during the last month. Scores are summed across items, with higher scores reflecting stronger sexual desire [32]. The scale has excellent psychometric properties and it has been used in the general population, in clinical samples, and had been validated in Spanish [33].

2.3. Procedure. Local researchers reviewed medical records to identify individuals with TBI who were treated at the Hospital Universitario Hernando Moncaleano Perdomo de Neiva, between October 2012 and June 2013 in Neiva. Each

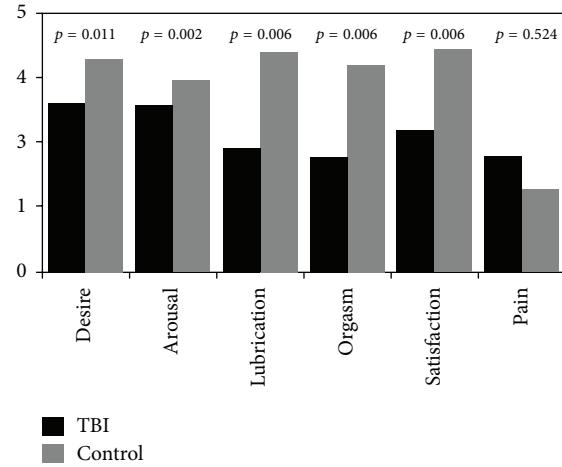


FIGURE 1: Female Sexual Function Index mean subscale scores.

candidate was screened by telephone to determine whether he or she met inclusion or exclusion criteria. The healthy control group was recruited from the general population through flyers at neighborhood churches, stores, and restaurants and by general word of mouth. After the details of the study were explained to each eligible candidate, individuals who expressed interest were invited to participate. Once the individuals with TBI and healthy controls agreed to participate in the study, they were asked to sign a form that indicated their informed consent in accordance with regulations approved by Universidad Surcolombiana, Colombia. All of the participants completed an interview with a graduate student under the supervision of a university professor. The student collected demographic information and conducted a psychosexual evaluation with TBI survivors and the healthy controls. The interviews lasted for approximately 1 hour. This study was reviewed and approved by the ethics committee of Universidad Surcolombiana.

3. Results

Women with TBI reported significantly lower mean scores than the control group on the FSFI subscales of desire, arousal, lubrication, orgasm, and sexual satisfaction (see Figure 1). The mean overall FSFI score for women with TBI was 15.12, while it was 22.04 for the control group. 83% of the participants with TBI met the clinical cutoff for sexual dysfunction while 69% of the participants in the control group met the same criteria, although these differences were not statistically significant ($p > 0.05$).

Participants in the TBI group scored significantly lower on the SQoL and the SDI Dyadic subscale and notably higher than the women in the control group on the ISS. There were no statistically significant between-group differences with Overall SDI and the SDI Individual subscale scores. See Table 2.

Although the sample size for these regressions was limited to the 29 women with TBI in the current sample, multiple regressions with three predictors using this sample

TABLE 2: Sexuality measure mean scores in the TBI ($n = 29$) and control ($n = 29$) groups and between-group differences.

	TBI group		Control group		<i>p</i> value
	Mean (M)	Standard deviation (SD)	Mean (M)	Standard deviation (SD)	
SQoL	56.54	16.56	84.64	13.00	$p < 0.001$
SDI*	38.21	23.58	49.59	21.09	$p = 0.135$
SDI Dyadic*	26.38	18.67	37.38	15.76	$p = 0.027$
SDI Individual*	4.62	7.23	2.72	5.31	$p = 0.346$
ISS	47.44	14.75	22.61	8.96	$p < 0.001$

Notes: * Kolmogorov-Smirnov and Shapiro-Wilk; $p < 0.05$.

SQoL: Sexual Quality of Life Questionnaire; SDI: Sexual Desire Index; ISS: Index of Sexual Satisfaction.

approximately meet the conventional guidelines of having 10 participants per predictor variable. Additionally, a power analysis was conducted for a multiple regression with three predictors. With an $\alpha = 0.05$ and power $(1 - \beta) = 0.80$, the current study's sample size of 29 could uncover only large-sized effects (with an $f^2 > 0.44$). As a result, null omnibus results should be interpreted with caution. For the TBI group only, four simultaneous multiple regressions assessed the relationships between the variables of age, time since the injury (months), and injury severity as measured by GCS score at admission with the FSFI subscales of arousal, lubrication, orgasm, and satisfaction. The model for arousal was significant ($F(3, 25) = 8.028, p = 0.001, R^2 = 0.491$) and accounted for 49% of the variability of the arousal subscale. Age ($\beta = -0.443, p = 0.006$) and months since injury ($\beta = 0.472, p = 0.006$) statistically significantly added the model, while GCS did not ($\beta = -0.080, p = 0.613$).

