

THE NEW SWEDISH POST-CONCUSSION SYMPTOMS QUESTIONNAIRE: A MEASURE OF SYMPTOMS AFTER MILD TRAUMATIC BRAIN INJURY AND ITS CONCURRENT VALIDITY AND INTER-RATER RELIABILITY

Elisabeth Elgmark Andersson, OTR, PhD¹, Ingrid Emanuelson, MD, PhD², Margareta Olsson⁵, Daniel Stålhammar, MD, PhD³ and Jan-Erik Starmark, MD, PhD⁴

From the ¹Institute of Clinical Neuroscience, Rehabilitation Medicine, ²Institute for the Health of Women and Children, Section for Paediatrics, ³Institute of Clinical Neurosciences, Neurosurgery, ⁴Institute of Clinical Neuroscience, Unit of Neuropsychology and Neuropsychiatry, Neurology, Göteborg University, Göteborg, ⁵Rehabilitation Centre, Södra Älvsborg Hospital, Borås, Sweden

Objective: To study the concurrent validity and the inter-rater reliability of the Post-Concussion Symptoms Questionnaire.

Design: The approach was to study the concurrent validity of the Post-Concussion Symptoms Questionnaire when used as an interview questionnaire compared with a self-report questionnaire administered by the patients. The inter-rater reliability was also studied when 2 different raters administered the Post-Concussion Symptoms Questionnaire interview.

Patients: Thirty-five patients with mild traumatic brain injury were consecutively contacted by telephone and asked whether they would be willing to participate in a follow-up intervention.

Methods: The Post-Concussion Symptoms Questionnaire was completed by the patients, who answered “Yes” or “No” to the standardized questions. The patients were then interviewed to check the certain “Yes” or “No” answers, 0–10 days after having completed the first Post-Concussion Symptoms Questionnaire. The raters filled in their ratings independently.

Results: The concurrent validity of answers in the questionnaire compared with those in the interview ranged from 82% to 100% agreement. The inter-rater reliability results ranged from 93% to 100% agreement between the raters.

Conclusion: The Post-Concussion Symptoms Questionnaire with answers of “Yes” or “No” is a valid instrument. High reliability was found between the raters.

Key words: post-concussion, mild traumatic brain injury, rehabilitation, assessment methods.

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Correspondence address: Elisabeth Elgmark Andersson, OTR, PhD, School of Health Sciences, Department of Rehabilitation, Box 1026, SE-551 11 Jönköping, Sweden. E-mail: elisabeth.elgmark@hhj.hj.se

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INTRODUCTION

The incidence of traumatic brain injuries (TBI) has been reported in the range 130–596/100,000 a year (1–3). In Sweden the mean incidence of mild traumatic brain injury (MTBI) has been reported to be 175/100,000 a year (4). The incidence of TBI varies considerably according to how it is defined. Figures of

between 100 and 3000 per 100,000 a year have been published (3). In the literature, a large number of cases TBI are classified as mild, but the symptoms and complaints after an MTBI are not mild (5). The definition of MTBI in the literature varies when it comes to the length of amnesia and loss of consciousness (6). In the present study, the definition given by the Mild Traumatic Brain Injury Committee of the American Congress of Rehabilitation Medicine was used (7).

MTBI can be followed by post-concussion symptoms (PCS), such as headache, memory problems, dizziness, fatigue, irritability and poor concentration. Post-injury symptoms of this kind were reported at 3 months in 51–86% of cases by Ingebrigtsen et al. (8), at 6 months in 72–86% of cases by Wade et al. (9) and at 1 year in 10–40% of cases by Alves et al. (10). There is still controversy regarding the causes and development of these symptoms (11, 12).

Patients with MTBI usually report the resolution of most of their symptoms within 3 months after injury (13). Prospective studies indicate, nevertheless, that a substantial number of patients still report some symptoms 3 months after injury (14), as well as 1 year after injury (15, 16). Even if the number of persons with symptoms decreases, those with remaining symptoms do not function as well as before and consume healthcare resources (17).

