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Abstract

Objective: This systematic review examines the current literature of reliable and/or valid outcome measures for adults who have persistent post-concussion syndrome (PPCS) and their ability to engage in occupations.

Method: 2,491 articles from PubMed, CINAHL, PsycINFO, Web of Science, OTSeeker, and SPORTDiscus databases were examined. Peer-reviewed articles published in English that pertained to reliable and/or valid outcome measures for adults with PPCS were included in this review.

Results: The search strategy yielded seven studies that evaluated PPCS outcome measures. The two outcome measures that were occupation-based were Rivermead Head Injury Follow-up Questionnaire and World Health Organization Disability Assessment Schedule 2.0. The 12 item WHODAS 2.0 has internal consistency of 0.92 (Snell et al., 2017). RHFUQ has external construct validity of 0.83 when compared to the RPQ-13 (Eyres et al., 2005).

Conclusion: Occupational therapists frequently work with individuals experiencing PPCS. The reliability and validity of the two outcome measures could not be directly compared due to different qualifications. This systematic review as a result cannot compare the measures as a whole. Further research is needed to create an outcome measure that is occupation-based, reliable, and valid.

Evaluating Current Outcome Measures for Persistent Post-Concussion Syndrome

A concussion or mild traumatic brain injury (mTBI) is the result of a strong direct or indirect physical injury to the head, such as an automobile accident, fall, or being struck by an object (Chong, 2008). An estimated 75% of the nearly 1.7 million TBIs that occur each year are a concussion, otherwise known as a mTBI (Moore et al., 2016). The injury may cause confusion, brief memory loss, headaches, dizziness, and poor concentration (Anderson et al., 2006; Chong, 2008).

Following the injury, individuals are expected to reach full recovery, with all symptoms resolving, in two to three weeks (Anderson et al., 2006). However, a minority of patients experience concussion symptoms for a longer period of time. Continual experience of these symptoms is called persistent post-concussion syndrome (PPCS) (Anderson et al., 2006). Persistent post-concussion syndrome is the most recently accepted term to describe this experience, but other common names include post-concussion syndrome (PCS) and postconcussive syndrome. Three months post-injury, 30 to 80% of concussive patients will experience PPCS symptoms and 15% of those patients will continue to have symptoms one year following their injury (Preiss-Farzanegan et al., 2009). Patients are often discharged from treatment and do not notice long-term physical, cognitive, behavioral, and emotional changes until later on (Pelczar & Polityńska, 1997). It is unclear why some patients develop PPCS and not others. Female patients are at an increased risk for developing PPCS symptoms in comparison to male patients (Preiss-Farzanegan et al., 2009). However, this and many other factors thought to be associated with PPCS, such as age and history of previous brain injury, are not consistently evident in patients (Savola & Hillbom, 2003).

Relationship to Occupational Therapy

PPCS can lead to significant occupational performance issues (OPIs) due to its ability to affect many occupations at once, especially education, work, social participation, instrumental activities of daily living (IADLs), and self-care activities of daily living (ADLs). As a result, PPCS can hinder one's roles and influence their economic and social status. PPCS is unique to each client and will affect everyone differently. OT practitioners should conduct a comprehensive evaluation to fully understand how PPCS is impacting roles, routines, and one's capabilities. Therapists can help clients manage PPCS symptoms during occupational participation and help clients develop strategies to better tolerate certain tasks (Wheeler & Yamkovenko, 2016).

Occupational therapists can use theory, such as the Ecology of Human Performance model (EHP), to educate clients on PPCS and provide therapeutic strategies to cope with the symptoms. The Ecology of Human Performance model focuses on the person, task, context, and how the three variables relate to performance in occupations (Dunn, 2017). As a result, a person's ecology, or the relationship between the person and their environment, and context may need to be altered to promote successful occupational participation. For example, individuals with PPCS can have headaches or dizziness that may make them more sensitive to harsh lighting conditions or loud environments, and thus, less likely to be able to engage in meaningful occupations. Using this model, therapists can use a variety of strategies, such as establish and restore; adapt and modify; alter; prevent; and create. This leads to higher and more efficient occupational engagement for the client (Brown, 2019).

Insufficiency of Current Outcome Measures

There are a variety of outcome measures for individuals with PPCS, however, most fall short in many ways. Validity and reliability are essential for outcome measures and evaluating their efficacy. Many studies fail to detail the reliability and validity of the outcome measures used in their research (Shukla et al., 2011). For example, the Postconcussion Syndrome Checklist (PCSC) does not have reliability documented for this outcome measure (Sullivan & Garden, 2011).