The model for the FSFI lubrication subscale was statistically significant ($F(3, 25) = 6.416, p = 0.002, R^2 = 0.435$) and accounted for 44% of the variability of this subscale. The variables of age ($\beta = -0.473, p = 0.005$) and months since injury ($\beta = 0.413, p = 0.018$) were independently related to the lubrication subscale, but GCS score was not ($\beta = 0.083, p = 0.619$).

The third model with the orgasm subscale as the independent variable was statistically significant ($F(3, 25) = 7.887, p = 0.001, R^2 = 0.486$) accounting for 49% of the variance in this variable. Within this model, the variables of age ($\beta = -0.373, p = 0.018$) and months since the injury ($\beta = 0.563, p = 0.001$) were uniquely related to orgasm functioning, whereas GCS was not ($\beta = 0.759, p = 0.445$).

The final model for sexual satisfaction was significant ($F(3, 25) = 8.835, p < 0.001, R^2 = 0.515$) and accounted for 52% of the variance in this variable. Age ($\beta = -0.415, p = 0.008$) and months since injury ($\beta = 0.544, p = 0.008$) were independently associated with satisfaction, but GCS was not ($\beta = 0.226, p = 0.150$).

Also for the TBI group only, a series of simultaneous multiple regressions were performed in order to investigate the connections from age, months since injury, and TBI severity with sexual desire. The model with Overall SDI score as the dependent variable was statistically significant ($F(3, 25) = 7.913, p = 0.001, R^2 = 0.487$) and accounted for 49% of the variability. Age negatively predicted overall sexual desire ($\beta = -0.59, p < 0.001$), though months since injury ($\beta = 0.28, p = 0.081$) and GCS ($\beta = -0.747, p = 0.462$) did not. In another

regression, the same variables significantly accounted for 46% of the variability of the SDI Dyadic subscale ($F(3, 25) = 7.024, p = 0.001, R^2 = 0.457$). Age was the only variable with a unique effect ($\beta = -0.638, p < 0.001$), as months since injury ($\beta = 0.154, p = 0.313$) and GCS ($\beta = -0.040, p = 0.805$) were not statistically significant.

Five multiple regressions were also conducted to assess whether the independent variables of age, months since injury, and initial GCS were associated with the dependent variables of SQOL, FSFI Pain, FSFI Desire, ISS, and SDI Individual scores. None of these models were statistically significant.

4. Discussion

The principal objectives of this research were to evaluate the sexual functioning, desire, and satisfaction in women with TBI, as well as compare these areas with a control group. Women with TBI reported sexual difficulties in the six areas of sexual functioning evaluated and fared worse than the control group in eight of eleven sexuality constructs measured.

4.1. Sexual Functioning. The mean FSFI score for women with TBI was 15.12, well below the 26.55 cutoff for sexual dysfunction [34]. In reference to the FSFI, there were statistically significant differences between women with TBI and the control group on five of the six subscales. Women with TBI reported less desire, arousal, sexual satisfaction, lubrication, and orgasm function. Similar results of decreased sexual functioning in control studies were found in Australia using the Brain Injury Questionnaire of Sexuality [10] and in the United States [8]. When taking age into account, these differences were exclusive to the 46–55 age range in the Australian study [10]; this contrasts with the results of the present research where between-group differences were found with a nearly one decade younger average age (36.41 TBI group; 36.34 control group) of the participants. The American team found differences between the study group and control in arousal and vaginal lubrication, as was found in this study. However, they found a higher frequency of pain during sexual activity which was not reflected in these data.

The multiple regressions found that age has a negative relationship with both arousal and lubrication in women with TBI; similar results have been found by other authors in population-based studies [35, 36] and in persons with TBI

[8, 12, 16]. Conversely, months since injury had a positive relationship with these measures, such that sexual functioning may be improving over time. Sabhesan and Natarajan [36] reported that, without intervention, in twelve months after the incident, only 38% of people who had sustained a TBI returned to preincident sexual functioning. Ponsford et al. [11] found that shorter recovery time was related to lower sexual functioning. The findings of the present study suggest that the passage of time does correlate with improved sexual functioning in women with TBI. However, this does not fully resolve sexual dysfunction, perhaps indicating that sexuality-specific intervention programs may be beneficial toward recovering sexual functioning after TBI.

