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## **Improving guideline concordance for the treatment of mild TBI**

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## **Improving guideline concordance for the treatment of mild TBI**

**Purpose:** Widespread acceptance of treatment options for mild traumatic brain injury (mTBI) has so far been limited in the UK. Guidelines have been created to standardise treatment, based on expert consensus (Ontario Neurotrauma Foundation; ONF). However, research indicates that clinician guidelines are not always used consistently. This paper audits the use of ONF guidelines in one mTBI clinic and explores recommendations to improve concordance. **Methods:** Criterion-based audit was used to assess guideline usage for patients seen within the clinic between January and August 2016. **Results and conclusion:** Results indicated that the clinic provided thorough assessment and reliable information, although intervention guidelines were not used consistently. Inter-rater reliability suggests patient notes were difficult to interpret. **Outcome:** A checklist was developed to guide clinics in recording assessment and intervention in line with ONF guidelines. A pilot is required to assess usability.

### **Literature review**

Mild traumatic brain injury (mTBI) can cause cognitive-affective consequences which often resolve independently within 3 months (Carroll, Cassidy, Holm, Kraus, & Coronado, 2004). However, a proportion of patients experience more chronic symptoms, sometimes known as Post Concussion Syndrome (Ontario Neurotrauma Foundation, 2013). This term is controversial as ongoing debates regarding aetiology, diagnosis, pathophysiology and prognosis render the experience under-researched and poorly

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understood (Polinder et al, 2018). Nevertheless, incomplete recovery is observed in a proportion of patients, with a recent observational cohort study suggesting this 44% of patients had post-traumatic complaints 6 months after injury (van der Naalt et al., 2017). Accordingly, the term post-traumatic complaints will describe symptom experience that persists following mTBI regardless of time frame, whilst mTBI will be used to describe injury.

Post-traumatic complaints following mTBI are variable and often classified according to three categories: somatic, cognitive and affective (Nygren-de Boussard et al., 2014). These can include (but are not limited to): headaches, fatigue, cognitive difficulties and mood or anxiety disorders (Marshall, Bayley, McCullagh, Velikonja, & Berrigan, 2012). Understanding the development of such symptom experience is controversial, however symptoms may be a function of ‘biopsychosocial’ factors (Carroll, Cassidy, Peloso, et al., 2004; Ganti et al., 2014; Snell, Macleod, & Anderson, 2016; Waljas et al., 2015). That is, biological effects of mTBI may interact with illness beliefs or expectations about symptom likelihood and severity (Hou et al., 2012; Mah, Hickling, & Reed, 2017). For instance, those who believe they are likely to experience severe symptoms may develop a hypervigilance towards them (Whittaker, Kemp, & House, 2007). However, post-traumatic complaints are not condition-specific and can be reported by healthy populations (Iverson & Lange, 2003). Therefore, benign symptoms may be misattributed to mTBI, perpetuating anxiety about post-traumatic complaints and potentially leading to further symptom experiences or re-evaluations of perceptions of mTBI severity or ability to cope (Salkovskis & Warwick, 1986; Snell, Hay-Smith, Surgenor, & Siegert, 2013). Indeed, biological effects of mTBI appear to have much less predictive value on prognosis compared with psychological factors, such as premorbid

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mental health difficulties, post-traumatic stress and cognitive difficulties (Scheenen et al., 2017; Silverberg et al., 2015).

To better understand, prevent and treat post-traumatic complaints, psychosocial factors should be considered, and some authors have argued that neuropsychology plays a particularly important role in this (Nygren-de Boussard et al., 2014). However, research regarding best treatment options is limited, perhaps in part due to difficulties defining the aetiology of post-traumatic complaints and the consequent homogeneity of the population (Polinder et al, 2018). Furthermore, methodological limitations mean outcomes are not sufficiently robust to offer confident support for any form of treatment (Eliyahu, Kirkland, Campbell, & Rowe, 2016; Gravel et al., 2013; Nygren-de Boussard et al., 2014). The Ontario Neurotrauma Foundation (ONF, 2013) have attempted to overcome this by developing expert consensus guidelines to standardise treatment following mTBI, focussing on standardised assessment using clinical interview and/or psychometric tool, psychoeducation regarding symptoms and their normal course of resolution and symptom-specific pharmacological and psychological treatments (Marshall et al., 2012; Marshall et al., 2015). Whilst consensus guidelines may be limited by bias within the community and are less well supported by a clear evidence-base, they can act as a springboard to more rigorous, research-led guidelines.