Additionally, existing outcome measures fail to measure an individual's life before trauma. Gathering more information on a patient's history may help to determine which patients are more likely to have worse outcomes and to determine if other interventions should be implemented, such as treatment for mood symptoms (Scott et al., 2016). Further, many questionnaires used to assess post-concussion symptoms utilize self-report methods. This may lead individuals to under or over report symptoms (Voormolen et al., 2018).

Further, it is difficult for outcome measures to address all patients' individual needs because patients have unique experiences following a concussion (Daneshvar et al., 2011). "No single measure to date can adequately capture the multiplicity of difficulties that people with TBI may face" (Wilde et al., 2010, p. 1652). Most current outcome measures focus on specific symptoms rather than how the symptoms affect the individual and their occupational engagement. The Neurobehavioral Symptom Inventory (NSI) has been found to be a poor measure of successful employment or other daily living functional measures (Belanger et al., 2017). Additionally, the PCSC, British Columbia Postconcussion Symptom Inventory (BC-PSI), and Postconcussion Syndrome Symptom Scale (PCSSS) are simply lists of symptoms used to evaluate the duration, intensity, and occurrence of PPCS symptoms and does not look at

occupational engagement (Sullivan & Garden, 2011). Another issue is that most outcome measures are intended for individuals with TBIs rather than patients with PPCS. The lack of outcome measures for PPCS could be due to the fact that there is still much uncertainty in regards to the cause, treatment, and definition of PPCS (Willer & Leddy, 2006). In addition, symptoms are sometimes subtle, thus individuals may fail to recognize they are related to their head trauma (Willer & Leddy, 2006).

Direction of Research

Current studies do not adequately address the validity and/or reliability of PPCS outcome measures in adult populations. Oftentimes, outcome measures are designed for individuals who have a TBI and not PPCS. Current PPCS outcome measures lack in a multitude of ways, including inconsistent validity and reliability reporting, no focus on occupational engagement, insufficient consideration of prior trauma, and are not customized to unique client PPCS experiences. The purpose of this systematic review is to identify current reliable and/or valid PPCS outcome measures for adults and how well they assess an individual's ability to engage in occupations.

Method

Search Strategy

This systematic review was conducted using the PRISMA guidelines. Search strategies were determined in collaboration and partnership with the GVSU Health Science librarian who is trained in conducting systematic reviews (see Appendix A). PPCS search terms and keywords were then developed by the research team with guidance from the GVSU's librarian.The databases used were PubMed, CINAHL, PsycINFO, Web of Science, OTSeeker, and SPORTDiscus. After implementing the search strategies, 2491 articles were extracted with full

citations to a secure Excel sheet for review. The Excel document was managed by one research member for consistency purposes. Duplicate articles were deleted resulting in a total of 1534 articles. The total number of articles were divided in half between the four group members and were reviewed in pairs. Each member reviewed the abstracts of the assigned articles. If there was a disagreement regarding the criteria between a pair that reviewed the same articles, an assigned research member then reviewed the abstract and determined eligibility. After eliminating articles that did not meet the inclusion criteria, group members reviewed the full text of 25 articles and determined eligibility using the same procedure stated above. This process yielded seven articles in total that met the inclusion and exclusion criteria. These seven articles will form the basis of the PPCS systematic review and outcome measures connection to occupation.

Inclusion and Exclusion Criteria

Inclusion criteria included English-language, peer-reviewed articles of adults 18-years-old and above with PPCS, and outcome measures for PPCS that addressed its reliability and/or its validity. Exclusion criteria excluded studies that did not address reliability and/or validity of outcome measures for PPCS.

Results

The search strategy found 2491 articles. There were 1534 articles after the removal of duplicates. The 1534 article abstracts were then reviewed for inclusion and exclusion criteria, and 25 articles were found to be eligible for full-text review. At this stage, main reasons for article exclusion were the following: published in a different language, had a population of children, did not mention an outcome measure's reliability and/or validity, or did not mention PPCS within the population being studied. The review of full-text articles yielded seven articles which satisfied the inclusion and exclusion criteria. The seven studies were peer-reviewed

articles that were classified as cohort studies (six) and an individual case study. The most common reason for exclusion of full text peer-reviewed articles was that populations did not have PPCS. This includes members not having the condition or failure to meet the three month diagnosis threshold. Other reasons for exclusion of full-text articles were participants under 18 years old and a lack of reporting validity and/or reliability of outcome measures being studied. The selection process can be viewed in the PRISMA flowchart (see Figure 1).

