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Fatigue after Acquired Brain Injury: a model to guide clinical management

Summary

- Fatigue experienced following ABI is multifactorial and difficult to measure
- Fatigue impacts on rehabilitation, levels of social participation and quality of life
- There is a growing evidence base around fatigue, but this remains limited regarding management
- This clinical model may support development of a shared understanding, guide intervention and reduce vulnerability to fatigue for individuals
- More research into both the subjective (experienced, reported) and objective (physiological and neuropsychological) aspects of fatigue, and their interplay, is required

Fatigue is one of the most commonly reported, distressing and persistent of symptoms after acquired brain injury (ABI), including traumatic head injury and stroke, with an estimated incidence of more than 60% across the range of injury severity.^{1,2} Injury severity is not necessarily a predictive factor in severity of fatigue experienced, with fatigue reported after mild and very severe ABI.³ Persistent fatigue is associated with lower rates of return to work⁴ and higher mortality post-stroke.⁵ Despite this, evidence for management remains inadequate⁶ and clinically people report feeling unprepared for this consequence of their brain injury.

Defining and therefore operationalising fatigue is challenging as there are many confounding factors associated with it. It is now widely accepted as a multidimensional, biopsychosocial construct, authors describing both primary and secondary, or physiological (central and peripheral) fatigue and psychological fatigue impacting resultant behaviour, felt experience and its presentation within societal and cultural contexts.² Central fatigue is considered to result from impairment to structures within the central nervous system and is characterised by depletion of hormones and neurotransmitters. Peripheral fatigue is considered as a diminished ability to contract muscles, involving the peripheral motor and sensory systems.^{2,7} Brain structures and networks thought to be involved include the hypothalamic-pituitary axis, ascending reticular activating system, frontal cortex and basal ganglia. For example, neural circuits involved in the regulation of attention and executive function may contribute to development of tiredness and aversion to effort leading to fatigue,⁸ whilst other authors⁹ note involvement of the ventro-medial prefrontal cortex following penetrating traumatic brain injury.

Confounding factors contributing towards fatigue following brain injury incorporate pathophysiological, physical, mood and cognitive elements, including slowed speed of processing and difficulty sustaining attention,¹⁰ executive dysfunction,¹¹ reward and effort perception,⁹ anxiety and depression,^{12,13} sleep disturbance¹² and pain.^{14,15} Clinically these interacting elements may be considered as 'vulnerability factors' for fatigue as they are common consequences of an acquired brain injury and so addressing these factors may lead to a reduction in fatigue experienced

and enhance levels of social participation.

Many people experience fatigue as a consequence of participating in everyday activities. Pathological fatigue, which may indicate need for clinical intervention, does not necessarily dissipate with rest and is of greater intensity and duration compared to 'normal fatigue' experienced following exertion, with a corresponding impact on ability to undertake functional activities. People experiencing pathological fatigue following ABI frequently refer to their brain as "shutting off", with an intolerance to sensory stimuli and struggle to think and communicate effectively. 'Mental' fatigue (as opposed to peripheral fatigue) is frequently described as unpleasant and people perceive a lack of control over it with a negative impact on their level of self-efficacy.¹⁶ Cantor and colleagues⁶ suggests a 'coping hypothesis' with fatigue experienced considered a response to reduced cognitive functioning and tasks requiring more effort. They consider fatigue after brain injury as an "umbrella term" describing "different symptom clusters with potentially heterogeneous aetiologies and consequences"⁶ [p. 880]. Patients report that fatigue significantly impacts upon their ability to participate in rehabilitation and daily living activities and influences their mood, relationships and quality of life. Eilertsen, Ormstad and Kirkevold¹⁷ identified the need for acknowledgement of this distressing symptom from others as a key factor influencing coping as it presented as a 'hidden dysfunction' which could be misinterpreted by others.