However, guideline concordance should not be assumed (Francke, Smit, de Veer, & Mistiaen, 2008), and studies have shown poor adherence to Traumatic Brain Injury (Hesdorffer, Ghajar, & Iacono, 2002; Cnossen et al, 2016) and paediatric mTBI guidelines (Reisner et al., 2017), although the latter improved following an educational intervention. Accordingly, it is important to evaluate how clinics are using guidelines, and put in place interventions to improve adherence when this is poor.

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This study audited the use of ONF Guidelines in one mTBI clinic in the United Kingdom. The aim was to explore the consistency with which ONF guidelines were used, and identify potential improvements to enhance standardization.

### **Method**

#### **Governance and Ethical Considerations**

Ethical approval was received from the Research and Development office at the relevant NHS Trust and the University Psychology Ethics Committee.

#### **Design**

Criterion-based audit of patient case notes was conducted based on ONF guidelines. Criterion-based audit is an efficient and standardized method of linking audit with clinical guidelines (Hutchinson et al., 2010; Shaw, 1990).

#### **Participants**

Case notes for all patients discharged in 2016 ( $n = 23$ ) were collected. Case notes were excluded if assessment indicated that symptoms were not a function of mTBI ( $n = 6$ ). A total of 17 case notes were audited.

#### **Materials**

Relevant guidelines from ONF were used to develop a novel criterion-based checklist with two purposes: to provide a tool to enable regular audit and as a checklist to guide clinical sessions, both recognised as supporting guideline adherence (Francke et al., 2008). The checklist included 19 compulsory guidelines (largely screens) and 36 guidelines conditional on criteria being met (typically interventions). Two additional

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compulsory guidelines were added to the checklist to identify when a guideline had been partially met.

### **Procedure**

Case notes were analysed by the project lead and identified as having sufficient evidence each guideline was:

- Met (including referrals to appropriate services);
- Not applicable for the patient;
- No evidence of guideline being met.

A second rater assessed a sample of case notes ( $n = 6$ ). Inter-rater reliability was 59%. Discrepancies were explored and identified that the raters used the provided codes of 'not applicable' and 'no evidence' inconsistently. When these categories were collapsed, inter-rater reliability improved to 80%. It was important to maintain the distinction for audit purposes, therefore results should be interpreted with caution.

### **Analyses**

Compulsory and conditional guidelines were analysed separately. The percentage of times compulsory or conditional guidelines were met (or considered not applicable) was recorded across the whole data set to calculate overall guideline concordance. This was repeated for individual guidelines.

### **Results**

Fifty-seven percent of compulsory guidelines were met or not applicable across the data-set. However adherence varied between guidelines, with some being met more

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consistently than others (Table 1). Conditional guidelines were met or considered not applicable 58% of the time. However, the implementation of these guidelines were conditional on results of patient assessment (e.g. guidelines around headache interventions would only be required if headache was experienced). As assessments were not recorded consistently, it was difficult to identify which conditional guidelines were applicable. When rates were limited to those instances where need was assessed, adherence rate improved to 71% overall (Table 2). This might indicate that guideline adherence was underestimated due to missing or unclear information.

[Table 1; Table2]

### **Discussion**

The case-note audit indicated the mTBI service regularly adhered to some guidelines but neglected others. For instance, this service meets guidelines for referral to multi-disciplinary clinics for examination of contributing factors and consideration of management strategies in all cases. There is also good evidence for the clinic meeting guidelines around providing some education, fatigue management and headache, sleep and vestibular assessment. In contrast, assessment of mental health is evidenced on few occasions and cognition was rarely assessed formally. Additionally, it is observed that some guidelines were only partially met. For instance, whilst 88% patients received some education, only 6% received all the required education content, and there is no record of any being provided in written format, as recommended by the ONF.

Although criterion-based audit is an efficient and standardised method of linking audit with clinical guidelines (Hutchinson et al., 2010; Shaw, 1990b), it can only assess

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what is recorded. Unfortunately, inter-rater reliability for the case note audit was moderate, reducing confidence in determining the degree to which guidelines were being followed. This was particularly relevant for differentiating between guidelines that were 'not met' versus those that were 'not applicable'. These inter-rater reliability issues remained after a review of the coding instrument and instructions, and the ongoing difference in interpretation of case notes is likely to reflect limited standardisation of note-keeping between clinicians.

