Trajectories of self-reported competency up to 10 years following moderate-to-severe traumatic brain injury

Running head: Trajectories of self-reported competency

Abstract:

Objectives: To describe trajectories of self-reported functional competency up to 10 years following traumatic brain injury (TBI) and identify their predictors from baseline socio-demographic and injury severity characteristics.

Design and methods: Data from 94 participants from a longitudinal cohort of patients with moderate-to-severe TBI were analyzed. Socio-demographic and injury severity data were recorded at baseline. Participants completed the Patient Competency Rating Scale (PCRS) at 1, 2, 5, and 10 years. Hierarchical linear modelling was used to examine PCRS trajectories over time and assess baseline predictors.

Results: There was no significant change in average PCRS scores across the follow-up time points in the full sample. Emotional and cognitive competencies had the lowest mean scores. Gender, employment, and the interaction term between gender and time were significant predictors of PCRS trajectories. Females and those who were unemployed at the time of injury showed lower trajectories of self-reported competency.

Conclusion: Self-reported competency remained stable from one-year post injury for men only. Lower mean scores in the domains of emotional and cognitive competencies suggest a need for continued rehabilitation focus in the chronic phase after TBI. Special attention to women and individuals who are unemployed at the time of injury may be warranted.

Key words: Brain Injury, Outcome, Competency, Self-awareness, PCRS

INTRODUCTION:

Over the past decade, traumatic brain injury (TBI) has been conceptualized as a chronic health condition because TBI consequences continue to evolve and influence the lives of injured individuals long after the injury (1, 2). Thus, TBI presents a major challenge to healthcare systems particularly because of residual functional impairments in cognitive, behavioral, emotional and physical domains, as well as increased risk for long-term difficulties with participation in activities of daily living, family functioning, social reintegration and employment (1, 3-5). Participation in different aspects of daily life activities is identified as one of the most important outcomes of rehabilitation following TBI. In an everyday clinical practice, it is important to focus on patients' perceptions of daily functioning in order to ensure motivation and compliance during the rehabilitation process.

The Patient Competency Rating Scale (PCRS) (6) was originally designed to assess self-awareness after TBI by comparing patients and significant others' judgement of competency on behavioral, cognitive and emotional tasks (7, 8). However, relatives and health personnel may over- or underestimate non-physical problems such as cognitive and emotional/interpersonal difficulties (9). Additionally, the PCRS may be a useful measure of self-reported functioning and competency in daily activities (10-14). Hall et al. (10) compared some of the frequently applied functional measurements in TBI to identify the best- and least-suited outcome measures, and found that the PCRS was suitable for assessing functional status in long-term follow-up studies. To our knowledge, few studies have applied the PCRS as a measure of self-reported competency in daily life activities across the chronic stages of TBI (12, 13, 15). Wood & Rutterford (13) assessed psychosocial outcome in a severe TBI cohort between 10 and 32 years post injury, and

found that most participants rated their functional competency on the PCRS as slightly below the range of scores expected from non-disabled people. Sveen et al. (12) found that self-reported functional competency as rated by the PCRS three months post injury was a strong predictor of outcomes one year post injury, and specifically that the level of cognitive competency is an indicator for the potential for vocational and community integration one year after TBI. In general, acute GCS score and duration of post-traumatic amnesia (PTA) have been associated with self-awareness deficits (8, 16, 17), whereas other indices of injury severity have not shown this association (18). Regarding demographics, previous studies have found an association between male gender and early impaired self-awareness (19), whereas age as a predictor has shown contradictory results. Younger age (20) has been associated with early impaired self-awareness, on the other hand, higher age has been associated with impaired self-awareness at 12-month follow-up (8). However, less is known about the association between demographics, injury severity, and self-reported functional competency in the long-term.

Taken together, prior publications attempting to address patient-rated competency in daily life have been limited by the lack of longitudinal follow-ups, different sample characteristics and small sample sizes. Longitudinal studies of self-reported functional competency are important as the need for rehabilitation efforts after TBI can be long lasting, and the knowledge gained may be useful in guiding long-term rehabilitation programs.