There are numerous self-report fatigue scales available, though few valid and reliable measures have been developed for people with ABI. Such scales include the Barrow Neurological Institute Fatigue Scale¹⁸ for acute stages post-injury, the Mental Fatigue Scale¹⁹ which has been developed for the ABI population, the Neurological Fatigue Index – Stroke²⁰ which has been developed for Stroke. As a consequence, many clinicians and researchers make use of scales initially developed for other diagnostic groups, such as the modified Fatigue Impact Scale²¹ and the Fatigue Severity Scale.²² Additionally subscales of more generic ABI symptom questionnaires may indicate presence of clinically significant fatigue such as the Rasch-analysed EBIQ subscale²³ or the Profile of Mood States.²⁴

Scales available may address different aspects of fatigue (e.g. intensity, severity, characteristics and impact on activities of daily living) over different timeframes. Therefore from a clinical rehabilitation perspective, measures are selected based upon the clinical question to be addressed or the domain which is expected to be changed as a result of intervention. In our experience, when people begin to feel less fatigued, they naturally attempt to engage in more activity and so their overall level of fatigue may not reduce significantly, as measured on a fatigue scale. However, it is possible to capture changes in their felt experience, such as a reduction in level of worry about their fatigue, an increase

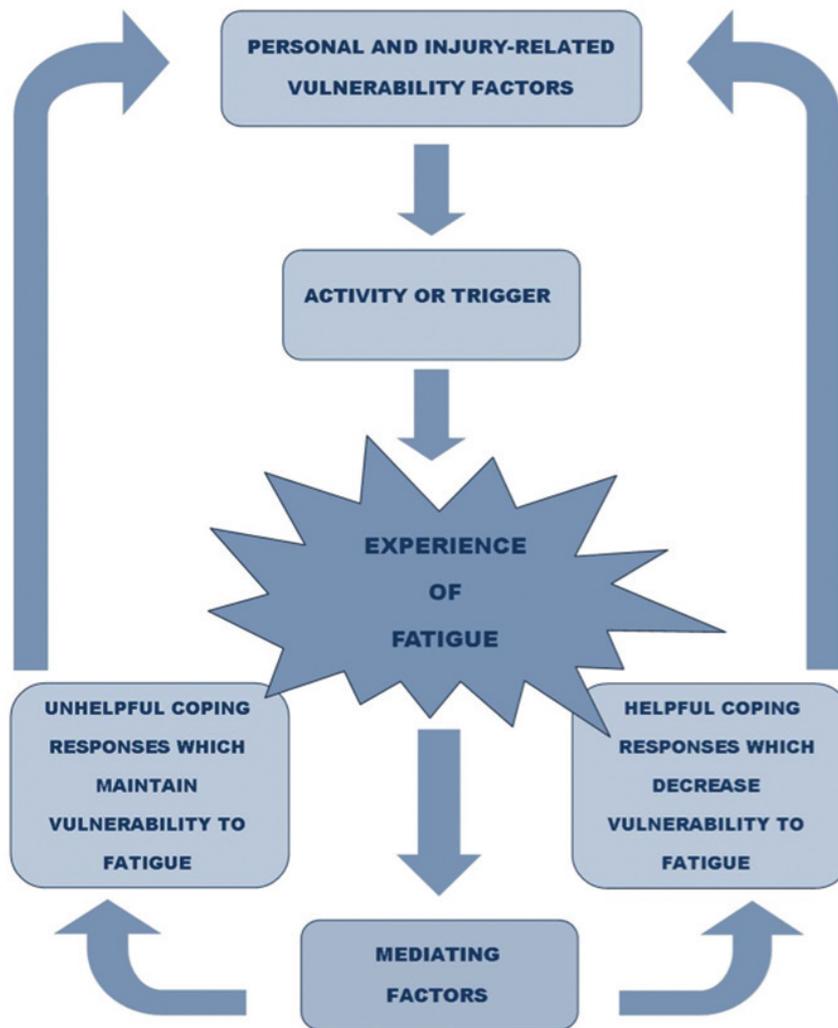


Figure 1: Clinical model for understanding responses to fatigue following acquired brain injury.

in their sense of control or self efficacy, an increase in their perceived quality of life or an increase in their awareness and understanding of fatigue. This change can be captured through using a recognised scale of these constructs or for example using an individualised likert scale before and after intervention.

In terms of clinical management, given that fatigue is considered a multidimensional construct, attention should be paid to the variety of factors which may contribute to both performance fatigability (objective signs) and perception of fatigue (subjective symptoms). This involves identifying and addressing both personal and injury-related factors (primary causes and secondary consequences) that make an individual vulnerable to fatigue following ABI. Awareness of indicators of fatigue for that individual, mediating factors affecting behaviour (e.g. what they know about management, what they are doing and context) and potential triggers need to be considered in order to understand how an individual may respond to fatigue and support them to develop more helpful coping strategies. Fatigue management aims to increase a

person's ability to participate in their desired activities more effectively, improve their quality of life and improve their sense of control over their fatigue.