Accordingly, whilst we can confidently state how many guidelines were followed, it is difficult to ascertain whether gaps in concordance arose because guidelines were neglected or because they were not needed. This is in line with research across TBI services, which indicates that guideline adherence can be variable and is a point for improvement (Cnossen et al., 2016)

Outcomes thus indicate that case-note records were sometimes affected by ambiguous or missing information, and that ONF guidelines might not be consistently adhered to. This could be improved significantly by employing the routine use of a checklist based on the requirements of the guidelines. This could act both as an aide memoire and to improve the ease with which practitioners can record guideline concordance in a standardised manner (Francke et al., 2008). A checklist incorporating ONF guidelines was created in collaboration with a clinical neuropsychologist (AT) and a pilot is recommended to evaluate usability. The checklist has been approved by the ONF (S.Marshall, personal communication, 30<sup>th</sup> November 2017).

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### **Strengths, limitations and future directions**

This study is the first to assess adherence to best practices guidelines in an adult mTBI clinic in the UK and has introduced a novel criterion-based checklist for ONF guidelines. There are limitations to the project. Whilst moderate inter-rater reliability was suggested to be a function of the quality of case notes, it is possible that the criterion-based audit was not rigorous enough. Secondly, the audit describes outcomes at one mTBI service within one locality in the UK with a small sample size, therefore results may not be generalisable. It is noteworthy that the service described is neuropsychology-led, and the checklist was adapted to reflect this way of working. However, it is not known the extent to which the ONF guidelines are being used within other mTBI clinics within the UK, so the checklist may not be sufficient to cover all relevant information in its current format. However, the checklist may offer a beneficial way to improve standardisation of care within and potentially between clinics. Future work should explore outcomes of another case note audit after the checklist has become embedded in the service, to test accuracy in clinical notes.

### **Summary and service outcomes**

Overall the outcomes from this case note audit indicate that the mTBI clinic is not meeting all guidelines consistently, as has been found in research on more severe forms of traumatic brain injury. From the currently available data, it was not possible to ascertain whether this reflects actual practice, or variation in quality of clinical note taking. A checklist based on the ONF guidelines has therefore been developed as a tool to improve accuracy of recording clinic outcomes and to promote guideline concordance. Piloting and review of this checklist is required to

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assess potential benefits. If findings are positive, it could be of benefit to other services employing the ONF guidelines, and committed to best care in mTBI.

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RUNNING HEAD: Improving guideline concordance in mild TBI

Table 1.

*Table Describing the Percentage of Cases where each Compulsory Guideline was Met.*

<b>Standard guideline</b>	<b>Evidence guideline met</b>
<i>All potential contributing factors to symptoms investigated and a management strategy considered</i>	100%
<i>Persons with mTBI and complicating health-related or contextual factors should be considered for early referral to a multidisciplinary treatment clinic</i>	100%
<i>Encouraged to gradually return to normal activity based on tolerance</i>	100%
<i>Assessed fatigue with focused history (questionnaires can assist with this)</i>	100%
<i>Screen for headaches</i>	94%
<i>Evaluated for cognitive difficulties with cognitive interview &amp; validated post-concussive questionnaire (Rivermead)</i>	94%
<i>Screened for sleep/wake disturbance</i>	94%
<i>Evidence of some relevant education provided in printed material combined with verbal review*</i>	88%
<i>Evaluation of vision, vestibular balance, coordination and/or hearing</i>	82%

<i>Dimensions of fatigue assessed and alternative/contributing causes considered</i>	65%
<i>Patient advised that they are likely to experience one or more symptoms as a consequence of mTBI and this may persist for a short period of time but is usually expected</i>	53%
<i>Patient advised that a full recovery of symptoms is seen in majority of cases</i>	47%
<i>Period of rest recommended with advice to avoid activities with risk of concussion</i>	41%
<i>For those slow to recover: low-level exercise recommended approx. one month post injury</i>	26%
<i>Second-person informant met</i>	18%
<i>Screened for mental health disorders</i>	6%
<i>Use of self-report mental health questionnaires (recommended: PHQ-9; GAD-7; PC-PTSD; PCL-CV; CAGE)</i>	6%
<i>Considered and evaluated relevant co-morbidities that might affect cognition</i>	6%
<i>Evidence of all relevant education should be provided in printed material combined with verbal review</i>	6%
<i>Advised that bed rest for more than 3 days is not recommended</i>	0%
<i>Use of cognition screening tool (MoCA)*</i>	0%

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*Note.* \*Added criteria to identify partial guideline concordance

Table 2. Table Describing the Percentage of Cases where Conditional Guidelines were Met, when Need for Intervention was Recorded.