The background to the performance of this study was that after MTBI many patients (in the age range 16–60 years) were referred to the Rehabilitation Centre at Södra Älvsborg Hospital, Borås. The patients presented with PCS, such as headache, tiredness, irritability, dizziness and depression. In a literature review in 1991, no valid Swedish checklist for measuring PCS after MTBI was found (12, 18). Previous studies have measured PCS solely by using a checklist for patients to report the presence or absence of symptoms and contain no data relating to the validity or reliability of the checklist (12, 18). Some investigators have published reliability studies of their checklists, for example, the Rivermead Post Concussion Symptoms Questionnaire (RPQ) (19) and the Problem Checklist from the New York Head Injury Family Interview (20). The RPQ is devised to gauge the severity of PCS and the patient is asked to rate the degree to which 16 PCS are

more of a problem compared with pre-morbid levels using values in the range 0–4. In the case of the Problem Checklist, the patients were interviewed. The checklist included 43 symptoms and the answers were “Yes” or “No”. In the event of a “Yes”, the patient was asked to rate the severity of the problem in the range 1–7. As the present study is part of a prospective, randomized, controlled trial (RCT) of MTBI, which ran for 4 years (from 6 September 1997 to 31 December 2001) in the area of Borås, Sweden (21), the RCT study was initially designed before the RPQ (28) and the Problem Checklist (20) were introduced. We therefore constructed a new PCS questionnaire (PCSQ) to determine whether there were any PCS after the MTBI. The 21 symptoms that are listed are the PCS most commonly reported in the published literature (12, 19, 22) and the answers are based on “Yes” and “No”.

The items in the PCSQ were used in a semi-structured interview and in a self-administered questionnaire and were tested in a pilot study with a different design by Emanuelson et al. (23). In this pilot study, 14 of the items were taken from the Comprehensive Psychiatric Rating Scale (CPRS) (24) and 7 were constructed for clinical purposes. In a study by Rödhholm et al. (25), items from the CPRS were also constructed and 5 of these items were the same as those used in the pilot study by Emanuelson et al. (23).

The aim of this study was to study the concurrent validity of the PCSQ when used as a self-report questionnaire administered by the patients compared with an interview questionnaire. The inter-rater reliability was also studied when 2 different raters administered the PCSQ interview.

METHODS

Patients

The patients in the present validity and reliability study participated in the prospective RCT study of MTBI (1997–2001) (21). In the RCT study, 1719 patients were assessed for eligibility. The inclusion criteria were being 16–60 years of age and satisfying the definition of a Mild Head Injury put forward by The American Congress of Rehabilitation Medicine (7). Patients were excluded on the following criteria: previous clinically significant brain disorders, a history of abuse, language difficulties (non-native Swedish speakers) and not resident in the catchment area. In addition, patients were excluded if they were registered more than 2 months after a registered injury. The remaining 395 patients were randomized to an intervention group and a control group. These patients were sent a postal PCSQ to gather information 2–8 weeks (median 3 weeks) after the injury and at a 1-year follow-up (21). This follow-up in the RCT study (21) is not presented in this paper.

Procedure

In the RCT study (21) mentioned above, 246 patients in the intervention group were contacted by telephone 2–8 weeks (median 3 weeks) after the MTBI. The patients were asked if anything had changed in their lives after the injury. There were 150 patients who had just a few PCS and stated that their health had been restored to pre-injury level and declined treatment. The remaining 96 patients who felt unwell because of PCS were offered an appointment at the rehabilitation centre. After the end of the intervention at the rehabilitation centre, 41 of the 96 patients from the intervention group were subsequently contacted by telephone an average of 20 months after the MTBI. They were asked whether they would be willing to participate in a new follow-up intervention. Of the

41 patients, 35 (21 males, 14 females) agreed to participate. Six patients refrained from participating.

To study the concurrent validity, another self-administered PCSQ was sent to the participants by post and 2 rates then interviewed them.

The self-administered PCSQs were completed by the patients themselves, rating each item as either (i) existing = “Yes” or (ii) not existing = “No”. The interviews were conducted by 2 trained raters (rater 1, the occupational therapist (EEA) and rater 2, the research secretary, (MO)) at the rehabilitation centre, at home or at work, whichever was most convenient for the patients. The raters had experience of patients with complaints after an MTBI.

To study the inter-rater reliability, the 2 raters interviewed the patients in random order to avoid bias. The rater who interviewed and the rater who observed rated the answers independently of each other. At the end of the interview, the rater who did not perform the interview had a chance to ask the patient additional questions to obtain enough information to rate the questionnaire. This technique is called the “Joint Assessment Method”, which is described in the Swedish version of the structured interview for the DSM III-R from 1989 (26).

For every item, the percentage of agreement between the answers given in the PCSQ was calculated.

PCSQ

The PCSQ consists of psychiatric and neurological questions based on a review of the literature, as well as clinical experience (Appendix I) (The complete questionnaire can be obtained from the corresponding author). Ten of the items are taken from the CPRS (24), 5 from Rödhholm et al. (25, 27), while the remaining 6 were constructed to fulfil the clinical purpose (Table I).