Quality Appraisal and Level of Evidence

The articles were assessed using the Oxford Centre for Evidence-based Medicine (CEBM): Levels of Evidence (2009 version). The CEBM system allows researchers to, "appraise evidence for prevalence, accuracy of diagnostic tests, prognosis, therapeutic effects, rare harms, common harms, and usefulness of (early) screening" (University of Oxford, 2020, para. 2). The CEBM is a scale that evaluates the level of evidence a study has based on its design. The level of evidence for each study was determined by utilizing the criteria within each category. A lower number indicates a study with higher rigor. One article received a level 1b, which indicates a high level of evidence according to the Oxford scale. Five articles were ranked as having a moderate level of evidence at level 2b, and one additional article was ranked at a lower level of evidence at a level 3b.

Outcome Measures

The seven included studies incorporated 13 outcome measures. The following outcome measures were found in the articles: Neurobehavioral Symptom Inventory (NSI), NSI Validity 10, Posttraumatic Checklist (PCL), Rivermead Postconcussion Symptoms Questionnaire (RPQ), the Postconcussion Syndrome Symptom Scale (PCSSS), Postconcussion Syndrome Checklist (PCSC), British Columbia Postconcussion Symptom Inventory (BC-PSI), Rivermead Head

Injury Follow-up Questionnaire (RHFUQ), Paced Auditory Serial Addition Test (PASAT), The Continuous Performance Test of Attention (CPTA), and Attention Monitoring and Rating Scale (ARMS), World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0), and Postconcussive Symptom Questionnaire (PCSQ-19). The articles that met the inclusion criteria were then documented in Table A1 to record the strength of their validity and reliability. Only two articles studied outcome measures that were occupation-based (Eyres et al., 2005; Snell et al., 2017). The two outcome measures that were occupation-based were Rivermead Head Injury Follow-up Questionnaire and World Health Organization Disability Assessment Schedule 2.0. The 12 item WHODAS 2.0 has internal consistency of 0.92 (Snell et al., 2017) and RHFUQ has external construct validity of 0.83 when compared to the RPQ-13 (Eyres et al., 2005).

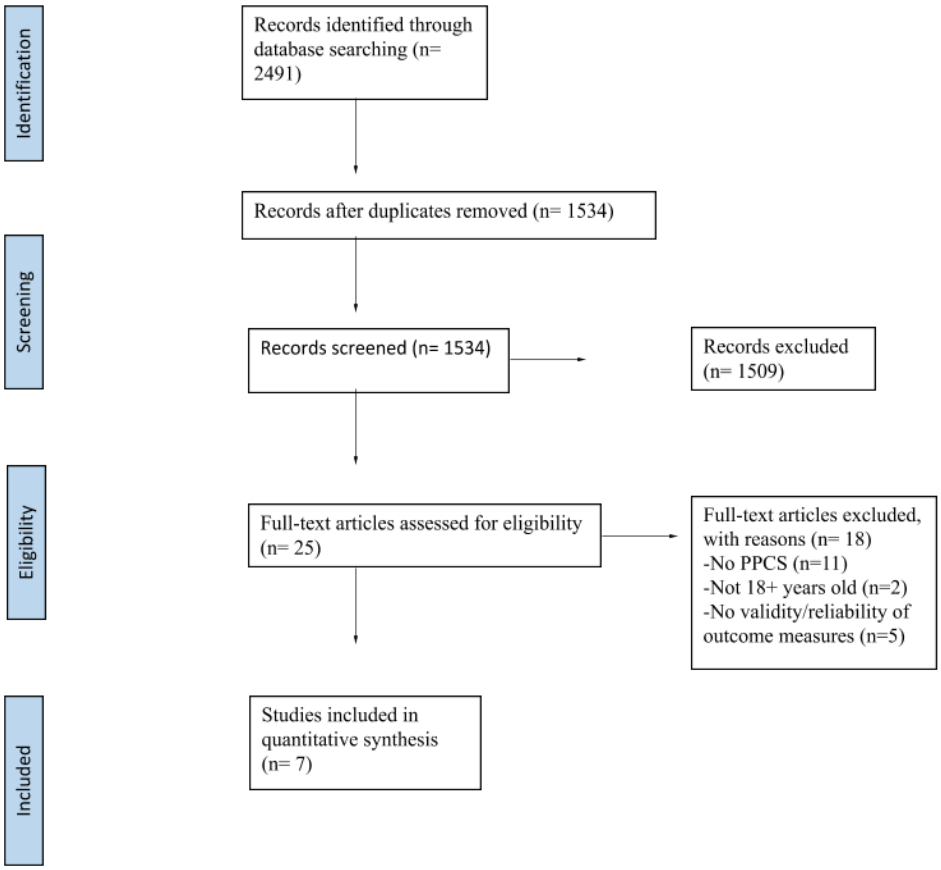
The RPQ and NSI outcome measures are represented twice in this review. An article concluded that the internal reliability of the RPQ outcome measure is 0.92 (Sullivan & Garden, 2011). Another article split up the RPQ outcome measure into the RPQ-13 and RPQ-3 with test-retest reliability scores of 0.89 and 0.72 respectively. The external construct validity for RPQ-13 is 0.83 and RPQ-3 is 0.62 (Eyres et al., 2005). Next, an article concluded the test-retest reliability of the NSI to be 0.78 (Belanger et al., 2016). The two components of validity measured for NSI were sensitivity and specificity. For NSI total scores above 36, sensitivity is 0.781 and specificity is 0.615. For total scores above 63, sensitivity is 0.300 and specificity is 0.943. The NSI Validity-10 scores above 10, sensitivity is 0.875 and specificity is 0.692. For NSI validity-10 scores above 22, sensitivity is 0.200 and specificity is 0.914 (Gradwohl et al., 2020). The only overlap between any of the reliability and validity measures was between the NSI and the RPQ, which both assessed test-retest reliability. Other types of validity and reliability assessed in