This study focuses on the long-term trajectories of patients' self-reported competency in daily tasks following moderate to severe TBI. Identification of distinct competency trajectories could improve our ability to predict outcomes and develop interventions in early and later phases. The

aims were to (1) describe trajectories of the PCRS at 1, 2, 5, and 10 years post-injury, and (2) investigate whether baseline socio-demographics and injury severity characteristics could predict the trajectories of self-reported competency in daily activities.

METHODS

Participants

Participants were part of a longitudinal cohort study of patients with acute TBI. Participants were recruited at the Trauma Referral Centre level 1 for South Eastern Norway between 2005 and 2007 and met the following inclusion criteria:, a) Age range 16 – 55 years, b) admitted with an ICD-10 diagnoses of S06.0 – S06.9 within 24 hours of the injury, c) admitted with a Glasgow Coma Scale score (GCS) (21) of 3 – 12, representing moderate to severe TBI at admission or before intubation, and d) residence in Eastern Norway. Exclusion criteria were: a) previously known neurological disorder, b) associated spinal cord injuries, c) previous diagnosis of severe psychiatric disorder or substance abuse disorders, and d) unknown address or incarceration at the time of admission. All patients underwent a baseline assessment in the acute phase, and received follow-up after 1-, 2-, 5 and 10 years (22, 23).

Of the original 133 patients, thirty-two patients died during the acute, post-acute or long-term TBI phases, and four withdrew. Three patients were excluded, as they did not have outcome data (measure of PCRS) at any follow-up points. Data from 94 of the 133 (71%) patients who were included in the original study were analyzed, as these 94 individuals are the survivors with a full data set on PCRS at the 1-year follow-up. At 10-years, 66 patients completed the PCRS; thus the attrition rate between the 1- and 10-year follow-up was 30%. Full information maximum likelihood (FIML) estimation was used to account for missing outcome data at various follow-up

points and allowed all 94 patients with at least one outcome measure at one of the four follow-up points to be retained in the model.

Measures

The dependent variable was the Patient Competency Rating Scale (PCRS) (14) at 1, 2, 5, and 10 years post-injury. The scale consists of 30 items assessing competency in specified tasks of daily life. In this study, we used the self-report version of the PCRS to assess the degree of functional competency on various behavioral, cognitive and emotional tasks (24). The previously proposed four-domain classification (ADL, cognitive, interpersonal and emotional functioning, see appendix) was used (25). Participants rated each item on a five-point Likert scale (1 = can't do, 2 = very difficult to do, 3 = can do with some difficulty, 4 = fairly easy to do, 5 = can do with ease).

The total PCRS score, ranging from 30 to 150 (higher score indicating greater perceived competency), was used for prediction modelling. The PCRS was translated to Norwegian and evaluated for its psychometric properties across different TBI severity levels and levels of functioning 12 months after injury (15), and was found to be a suitable measure of competency in the later phases of TBI.

Independent (predictor) variables recorded were age at time of injury, gender (male vs. female), relationship status at admission (partnered vs. single), educational level (<12 years vs. >12 years), employment status at injury (employed vs. unemployed), occupational status at admission (blue collar [physical] vs. white collar [non-physical]), cause of injury (traffic accident vs. other), acute GCS (3-8 vs. 9-12), length of PTA (number of days), Injury Severity Score (ISS) (26) (range 1 – 75, best to worst), and CT severity score categorized according to the Marshall CT

classification which places patients in one of six categories (I to VI) of increasing brain injury severity on the basis of CT findings (27).

Procedure

The study was approved by the Regional Committee for Medical Research Ethics in Southeast Norway and performed in accordance with the Helsinki Declaration. Written consent was obtained from all participants. Data on medical and clinical characteristics were collected from hospital admission medical records during the acute hospital stay. Assessment of the participants at 1, 2, 5 and 10 years post-injury were performed by a physiatrist mainly at an outpatient department, some were assessed through a home visit upon request from participants.

Statistical Analyses

Descriptive statistics were used to summarize participants' demographic and injury characteristics at baseline. Mean scores and standard deviations (SD) were calculated for the four PCRS domains at 1, 2, 5 and 10 years after injury. Additionally, paired sample t-tests were employed to investigate differences in means for the PCRS scores across the four time points. Hierarchical linear modeling (HLM) was used to examine baseline predictors of PCRS trajectory architecture across 1, 2, 5, and 10 years after injury. A conditional (null) model was run first to determine whether there was sufficiently large clustering of PCRS score variance within participants to proceed with HLM. Unconditional growth linear, quadratic, and cubic models were then run with no predictors to determine the most accurate model for linear or polynomial architecture of PCRS scores over time.