4.2. Sexual Satisfaction. Two measures for sexual satisfaction were utilized, the Female Sexual Functioning Index Satisfaction subscale and the Index of Sexual Satisfaction. For both measures, women with TBI reported significantly lower sexual satisfaction than their counterparts in the control group. This disparity could be related to the difficulties reported with desire, arousal, lubrication, and orgasm. Consistency in orgasm frequency has been found to influence sexual satisfaction in Spanish women without TBI [37] and may likely have played a role in the current sample. The multiple regression analyses utilizing the FSFI Satisfaction subscale found that age has a negative relationship with sexual satisfaction similar to results from other studies in general populations [38]. This relationship does not explain between-group differences; however, the average age of the study and control group participants was not statistically different. While age appears to be a factor in sexual satisfaction, it does not account for the lower reported sexual satisfaction levels in TBI survivors compared to the control group.

4.3. Desire. Of the two measures used to assess sexual desire, differences between the study groups were found with the FSFI Desire subscale and the Sexual Desire Inventory Dyadic subscale; women with TBI endorsed less desire than participants without. Similar differences were not found in a comparable control group method study [39]. Although no significant between-group differences were found in the SDI Individual subscale, women with TBI reported on average more desire for self-pleasure than women in the control group (see Table 2). Perhaps because of the many between-group differences outlined above, holistically, women with TBI reported overall lower sexual quality of life, as indicated by FSFI and SQoL scores. Altered sexual functioning after TBI may negatively impact one's sexual relationships, sexual confidence, and emotional well-being. Together, these results add to the literature documenting disparities in sexuality among women with TBI compared to the general population. In clinical settings, rehabilitation programs should pay specific attention to sexuality issues in order to improve quality of life after TBI. Further research would benefit from assessing possible physiological causes of sexual difficulties such as posttraumatic hypopituitarism, which has been found to be present in approximately 35% of people with moderate to severe TBI [40]. Other studies should use qualitative methods to further understand women's experiences. Unfortunately, to

date, no standardized and empirically supported intervention exists for sexuality after TBI, and as a result, many of the disparities documented in the current study are going unaddressed by the rehabilitation community. The evaluation of sexuality-specific intervention programs is a critical next step in TBI rehabilitation.

4.4. Limitations. A limitation of this study is the relatively small sample size; therefore these results should be interpreted with caution. In fact, various effects should be interpreted with caution, due to the fact that familywise error corrections were not used because of the study's limited sample size. The cross-sectional design of this study is a potential limitation, because the results speak to a specific moment in time. Longitudinal methods would be required to verify whether the sexual difficulties and disparities in sexuality measures between women with TBI and control groups found are maintained over time. Preinjury sexual functioning, desire, and satisfaction were not assessed in this study; therefore, no comparison of the results can occur regarding pre- and postinjury sexuality. The participants of this study were recruited in a specific region of Colombia, where they did not have access to rehabilitation programs, as compared to many other studies [15]. This is both a limitation and an advantage of this study; these data only allow one to better understand the ramifications of moderate to severe TBI on sexuality when general and specific rehabilitation strategies have not been carried out.

Sexuality was assessed through self-report measures, and social desirability may play a role in such a sensitive and often stigmatized construct. Similarly, individuals with TBI frequently do not accurately perceive changes in their functioning levels [41], and anosognosia could have influenced these results. In order to avoid this possible limitation or reporting bias, studies could contrast self-report data with their partner's evaluation of sexual functioning. Other factors, which could influence sexual functioning, desire, and satisfaction, are self-esteem and fatigue [39], employment status and annual income [42], presence of endocrine disorders [2], lesion location [6], use of antidepressants [5], decreased social participation [15], and depression [11, 15] or partners' possible sexual difficulties, which were not evaluated in this project and should be considered in follow-up studies.

The participants with TBI all had moderate to severe TBI according to the GCS. These results cannot be extrapolated to people with mild TBI. GCS scores did not correlate with or predict any other variables. As indicated by Balestreri et al. [43], this measure does not have a high predictive value for outcomes. The results from this study imply that this measure also does not have a high predictive value for these sexuality measures.

5. Conclusions

This cross-sectional self-report control group design study gives insight into sexual functioning, desire, and satisfaction in women with TBI. Compared to the control group, women with TBI had reduced sexual desire, arousal, orgasm function, sexual satisfaction, and lubrication. No between-group

differences were found with pain during sexual activity or overall sexual desire scores. TBI severity as evaluated by the GCS did not predict any of the variables, while age was negatively associated with arousal, lubrication, orgasm, and sexual satisfaction and months since injury positively influenced the same areas of sexuality. These findings suggest the critical need for sexual rehabilitation interventions for women with TBI.

Conflict of Interests

The authors declare that there is no conflict of interests regarding the publication of this paper.

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