The CPRS items of fatigability, concentration difficulties, increased sleep, irritability/aggressiveness, failing memory, sadness/depression, anxiety, reduced sleep, neck pain and loss of sensation or movement were selected. The definition of the item “fatigability” is the individual’s capacity to perform activities in his or her daily life. For the symptoms of light and sound sensitivity, emotional instability, dizziness and headache, CPRS-like items were constructed by Rödhholm et al. (25, 27), as there were no corresponding CPRS items. These items had been used as part of a follow-up study after aneurysmal subarachnoid haemorrhage (25, 28) and the validity and reliability of most of them have been reported previously for the psychiatric diagnosis of astheno-emotional disorder (25, 27). For the items of reduced simultaneous capacity, anosmia, impaired hearing, orientation problems, visual impairment and language difficulties, suggested standardized questions were constructed, as there were no corresponding CPRS items. In the pilot study by Emanuelson et al. (23), the same PCSQ with all 21 items was used and the concurrent validity was tested, even though the design was different.

In the self-administered PCSQ, the patients filled in the answers “Yes/No”. In the clinically administered PCSQ interview, definitions similar to those from the CPRS were used, in order to increase the sensitivity. In

Table I. Post-concussion symptoms from different questionnaires

CPRS (24)	Svensson & Starmark (28) Rödhholm et al. (25)	Borås Rehabilitation Centre
Fatigability	Light sensitive	Reduced simultaneous capacity
Concentration difficulties	Sound sensitive	Anosmia
Increased sleep	Emotional instability	Impaired hearing
Irritability	Dizziness	Orientation problems
Failing memory	Headache	Visual impairment
Depression		Language difficulties
Anxiety		
Reduced sleep		
Neck pain		
Loss of sensation or movement		

CPRS = Comprehensive Psychiatric Rating Scale.

the CPRS, each item is rated on a 7-point (0–3 points, in steps of 0.5) ordered categorical scale, with descriptions for the levels 0, 1, 2 and 3. As a result, the wording of level 2 for each item was defined as a cut-off for a positive response and a “Yes” was recorded. In this interview, the specificity of a “Yes/No” response was recorded for each item. The information related to each question is also recorded as “unavailable, absent, doubtful or present”. The use of this technique was justified as a further check of the accuracy of the “Yes/No” response.

The Ethics Committee at Göteborg University approved the study. All the patients received a leaflet explaining the purpose of the study and gave their verbal consent.

Statistical methods

To estimate the concurrent validity and the inter-rater reliability of answers, the percentage of agreement was calculated. For the kappa test, the following values were considered: <0.20 poor, 0.21–0.40 fair, 0.41–0.60 moderate, 0.61–0.80 good and 0.81–1.00 very good agreement.

McNemar’s test (29) was used to estimate systematic differences between the self-administered PCSQ and the clinically administered PCSQ and to check bias in the study of inter-rater reliability.

RESULTS

All 35 patients who completed the self-administered PCSQ with the answers of “Yes” and “No” were interviewed 0–10 days after receiving the self-administered version of the PCSQ.

The results of the concurrent validity study, i.e. the relationships between the self-administered PCSQ with the answers of “Yes” and “No” and expert-rated PCS with the clinically-administered PCSQ interview, are given in Table II. The result of the concurrent validity study ranged from 82% to 100% in terms of agreement. The most valid answers between the self-administered PCSQ and the clinically-administered PCSQ were found for the items of reduced simultaneous capacity, sound

Table II. Number of Post-Concussion Symptoms (PCS) for each item in the self-administered Post-Concussion Symptoms Questionnaire (PCSQ). Concurrent validity between the self-administered PCSQ and the PCSQ interview

Item	PCS n (%)	Percentage agreement	Kappa
Fatigability	31 (86)	91	0.68
Headache	27 (77)	94	0.84
Irritability	26 (74)	89	0.72
Depression	24 (69)	88	0.74
Failing memory	24 (69)	91	0.80
Dizziness	23 (66)	94	0.87
Sound sensitivity	22 (63)	97	0.94
Concentration difficulties	22 (63)	94	0.87
Neck pain	22 (63)	97	0.94
Language difficulties	21 (60)	91	0.82
Anxiety	20 (57)	85	0.70
Increased sleep	19 (54)	82	0.65
Emotional instability	19 (54)	88	0.76
Reduced simultaneous capacity	18 (51)	100	1.00
Visual impairment	17 (49)	97	0.94
Light sensitivity	16 (46)	97	0.94
Loss of sensation or movement	13 (37)	89	0.74
Impaired hearing	11 (31)	97	0.93
Reduced sleep	10 (29)	94	0.87
Anosmia	7 (20)	97	0.92
Orientation problems	4 (11)	94	0.72

sensitivity, neck pain, visual impairment, light sensitivity, impaired hearing and anosmia.