Once the most accurate curvature model was identified, predictors were entered simultaneously as fixed effects into an HLM after being centered or given a reference point of 0, along with time (due to the selection of a linear trend of PCRS scores over time, outlined below). The first full model used HLM to determine whether linear trajectories of PCRS scores across the four time points could be predicted by the demographic and injury characteristics of time (coded as 0 [1 year], 1 [2 years], 4 [5 years], or 9 [10 years] to reflect actual spacing between time points), gender (1 = woman, 0 = man), age, relationship status (1 = partnered, 0 = single), education (<12 years vs. >12 years), employment at admission (1 = employed, 0 = unemployed), occupational status (1 = white collar, 0 = blue collar), GCS score (3-8 vs. 9-12), cause of injury (1 = motor vehicle, 0 = not motor vehicle), length of PTA (days), CT severity score, and ISS. A final HLM included the previously significant predictors from the first full model, time, and the interaction terms between time and the previously significant predictors.

RESULTS

Demographic and injury-related characteristics

Table 1 shows participants' demographic and injury characteristics at baseline. Mean age at the time of injury was 30.5 (SD =11.0), and more than two thirds of the patients were male. Slightly more than half of the participants had less than 12 years of education and 83% worked at the time of injury. More than half of the participants were injured in a traffic accident, and two thirds had sustained a severe TBI. Median length of stay in acute hospitals was 22 days (IQR 10-38) (n=94) whereas median length of stay in subacute in-hospital rehabilitation units was 54 days (IQR 30-84) (n=64).

- Insert Table 1 here

Changes in PCRS score over time

Overall, the mean PCRS scores (SD) for the full sample did not show any statistically significant upward or downward movement over time across the four follow-ups: 120 (19) at the 1-year follow-up (n=94), 120 (20) at 2 years (n=89), 121 (16) at 5 years (n=85), and 123 (15) at 10 years (n=66). The descriptive data on PCRS domains (ADLs, Cognitive, Interpersonal and Emotional) indicated that the mean rating scores were lowest (< 4; i.e., between the ratings ‘‘can do with some difficulty’’ and ‘‘fairly easy to do’’) for the emotional competency at all follow-up times, followed by cognitive competency. The ADL competency was rated as the highest (> 4, i.e., between the ratings “fairly easy to do” and “can do with ease”), see Figure 1.

- Insert Figure 1 here

Additionally, 66 patients with data at both 1- and 10-year follow-up showed similar results regarding mean (SD) PCRS scores (121 (17) vs. 123 (15), respectively, p=.210) and distribution of mean scores across the PCRS domains, except for ADL competency that increased significantly from 1- to 10-year (mean 4.28 (.69) vs. mean 4.48 (.58), p=.03). In the emotional domain, the lowest rated items were competency for keeping my emotion from affecting my daily activities (mean 3.6) and controlling my temper (mean 3.6) at 1-year; and controlling my temper and adjusting to unexpected changes (both mean scores 3.6) at 10-year. In the cognitive domain, the lowest rated items were competency for staying involved in work activities (mean

3.6) and understanding new instructions (mean 3.7) at 1-year; and the same results were revealed at 10 years follow-up.

Unconditional Model and Unconditional Growth Models

The intraclass correlation coefficient of the unconditional model was.80, indicating that approximately 80% of the total variance of PCRS scores was associated with the participant grouping and that the assumption of independence was violated. This suggests that there was sufficiently large clustering of PCRS score variance within participants (i.e., participants' PCRS scores were highly correlated with each other over time) to proceed with HLM. The unconditional model was then run separately with the successive additions of time, quadratic time, and cubic time in order to determine the shape of the best fitting architecture of PCRS over time (Table 2), suggesting that a linear trajectory best fitted PCRS scores over time.