different outcome measures were internal validity, internal consistency, person reliability, and item reliability.

Figure 1

PRISMA Flowchart

Note.



PRISMA Flowchart displaying selection process for inclusion of studies reviewed

Discussion

The purpose of this systematic review is to evaluate current reliable and/or valid PPCS outcome measures for adults and how well they assess an individual's ability to engage in occupations. The RPQ and NSI can be compared because both studies assessed test-retest

reliability. RPQ-13 has been found to have stronger reliability than RPQ-3 and NSI. For all other outcome measures, it was difficult to compare the level of reliability and validity, because they used a variety of reliability and validity measures. For example, some studies used test-retest reliability and others used internal reliability. These types of reliability measure different things and cannot be directly compared. Additionally, some studies failed to address both reliability and validity and focused on one or the other. It is challenging to determine the efficacy of an outcome measure when only one is addressed.

Further, most outcome measures in this review focus on a person's symptoms rather than their ability to function in various areas of life. It is important to have an outcome measure that is occupation-based in order to determine *how* an individual's symptoms are negatively impacting their daily performance and to determine what occupations are being impacted the most. This review was able to identify two outcome measures that are occupation-based: the 12-item WHODAS 2.0 and RHFUQ. These measures were considered to be occupation-based because they consider specific engagement in activities or tasks. The 12 item WHODAS 2.0 outcome measure evaluates engagement in various occupations such as dressing, bathing, walking, work, and household responsibilities (Snell et al., 2017). The RHFUQ outcome measure evaluates engagement in occupations such as leisure, work, and relationships (Eyres et al., 2005). However, the two measures could not be compared for reliability and validity because the two studies did not assess the same types of reliability and validity. The WHODAS 2.0 included internal consistency and the RHFUQ measured external construct validity.

There is not a clear definition for PPCS. Many articles refer to it as post-concussion syndrome (PCS) or a mild traumatic brain injury (mTBI) or see it as a sort of psychosomatic disorder. It was discovered that the onset of PPCS was also inconsistent across studies. There are

many definitions of PPCS with varying symptoms. Furthermore, a few of the articles did not have a population solely of individuals who were experiencing PPCS. It is difficult to create and evaluate outcome measures when the diagnosis is still a moving target.

Future Research within OT

The results of this study found that there are no outcome measures that are both occupation-based and are reliable and valid. It is best practice to utilize reliable and valid occupation-based outcome measures in order to provide client-centered care. If it cannot be determined which occupations are impacted, it is difficult to determine quality occupational therapy interventions.