Table II shows the number of PCS in the self-administered PCSQ for each item. The most frequently rated PCS were fatigability (86%) and headache (77%), followed by irritability (74%), depression (69%), failing memory (69%) and dizziness (66%). The corresponding kappa values were a mean of 0.83 (0.68–1.0) ($p < 0.001$) and the highest kappa values were between 0.94 and 1.0 for 5 of the items: neck pain, sound sensitivity, visual impairment, light sensitivity and reduced simultaneous capacity. There were no systematic differences between the self-administered PCSQ and the PCSQ interview; all the items had a p -value of > 0.05 according to McNemar’s test (29).

The results of the inter-rater reliability study are presented in Table III. The inter-rater reliability, i.e. the relationship between the 2 raters, were in the range 93–100% in terms of agreement and had a mean kappa value of 0.98 (0.84–1.0) ($p < 0.001$).

Eighteen of 21 items had a kappa value of 1.0, while the remaining 3 items had a kappa value of between 0.84 and 0.97. The number of PCS in the clinically administered PCSQ interview for each item (from rater 1) are presented in Table III. The most frequently rated PCS in the clinically-administered PCSQ interview were fatigability (80%) and headache (71%), the same as in the self-administered PCSQ, followed by concentration difficulties (69%), irritability (69%), failing memory (69%) and dizziness (66%) (Table III).

There were no systematic differences between the 2 raters; all the items had a p -value of > 0.05 according to McNemar’s test (29).

Table III. Number of Post-Concussion Symptoms (PCS) for each item in the Post-Concussion Symptoms Questionnaire (PCSQ) interview. Inter-rater reliability between the 2 raters in the PCSQ interview

Item	PCS n (%)	Percentage agreement	Kappa
Fatigability	28 (80)	100	1.00
Headache	25 (71)	100	1.00
Concentration difficulties	24 (69)	100	1.00
Irritability	24 (69)	100	1.00
Failing memory	24 (69)	100	1.00
Dizziness	23 (66)	100	1.00
Sound sensitive	22 (63)	100	1.00
Neck pain	21 (60)	100	1.00
Depression	20 (57)	94	0.87
Language difficulties	20 (57)	100	1.00
Reduced simultaneous capacity	18 (51)	100	1.00
Emotional instability	17 (49)	97	0.94
Visual impairment	15 (43)	100	1.00
Increased sleep	15 (43)	97	0.94
Light sensitivity	15 (43)	100	1.00
Anxiety	15 (43)	100	1.00
Reduced sleep	12 (34)	100	1.00
Impaired hearing	10 (29)	100	1.00
Anosmia	8 (23)	100	1.00
Extremity weakness	9 (26)	100	1.00
Orientation problems	4 (11)	97	0.84

DISCUSSION

The PCSQ is a valid instrument for measuring PCS after an MTBI, regardless of whether it is used as a self-administered or a clinically administered interview measure. The self-administered PCSQ with the answers of "Yes" or "No" is a short questionnaire and a screening schedule for complaints after an MTBI.

In the concurrent validity study, the most validly rated PCS were reduced simultaneous capacity, sound sensitivity, neck pain, visual impairment, light sensitivity, impaired hearing and anosmia.

The inter-rater reliability study revealed a high percentage of agreement between the raters.

The self-administered PCSQ is an instrument for assessing patients after an MTBI in a normal clinical situation. The patients were asked whether they had had any symptoms before the MTBI and this estimated the level of symptoms before the concussion as the baseline. Symptoms and signs existing before the concussion were therefore rated as "No", provided that they did not worsen after the concussion. If there were any complaints, a structured interview could be carried out to determine the severity of these complaints.

We believe that the effort of performing a pilot study with the self-administered and clinically administered PCSQ interview (23), as well as sharply defined levels for the "Yes/No" responses, are the main reasons for our results, which indicate high validity for the items. The construction of the PCSQ with a standardized cut-off for "Yes" or "No", in combination with the requirement of new or worse symptoms compared with an individual baseline, possibly enables the estimation of lasting morbidity—at least for 1 year after MTBI. The technique of using the definitions in the CPRS items with a cut-off at level 2 means that only very clear-cut symptoms are recorded. As a result, minor symptoms in our study were undetected and might remit spontaneously or be accessible to rehabilitation measures (21).