Insert table 2 here

Full Model

The full HLM examined whether linear trajectories of PCRS scores over time could be predicted by demographic and injury characteristics at baseline. All statistically significant and non-significant fixed effects from the full HLM and their b-weights, *p*-values, and 95% confidence intervals appear in Table 3. Gender and employment at admission yielded statistically significant effects on participants' PCRS linear trajectories. Men had higher PCRS scores trajectories across the four time points compared to women (Figure 2). Individuals who were employed at admission had higher PCRS scores trajectories than those unemployed (Figure 3).

Insert table 3 here

Insert figure 2 here

Insert figure 3 here

Final Model with Time Interactions

A final HLM examined whether linear trajectories of PCRS scores could be predicted by the previously significant predictors, as well as their interactions with time. All statistically significant and non-significant fixed effects from the final HLM and their b-weights, *p*-values, and 95% confidence intervals appear in Table 4, although only the significant interaction terms will be focused on for interpretation. The significant time*gender interaction effect suggested that men tended to start higher in PCRS scores and then increased over time, whereas women's scores started lower and then decreased over time (Figure 2).

Insert table 4 here

DISCUSSION

The present study describes the long-term trajectories of patients' self-reported competency in daily tasks as assessed by the PCRS at 1, 2, 5, and 10 years following TBI. The mean overall PCRS score across the four follow up time points was around 120, indicating that the patients could perform the various activities "fairly easily." This finding is in accordance with previous studies reporting a 'plateauing' of functional recovery after the first year following TBI (28, 29).

The average responses on the majority of the PCRS sub-domains fell between the ratings of ‘‘can do with some difficulty’’ and ‘‘fairly easy to do’’, in accordance with a study by Wood and Rutterford that assessed 80 patients who had suffered severe brain injury on average 17 years previously (13). The study by Hall et al. suggested that these scores are slightly below the range of scores expected from non-disabled people that would respond with a rating of “fairly easy” and “easy” for most of the items (10). It is worth mentioning that the first follow-up reported in our sample was on average 1 year post-injury, and we can speculate whether a more recently injured sample would have reported greater deficits on the PCRS (10).

The average ratings of sub-domains were lowest for emotional competency followed by cognitive competency, while ADL competency was highest across all time points and improved most from 1- to 10-year follow-up. The results may indicate that emotional and cognitive tasks remain the most challenging and should be a focus area in follow-up and rehabilitation programs in the long-term perspective. These average domain scores are similar to those found by Leathem and colleagues (25) who reported lowest average scores for emotional and cognitive competency in a group of TBI patients with a median of 2 years post-injury. A cross-sectional study by Wood and Rutterford (13) found lower average scores overall, with the lowest average PCRS scores for interpersonal and emotional competency. Despite discrepancies in findings, it may be suggested that cognitive and emotional competencies remain a challenge in the long term following moderate and severe TBI. This is further supported by studies investigating long-term cognitive and emotional/behavioral sequelae after TBI that have reported persisting cognitive and emotional problems which require professional help even 5 years after the injury (30, 31).

Gender and employment status at the time of admission were significant predictors of self-reported competency across 10 years. Female gender and being unemployed at the time of injury were associated with lower self-reported functional competency. Women initially reported lower competence, which continued to decline while men reported increasingly higher self-reported competency across the 10-year trajectory. There have been reported mixed findings in post-TBI outcomes research for men and women (32, 33). Some studies have reported women doing better compared to men in terms of rehabilitation outcomes (32) and community integration (34). Conversely, studies on self-reported symptoms and outcomes following TBI have found that women fare worse than men across different symptom domains including physical, cognitive and emotional functioning (35, 36). This is in line with studies in the general population where women are more likely to report health problems, and disability compared to men (37, 38). Previous research also has suggested that gender differences in socialization and gender-role expectations that change over time can moderate the relationship between gender and outcome measures after TBI (19, 33).

Being employed at the time of injury was a significant predictor of better PCRS trajectories scores at all follow-up times compared to unemployed patients. This is in line with previous studies that have demonstrated a significant association between pre-injury employment and functional outcomes following TBI (39, 40).

In contrast to previous studies (8, 16, 17), age and injury severity characteristics (GCS score, length of PTA and ISS) were not significant predictors of PCRS (trajectories), although PTA and ISS showed trends towards the significance level ($p = .057$ and $p = .070$, respectively) (8).