<b>Conditional guidelines</b>	<b>N</b>	<b>Evidence guideline met</b>
<i>Interventions for mental health</i>	2	100%
<i>Interventions for fatigue</i>	17	94%
<i>Interventions for vestibular/vision/hearing</i>	14	79%
<i>Interventions for headaches</i>	16	68%
<i>Interventions for sleep/wake disturbance</i>	16	58%
<i>Interventions for cognitive difficulties</i>	16	55%
<i>Interventions for return to work**</i>	17	32%

Note. \*Records for all notes are reported as occupation

### mTBI Clinic: Assessment and Intervention Checklist

<b>Name:</b>			
<b>DOB:</b>		<b>NHS no:</b>	
<b>Address:</b>			

INITIAL ASSESSMENT	
Is a second-person informant in attendance?	Yes / No
Has Rivermead Post Concussion Questionnaire been completed and returned?	Yes / No
Administered self-report questionnaires (PHQ-9; GAD-7; PC-PTSD; PCL-CV; CAGE)	Yes / No
Have contributing factors been investigated, and onward referrals been made (where applicable)?	Yes / No
Are other significant potentially causative factors present	Yes / No
Was patient referred to the multidisciplinary treatment clinic within 1 month of injury?	Yes / No

PSYCHOEDUCATION	
Advise patient advised that are likely to experience one or more symptoms as a consequence of mTBI and this may persist for a short period of time but is usually expected	Yes / No
Advise patient that a full recovery of symptoms is seen in majority of cases	Yes / No
For those slow to recover: low-level exercise approx. 1 month post injury	Yes / No / NA
Education regarding the following has been provided in printed material and discussed: <sup>[[SEP]]</sup> a. Symptoms and expected outcomes. <sup>[[SEP]]</sup> b. Normalizing symptoms (education that current symptoms are expected and common after injury event). <sup>[[SEP]]</sup> c. Reassurance about expected positive recovery. d. Gradual return to activities and life roles. <sup>[[SEP]]</sup> e. Techniques to manage stress. f. Diet	Yes / No Yes / No Yes / No Yes / No Yes / No Yes / No

<b>HEADACHE</b>	
<b>Are headaches present?</b> <i>(If 'No', go to 'Sleep/wake disturbance')</i>	<b>Yes / No</b>
<i>Headache frequency</i>	
<i>Headache duration</i>	
<i>Headache location</i>	
<i>Headache intensity</i>	
<i>Quality of the pain (pressure, throbbing, stabbing)</i>	
<i>Associated symptoms (e.g. nausea/vomiting)</i>	
<i>Precipitating/provoking factors</i>	
<i>Alleviating factors</i>	
<i>Previous treatment experiences and responses to date (including benefits and side-effects)</i>	
<i>Degree of headache-related disability?</i>	
<b>Non- pharmacological Treatment</b>	
Provide education for lifestyle strategies/self-help to minimise headache	Yes / No / NA
Non-pharmacological therapies been considered (relaxation, biofeedback, fatigue management, CBT, manual therapy of the spine)	Yes / No / NA
Have non-pharmacological treatments been successful? <i>(If yes, go to 'sleep/wake disturbance')</i>	Yes / No / NA
<b>Pharmacological Treatment</b>	
Medication has been discussed and patient advised to discuss further with GP?	Yes / No / NA
Advise patients to maintain an accurate headache and medication calendar	Yes / No / NA
For patients with post-traumatic headaches that are migrainous in nature, has referral to neurologists been made?	Yes / No / NA
Narcotic analgesics should be avoided or restricted to "rescue therapy" for acute attacks when other first- and second-line therapies fail or are contraindicated. Advise patient to discuss further with GP.	Yes / No / NA
Prophylactic therapy should be considered if headaches are occurring too frequently or are too disabling, or if acute headache medications are contraindicated, poorly tolerated, or being used too frequently. Advise to discuss further with GP	Yes / No / NA

<b>SLEEP/WAKE DISTURBANCE</b>	
<b>Is sleep/wake disturbance present?</b> <i>(If no, go to 'persistent mental health disorder')</i>	<b>Yes / No</b>
Are there medical conditions, current medication use, comorbid psychopathology, and risk factors for sleep disturbances, which may influence the sleep/wake cycle <i>Please list:</i>	Yes / No / NA

Has patient been referred to specialist to manage treatment? ( <i>Recommended if sleep disturbances persist or if there is suspicion of sleep-related breathing disorders, nocturnal seizures, periodic limb movements, or narcolepsy</i> ) ( <i>If yes, go to 'persistent mental health disorder'</i> )	Yes / No / NA
<b>Non-pharmacological treatment</b>	
Recommended programme of sleep hygiene (in addition to other intervention)	Yes / No / NA
Recommended CBT for either primary insomnia or insomnia co-morbid to a medical or psychiatric condition.	Yes / No / NA
Considered other interventions such as exercise, and mindfulness-based stress reduction.	Yes / No / NA
<b>Pharmacological Treatment</b>	
Advised that this should be used on a short-term basis only due to risk of dependence.	Yes / No / NA
Advise patient to discuss medication with their GP	Yes / No / NA