Further studies should be done to increase the knowledge of the validity and reliability of the occupation-based outcome measures, WHODAS 2.0 and the RHFUQ. While the WHODAS 2.0 and RHFUQ address some occupations, there is not an available outcome measure that addresses the range of occupations included in the scope of occupational therapy. More knowledge of the validity and reliability of these measures will help researchers to determine if a new occupation-based outcome measure should be created to better assist occupational therapists in treating individuals with PPCS. This may assist future occupational therapists in deciding where to focus their treatment and to develop treatment plans that are client-centered. The profession of OT needs a reliable and valid outcome measure in order to be more efficient and effective in evaluating and treating individuals with PPCS.

Limitations

A variety of limitations were noted regarding this systematic review. Research members often had to infer what studies included PPCS populations because of vague definitions in the literature. For example, studies had to be excluded if they were assessing populations

immediately following injury instead of three months post-injury. Further, the GVSU library provided access to a limited number of articles within various databases. Lastly, the search strategies were only implemented once in the different databases. As a result, it failed to include articles published after the start of this systematic review, May 21, 2020.

While bias is a common limitation of studies, we took careful measures to limit it. We evaluated all of the included studies for overall quality and level of evidence using the Oxford Centre for Evidence-based Medicine: Levels of Evidence. The higher the level of evidence found with this scale, the lower the risk of bias in the article.

Conclusion

Current literature is limited on reliable, valid, and occupation-based outcome measures. One potential reason for this is an inconsistent understanding of PPCS between studies. Two outcome measures, the WHODAS 2.0 and RHFUQ, were found to be occupation-based. However, the outcome measures do not address the entire scope of occupational therapy practice. The reliability and validity of the two outcome measures could not be compared due to different statistical evaluations. Further research is needed to create a reliable, valid, and occupation-based outcome measure that meets the needs of occupational therapists and the clients they treat.

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Wilde, E.A., Whiteneck, G.G., Bogner, J., Bushnik, T., Cifu, D.X., Dikmen, S., von Steinbuechel, N. (2010). Recommendations for the use of common outcome measures in traumatic brain injury research. *Archives of Physical Medicine and Rehabilitation*, 91(11), 1650–1660.

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Appendix

Appendix A

Full Search Strategy from PubMed

(("Brain Concussion"[Mesh]) OR (“postconcussion”[tw] OR “post concussion”[tw] OR “post-concussion”[tw] OR “PCS”[tw] OR “post-concussive”[tw] OR “postconcussive”[tw] OR “post concussive”[tw]))
AND
((“Validation Study”[Publication Type]) OR ("Validation Studies as Topic"[Mesh]) OR ("Reproducibility of Results"[Mesh:NoExp]) OR ("Data Accuracy"[Mesh:NoExp]) OR ("validation"[tw] OR "validity"[tw] OR “validated”[tw] OR “valid”[tw] OR "psychometric properties"[tw] OR "psychometric testing"[tw] OR "measurement properties"[tw] OR “reliable”[tw] OR "reliability"[tw] OR “reproducibility”[tw] OR “reproducible”[tw] OR “data accuracy”[tw] OR “data quality”[tw]))
AND
("Surveys and Questionnaires"[Mesh]) OR ("Outcome Assessment, Health Care"[Mesh]) OR (“Assessment”[tw] OR “assessments”[tw] OR “measure”[tw] OR “measures”[tw] OR “measurement”[tw] OR “survey”[tw] OR “surveys”[tw] OR “questionnaire”[tw] OR “questionnaires”[tw] OR “scale”[tw] OR “scales”[tw] OR “screening”[tw] OR “test”[tw] OR “tests”[tw])

Table A1

PPCS Level of Evidence

Citation	Study Design	Level of Evidence	Name of Outcome Measure	Type/Values for Validity/ Reliability	Occupation -Based
Belanger, H. G., Lange, R. T., Bailie, J., Iverson, G. L., Arrieux, J. P., Ivins, B. J., & Cole, W. R. (2016). Interpreting change on the neurobehavioral symptom inventory and the PTSD checklist in military personnel. *The Clinical Neuropsychologist*, *30*(7), 1063-1073.	Individual Cohort Study	2b	Neuro-behavioral Symptom Inventory (NSI) Posttraumatic Checklist (PCL)	**Test-retest reliability** for NSI r=0.78; PCL r=0.70	No
Cicerone, K. D., & Azulay, J. (2002). Diagnostic utility of attention measures in postconcussion syndrome. *The Clinical Neuropsychologist*, *16*(3), 280-289.	Individual Case-Control Study	3b	Paced Auditory Serial Addition Test (PASAT) The Continuous Performance Test of Attention (CPTA) Attention Monitoring and Rating Scale (ARMS)	ARMS **internal validity** (Cronbach's alpha = 0.93) and correlations between .85-.91 **Sensitivity:** PASAT and CPTA demonstrated the greatest sensitivity to impairment in persons diagnosed with PCS **Specificity:** Both measures (CPTA and PASAT)	No