Strengths and limitations

The current study is an extension of an existing longitudinal TBI research project (3, 41, 42). It is the first study to report on self-reported competency over a 10-year trajectory and investigate predictive demographic and injury-related factors for self-reported functional outcomes. The majority of previous studies on self-awareness and self-reported competency are limited to follow up during the first year post injury.

The overall sample size for the current study is relatively small and the age range limited to participants of working age (16-55 years at study enrollment). Of the 94 eligible participants, 28 (30%) underwent attrition of which 39% (n=11) were due to not completing the PCRS questionnaire at 10-year follow-up and 61% (n=17) were due to loss to follow-up. This may further limit the study generalizability. However, the statistical modelling that was applied handles missing data well, and the longitudinal design with four follow-up time points renders the trajectory analysis stronger concerning the statistical power. Future studies with a larger sample size and broader age range are needed to verify the present findings, and to account for factors other than baseline characteristics (such as functional status) which we did not assess in this study. The present study only described length of acute treatment and in-hospital rehabilitation provided to the patients during the acute and subacute TBI phases. Ideally, the course and content of rehabilitation provided in a 10-year perspective should be described as rehabilitation services may impact functional outcomes of TBI.

Although studies assessing self-awareness are important and have been the main focus in the literature, assessing self-reported competency in itself is important in order to identify patients' experiences as they are closer to the issues in question, and the information they provide may be more accurate for their situation and motivation for rehabilitation. If the individual with TBI indeed had reduced self-awareness, self-reporting of perceived competency is essential to find

common grounds for establishing treatment goals that both the individual and clinician find relevant and realistic (25). Therefore, in clinical practice, it would be preferable to have both self-reported and informant reported competency available when assessing patients (43). If disagreement in informants' and patients' scores exists, this could be addressed in a common discussion (25).

Other informants are, however, limited to reporting the obvious side of patients' experience through their behavior and verbal responses, while patients may be able to control or hide difficulties they experience from informants (25). Thus, informants may over- or underreport patients' problems, thereby reducing ecological validity, which has been reported as a strength when using self-report measures in general (25).

Implications and future studies

The results of the present study provide important information regarding patients' functional competence up to ten years that may be useful when designing long-term rehabilitation programs for patients in the chronic phase after TBI. While it is important to assess self-awareness as it is known to affect rehabilitation outcome in the acute and post-acute phases, it is also important to assess self-reported competency in the chronic phase of TBI as it provides insight into functioning. Future longitudinal studies should also document the kind of post-injury rehabilitation services patients have received as these are likely to influence self-perceived functional competency.

Conclusion

The present study proposes that while self-reported functional competency remains stable from one-year up to ten years post injury for men, both men and women's scores still lie below the range of scores expected from non-disabled people. Since the lowest scores were on emotional and cognitive competencies, rehabilitation programs may need focus on these difficulties in the chronic phase after TBI. Special focus of rehabilitation on women and patients who are unemployed at time of admission may be warranted, as these individuals fared worse across the 10-year trajectories.

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Declaration of interest

The authors report no conflict of interest.

Biographical note on the authors

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Tables

Table 1. *Demographics at time of injury and injury-characteristics*

Variable	**n (%)**	**Total n**
Age at injury		94
Mean (SD)	30.5 (11.0)	
Gender		94
Male	73 (78.0)	
Female	21 (22.0)	
Relationship status		94
partnered	28 (30.0)	
single	66 (70.0)	
Educational level		93
< 12 years	52 (56.0)	
≥ 12 years	41 (44.0)	
Employment status		94
Yes	78 (83.0)	
No	16 (17.0)	
Injury cause		94
Traffic accident	55 (58.5)	
Other	39 (41.5)	
Glasgow Coma Scale (GCS)		94
Median (IQR)	7 (5-11)	
Moderate (9-12)	32 (34.0)	
Severe (3-8)	62 (66.0)	
Post traumatic amnesia (PTA)		88
Days, Mean (SD)	26 (30.0)	
CT head Marshall score		94
Mean (SD)	3.0 (1.0)	
Score 1-2	45 (48.0)	
Score 3+	49 (52.0)	
Injury severity score		94
Mean (SD)	30.0 (13.0)	

Table 2. *Model fit for PCRS trajectories over time.*

Model	-2 Log Likelihood
Linear	2136.26
Quadratic	2136.21
Cubic	2135.37

Note. Critical χ^2 value for significant difference at $\alpha = .05$ is $\geq$ 3.841 drop from the previous model.