<b>PERSISTENT MENTAL HEALTH DISORDER</b>	
<b>Do outcomes of screen and self-report questionnaires indicate mental health disorder?</b> ( <i>If no, go to 'persistent cognitive difficulty'</i> )	<b>Yes / No</b>
Referral to appropriate specialist for mental health if: <ul style="list-style-type: none"> <li>• The presentation is complex and/or severe<sup>[SEP]</sup></li> <li>• The risk of suicide is judged significant<sup>[SEP]</sup></li> <li>• Initial treatment is not effective within two months</li> <li>• Failure of or contraindication to usual medication strategies<sup>[SEP]</sup></li> <li>• Presence of prominent/major risk factors known to potentially affect the course of recovery</li> </ul>	Yes / No / NA
CBT considered for mood/anxiety disorder	Yes / No / NA
Advise patient to discuss medication queries with GP	Yes / No / NA

<b>PERSISTENT COGNITIVE DIFFICULTIES – after fatigue management plan</b>	
<b>Are cognitive difficulties present following fatigue management plan?</b> ( <i>If no, go to 'vestibular/hearing dysfunction'</i> )	<b>Yes / No</b>
Evaluated for cognitive difficulties with cognitive interview	Yes / No
Evaluated for cognitive difficulties with cognition screening tool (MoCA)	Yes / No
Considered and evaluated relevant co-morbidities	Yes / No
Considered for neuropsychological assessment	Yes / No / NA
Rehabilitation strategies used consisting of compensatory strategies and remediation if individual exhibits persisting cognitive impairments or learning of compensatory strategies is necessary in order to facilitate the resumption of functional activities and work.	Yes / No / NA
Efforts made to inform employers/teachers of potential accommodations if persistent cognitive deficits identified	Yes / No / NA

<b>VESTIBULAR/HEARING DYSFUNCTION</b>	
<b>Are vestibular, hearing or visual dysfunctions present?</b> ( <i>If no, go to 'persistent fatigue'</i> )	<b>Yes / No</b>

Has patient been referred to physiotherapy to manage vestibular treatment and/or nausea?	Yes / No / NA
Has patient been referred to audiology to manage hearing treatment?	Yes / No / NA

<b>PERSISTENT FATIGUE</b>	
<b>Is persistent fatigue present?</b> <i>(If no, go to 'return to activity consideration')</i>	<b>Yes / No</b>
Dimensions of fatigue assessed and alternative/contributing causes considered	Yes / No / NA
If fatigue identified, fatigue management plan considered, including <ul style="list-style-type: none"> <li>• Aim for a gradual increase in activity levels that will parallel improvement in energy levels.</li> <li>• Reinforce that pacing activities across the day will help patients to achieve more and to avoid exceeding tolerance levels.<sup>[1]</sup></li> <li>• Encouraging good sleep hygiene (especially regularity of sleep/wake schedules, and avoidance of stimulants and alcohol), and proper relaxation times</li> <li>• Using a notebook or a diary to plan meaningful goals, record activity achievement, and identify patterns of fatigue.</li> <li>• Acknowledging that fatigue can be exacerbated by low mood or stress.</li> </ul>	Yes / No / NA
Leaflet with advice on coping strategies for fatigue provided	Yes / No / NA

<b>RETURN TO ACTIVITY CONSIDERATIONS</b>	
Recommended a period of rest with advice to avoid activities with risk of concussion	Yes / No
Bed rest for more than 3 days is not recommended	Yes / No
Encouraged to gradually return to normal activity based on tolerance	Yes / No
If normal activity involves significant physical activity: Exertion testing	Yes / No / NA
If at high risk of injury/reinjury: a more in-depth assessment of symptoms and accommodations/work restrictions identified	Yes / No / NA
If experience persistent impairment or not fully returned to pre-injury work: Referral for vocational assessment	Yes / No / NA
Is patient of school age and/or in education? <i>(If no, checklist is complete)</i>	Yes / No
Advised to, refrain from attending school/ academic activity if symptomatic in first 72 hours. If remain symptomatic following this time, avoid school for 1 week. If still symptomatic, avoid school for another week. Should return after 2 weeks	Yes / No / NA
If no return /ineffective reintegration after 4 weeks: accommodations considered	Yes / No / NA
If asymptomatic in first 72 hours: advised that can attend school but not tests and include accommodations	Yes / No / NA

The checklist has been viewed and approved by the original authors of the ONF guidelines, and they have given permission for this checklist to be used as described in this article