In the RPQ study, it was shown that the reliability of the self-administered and the clinically administered RPQ was good (19). The RPQ study was performed 6 months after head injury and it found that the most reliably rated PCS were headaches, dizziness, noise sensitivity, forgetfulness and poor concentration. These symptoms are probably most easy to identify during the first 6 months after a head injury. A study by Rödhölm et al. (25) demonstrated that neuropsychiatric symptoms, such as concentration difficulties, memory difficulties and noise sensitivity, after an aneurysmal subarachnoid haemorrhage, decreased in severity within the first year of follow-up. The symptoms after an MTBI, aneurysmal subarachnoid haemorrhage and psychiatric disorders could be the same; they can include extreme tiredness, concentration difficulties and failing memory and the technique which was designed by Åsberg et al. (24) in the CPRS could therefore be used for different diagnoses.

In the RCT study (21), the most common PCS after MTBI were headache, fatigue, depression, irritability and neck pain at the 1-year follow-up. In this study, fatigue and headache were also the most common symptoms, followed by irritability, concentration difficulties, failing memory and depression. This study was performed a mean of 20 months after MTBI and these symptoms may be the most consistently experienced symptoms over time. Some PCS, such as sleeping disturbances, headaches, poor concentration, fatigue and depression, have high base rates in the normal population of between 26% and 62% (30) and, under conditions of stress and emotional distress, the prevalence might be even higher (31). When it comes to the past medical history of the patients, they must be explicitly asked to compare their present state with their own habitual function, which is then the norm. In the present study, we attempted to exclude individuals with pre-morbid features, such as significant previous brain injury, psychiatric disorders or any history of substance abuse. The exclusion rate due to the above-mentioned reasons was 31% (177 of 572). Furthermore, the patients in the present study were explicitly asked to compare their situation to see whether there were any new or exacerbated symptoms after the MTBI, which presupposes that the symptoms were mainly due to the MTBI (21).

The validity of self-administered questionnaires for rating PCS has been questioned, mainly due to the high base rate of symptoms in the population. However, the risk of over-rating is probably even higher in a standardized interview (32). In a study by Ljunggren et al. (33), there was evident disagreement between patients' self-reported questionnaires and the results of the clinical interview. As a result, self-administered questionnaires are still the best instrument that is currently available for registering these data.

The high agreement between 2 raters with different occupations indicates that different team members can handle the clinically administered PCSQ interview and this is valuable in the rehabilitation of patients with MTBI.

In the pilot study by Emanuelson et al. (23), the occupational therapist (EEA) used the PCSQ clinically administered interview and the self-administered questionnaire. The secretary (MO), who had worked as a research secretary at the RCT for 6 years, had performed interviews with patients with MTBI in person and at telephone follow-ups. Before the validity and reliability study started, the occupational therapist and the research secretary were trained by 1 of the authors (JES). To ensure that the assessment of the raters was correct, McNemar's test was used to test whether there were any systematic differences between the 2 raters. There were no systematic differences between the raters and the conclusion is that the raters were adequately trained to perform the interviews.

The limitation of the present study was that we did not test the instrumental validity of the PCSQ compared with similar instruments. However, the validity of this study is probably due to clinical experience and the items are the same or almost the

same as those in the RPQ (19) and the Problem Checklist (20). A comparison of different questionnaires will be made in a forthcoming study.

In conclusion, the PCSQ with the answers of "Yes" or "No" is a valid instrument. It is a short, self-administered means of screening complaints after an MTBI. The PCSQ interview has high reliability between different professions.

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APPENDIX I

Post Concussion Symptoms Questionnaire (PCSQ) "Yes" or "No"

How are you now after the accident?

PROBLEMS after the accident

Have you developed any of the following problems after the accident:

- Have you noticed weakness in your arms or legs?
- Have you become sensitive to sudden or loud noises?
- Do you think your hearing is worse than it was before the accident?
- Have you become sensitive to light, such as strong sunlight?
- Do you think your vision has deteriorated in any way?

- Do you think your taste and smell have changed or deteriorated in any way?
- Do you have any problems with dizziness?
- Do you have more difficulty finding words when you speak? Or do you have more difficulty understanding what is said or what you read or do you have more difficulty formulating words?
- Do you have difficulty recognizing where you are?
- Do you have more difficulty than before doing two things at the same time?
- Do you become tired more easily than you did before the accident?
- Do you have difficulty gathering your thoughts and concentrating?
- Do you have any problems with your memory?
- Do you have less patience, making you more easily irritated than you were before?
- Do you feel more mentally tense or worried since the accident?
- Have you recently felt depressed or low-spirited?
- Do you think you are more sensitive than before?
- Do you sleep less or more restlessly than before?
Answer yes, if you think you have lost at least 2 hours' sleep a night.
- Do you sleep more than before?
Answer yes, if you sleep at least 2 hours more than before.
- Have you had more headaches?
- Have you had more neck pain?