Table 3. *Full hierarchical linear model with demographic and injury predictors of PCRS trajectories across 1, 2, 5, and 10 years.*

Predictor	b-weight	*SE*	*p*-value	95% Confidence Interval	
				Lower Bound	Upper Bound
Intercept	111.71***	4.94	.000	101.89	121.53
Time	.04	.17	.827	-.31	.38
Gender (1 = woman, 0 = man)	-9.53*	3.99	.019	-17.47	-1.59
Age	-.34	.19	.069	-.72	.03
Relationship Status (1 = partnered, 0 = single)	2.15	4.25	.615	-6.32	1.61
Education	1.80	2.18	.411	-2.54	6.14
Employment (1 = employed, 0 = unemployed)	13.58**	4.49	.003	4.64	22.52
Occupational Status (1 = white collar, 0 = blue collar)	2.05	3.69	.580	-5.30	9.41
GCS	.13	.60	.831	-1.06	1.31
Cause of Injury (1 = motor vehicle, 0 = not motor vehicle)	-3.12	3.68	.399	-1.45	4.21
PTA	-.13	.07	.057	-.26	.00
CT Severity Score	.85	1.63	.604	-2.40	4.10
ISS	.25	.14	.070	-.02	.52

Note. * = $p < .05$; ** = $p < .01$; *** = $p < .001$.

Table 4. *Final hierarchical linear model with previously significant predictors and time interactions on PCRS trajectories across 1, 2, 5, and 10 years*

Predictor	b-weight	*SE*	*p*-value	95% Confidence Interval	
				Lower Bound	Upper Bound
Intercept	103.72***	5.21	.000	93.39	114.05
Time	.77	.49	.119	-.20	1.74
Gender (1 = woman, 0 = man)	-3.10	4.86	.526	-12.75	6.55
Employment (1 = employed, 0 = unemployed)	18.01**	5.57	.002	6.95	29.07
Time*Gender	-1.05*	.40	.010	-1.85	-.26
Time*Employment	-.50	.51	.335	-1.51	.52

Note. * = $p < .05$; ** = $p < .01$; *** = $p < .001$.

Figures

Figure 1. Mean rating scores of PCRS domains across follow-up times.