There is an acknowledged discrepancy between objective signs (performance fatigability) and subjective experience (perception) of fatigue in the literature, which has led to a proposal for a unified taxonomy to guide assessment and intervention.²⁵ Several models of fatigue have been proposed in the literature. However, to date, none of these have been found to be clinically useful for understanding fatigue following acquired brain injury, to capture all aspects of this challenging construct and an individual's potential responses to it. The following model has therefore been developed by our clinical team, inspired by the fatigue model proposed for multiple sclerosis [cited in 26], current evidence and clinical experience, and it has been found useful when working with people with fatigue following ABI.

The clinical model proposed provides guidance on domains of functioning to assess and support fatigue management. A review of personal factors, including coping styles and

co-morbid illness, is recommended, with evaluation of injury-related vulnerability factors that could be contributing to fatigue based on pathology and assessment of associated physical, cognitive and psychological factors. This may indicate medical referral if physiological or psychiatric conditions are suspected which require further assessment and intervention e.g. endocrine dysfunction.

In terms of identifying triggers for fatigue, it is recommended to support the individual, and/or their significant other, to keep a 'fatigue diary' by monitoring changes in levels of fatigue before and after engagement in certain activities. By operationalising changes in energy levels, this could potentially enable assignment of 'points' to different activities to support pacing, identifying those activities or situations which 'drain' the resources and those which may 'recharge the body/mind' to support participation throughout the day. Use of analogies in fatigue management, such as recharging a phone battery, can be helpful. One important aspect of clinical intervention for people with ABI is to notice signs and symptoms of fatigue before they perceive their brain as 'shutting down' or fully 'draining their battery'. Self-monitoring of fatigue levels can be challenging following ABI secondary to dysexecutive syndrome, or as a consequence of reduced interoception. Identifying personal signs and symptoms of fatigue, through discussion, observation and asking others for signs of fatigue they notice will enable creation of a personalised 'fatigue

scale' to indicate signs and symptoms of fatigue at an early enough stage to take action.

Neuropsychological formulation and multidisciplinary assessment can then support identification of current coping responses (helpful and unhelpful) and mediating factors influencing choice of coping, which may include knowledge and awareness of fatigue and management strategies, the context, beliefs and preferred coping styles. Unhelpful coping responses may include a 'boom and bust' approach, avoidance of activity and overuse of stimulants such as coffee or energy drinks. Education about fatigue has been demonstrated as an effective intervention via group^{27,28} and/or individual intervention for people with Stroke and ABI. Mindfulness-Based Stress Reduction has also been demonstrated as effective when delivered as an eight week group programme.²⁹ Sinclair and colleagues³⁰ have identified short wave (blue) light therapy as a potentially useful intervention. Cognitive and environmental strategies and mood management all contribute towards reducing effort involved in completing activities and associated errors, which may then contribute towards reducing rumination and self criticism. Adequate hydration, nutrition and physical exercise, implementing good sleep hygiene and having an understanding of preferences and challenges in sensory processing will also aid fatigue management depending on vulnerability factors identified. Use of behavioural

experiments to test out the impact of coping strategies and beliefs about the self has been useful in fatigue management intervention within our neuropsychological rehabilitation setting. It is recommended to identify helpful coping responses to both reduce effort involved and to re-energise oneself, both 'in the moment' and 'in anticipation' of certain triggers when planning to support an individual to pace themselves. Through creation of a personalised fatigue formulation and management plan, based on the proposed clinical model, a shared understanding and validation of the fatigue experience can be facilitated.

Assessment and management of fatigue remains complex and challenging for both clinicians and researchers. A clinically useful model to aid a shared understanding and response to fatigue and thereby reduce an individual's vulnerability to fatigue is proposed. This model, developed by the clinical team at the Oliver Zangwill Centre for Neuropsychological Rehabilitation (www.ozc.nhs.uk), seems to provide a helpful tool to support management advice and is based upon current evidence available. Further research is required to operationalise and validate fatigue assessment tools and to identify specific interventions that may reduce an individual's vulnerability to fatigue following ABI. Given the multiple factors and interventions that may be involved, a specialist neurological multidisciplinary rehabilitation team are likely best placed to support people with fatigue following ABI. ♦

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