				demonstrate specificities greater than 70% at the most lenient criteria for identifying impairment, and quite acceptable levels of specificity at more stringent criteria.	
Citation	Study Design	Level of Evidence	Name of Outcome Measure	Type/Values for Validity/ Reliability	Occupation -Based
Eyres, S., Carey, A., Gilworth, G., Neumann, V., & Tennant, A. (2005). Construct validity and reliability of the Rivermead post-concussion symptoms questionnaire. *Clinical rehabilitation*, *19*(8), 878-887.	Inception Cohort Study	1b	Rivermead Post-Concussion Symptoms Questionnaire (RPQ) Rivermead Head Injury Follow-up Questionnaire (RHFUQ)	**RPQ-13 Test-retest reliability** 0.89, individual items ranging from 0.62-0.85 **RPQ-3 test-retest reliability** 0.72, individual items ranging from 0.59-0.69. **External construct validity** for RPQ-13 and RHFUQ was 0.83. Individual items ranged from 0.52 to 0.71. RPQ-3 and RHFUQ was 0.62 and individual items ranging from 0.4 to 0.6.	RPQ – No RHF UQ- Yes
Citation	Study Design	Level of Evidence	Name of Outcome Measure	Type/Values for Validity/ Reliability	Occupation -Based

Gardizi, E., Millis, S. R., Hanks, R., & Axelrod, B. (2012). Rasch analysis of the postconcussive symptom questionnaire: Measuring the core construct of brain injury symptomatology. *The Clinical Neuropsychologist*, *26*(6), 869-878.	Cohort Study	2b	Postconcussive Symptom Questionnaire-19 (PCSQ-19)	**Person reliability** 0.81 **Item reliability** 0.94	No
Gradwohl, B. D., Mangum, R. W., Tolle, K. A., Pangilinan, P. H., Bieliauskas, L. A., & Spencer, R. J. (2020). Validating the usefulness of the NSI validity-10 with the MMPI-2-RF. *International Journal of Neuroscience*, 1-7.	Cohort Study	2b	Neuro-behavioral Symptom Inventory (NSI) Total Scores NSI Validity-10	NSI Total Scores above 36 [**sensitivity** = 0.781, **specificity** = 0.615] NSI Total Scores above 63 [**sensitivity** = 0.300, **specificity** = 0.943] NSI Validity-10 scores above 10 [**sensitivity** = 0.875, **specificity** = 0.692] NSI Validity-10 scores above 22 [**sensitivity** = 0.200, **specificity** = 0.914]	No
Citation	Study Design	Level of Evidence	Name of Outcome Measure	Type/Values for Validity/ Reliability	Occupation-Based
Snell, D. L., Iverson, G. L., Panenka, W. J., &	Prospective Cohort Study	2b	World Health Organization Disability	**Internal consistency** 0.92	Yes

Silverberg, N. D. (2017). Preliminary validation of the World Health Organization Disability Assessment Schedule 2.0 for mild traumatic brain injury. *Journal of neurotrauma*, *34*(23), 3256-3261.			Assessment Schedule 2.0 (WHODAS 2.0) - 12 item		
Sullivan, K., & Garden, N. (2011). A comparison of the psychometric properties of 4 postconcussion syndrome measures in a nonclinical sample. *The Journal of head trauma rehabilitation*, *26*(2), 170-176.	Cohort Study	2b	Rivermead Post-concussion Symptoms Questionnaire (RPQ) Post Concussion Syndrome Symptom Scale (PCSSS) Post - concussion Syndrome Checklist (PCSC) British Columbia Post-concussion Symptom Inventory (BC-PSI)	**Internal reliability** RPQ = 0.92 BC-PSI =0.93 PCSC = 0.92 PCSSS = 0.95 **Convergent validity** significant moderate positive correlations that ranged from 0.59 to 0.78 were observed across the four measures between total scale scores **Divergent validity** Significant moderate positive correlations that ranged from 0.59 to 0.77 were found between the 4 PCS measures and the BDI-II	No