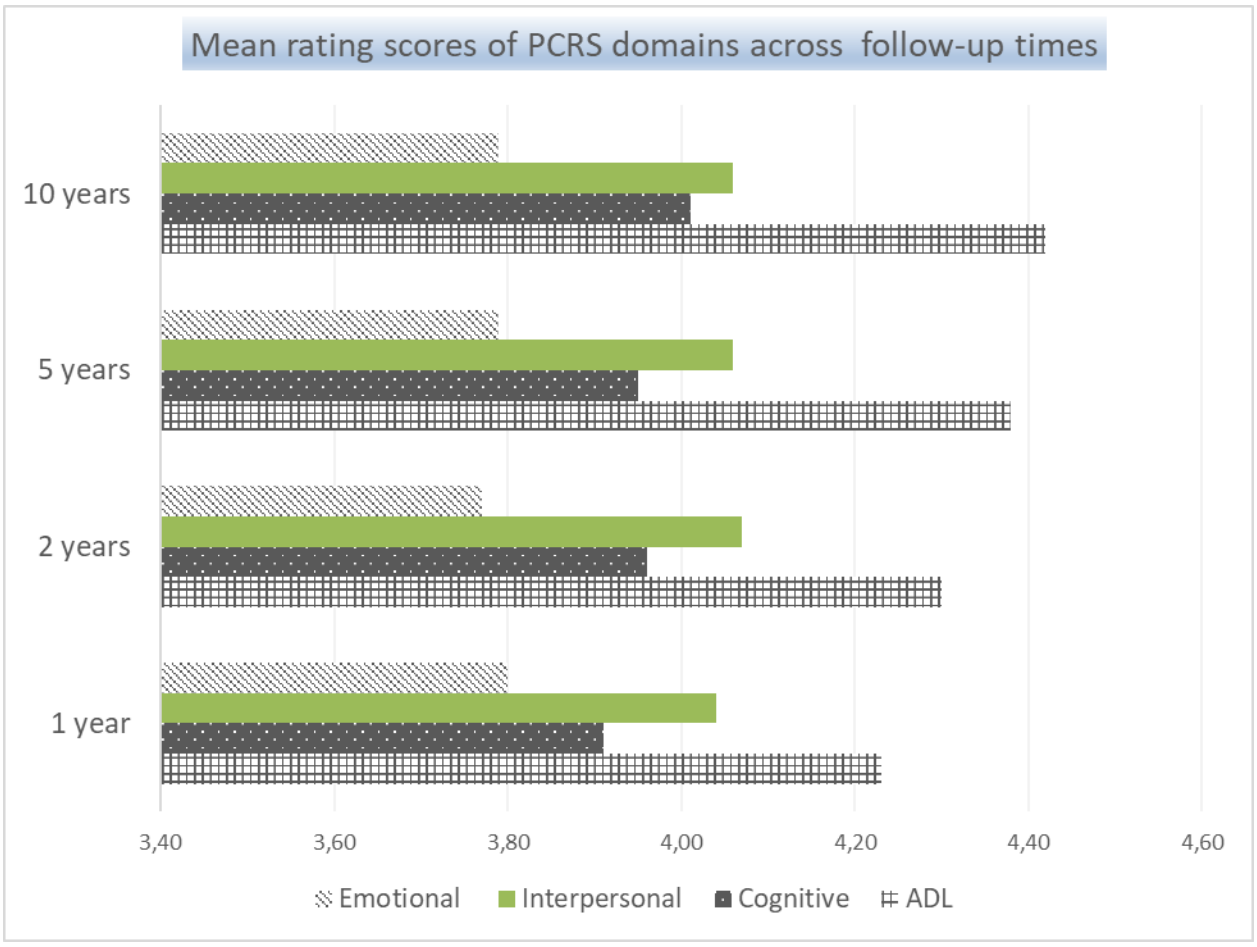

Figure 2. Main effect and time interaction of gender on PCRS trajectories.

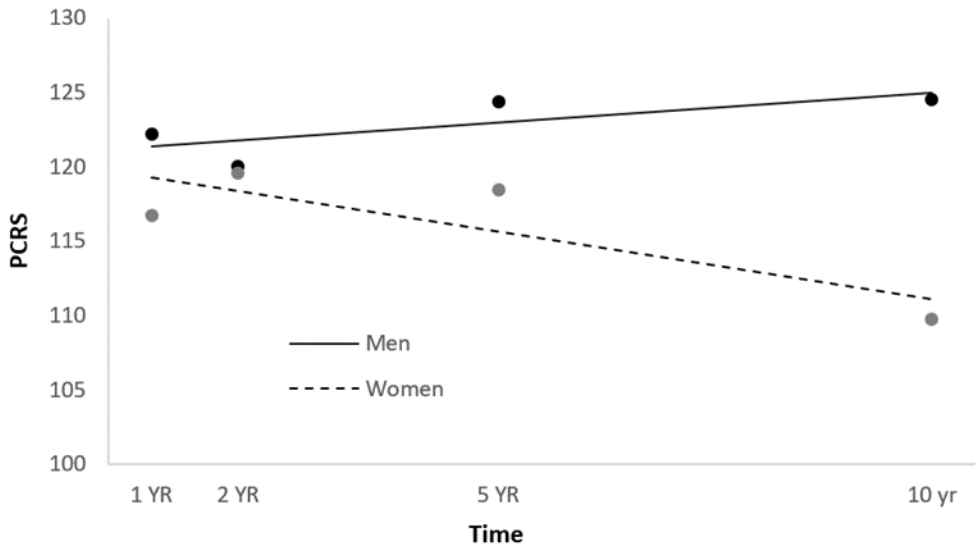

Figure 3. Main effect of employment at time of injury on PCRS trajectories.