

An enquiry of the usability of a fatigue ecological momentary assessment (fatigue smart-EMA) in supporting fatigue management

Key findings

- Participants with ABI found the experience of tracking their fatigue in real-time easy to do and recognised that it drew their attention to their fatigue and daily activities.
- Attending to fatigue was not always considered helpful, particularly where participants prioritised doing their chosen activity rather than pacing themselves.
- Discrepancies between participants' beliefs around their fatigue and the data summaries caused several participants to doubt the accuracy of their summarised data but might also reflect the difference between recording experience in real-time and recall of events.
- Processing information from the data summaries was challenging for people with ABI and many needed support to draw inferences from their data.
- Therapists identified ways in which the summarised data would support their fatigue interventions, particularly as discussion points, raising awareness of fatigue triggers and empowering people to self-manage their fatigue.
- Therapists reported that managing the large amount of data generated requires considerable data literacy skills as well as time and resources. This was perceived to be a barrier to implementing this approach to fatigue monitoring in routine practice.
- Therapists perceived there to be benefits in using an occupational lens to view fatigue, particularly considering how interactions between fatigue and cognitive impairments might affect an individual's engagement with their daily occupations.

Project aims: the aim of this study was to understand the usability and usefulness of EMA to track fatigue and activity in real time (both the process and subsequent data summaries) from the perspective of ABI survivors and occupational therapists.

Background

In the UK over 300,000 people experience a brain injury and over half experience troublesome fatigue (Andelic et al 2021; Cumming et al 2016). Occupational therapists usually teach people how to manage their fatigue but established methods to assess fatigue do not capture the effects of therapy. Ecological momentary assessment (EMA) is an approach that uses surveys delivered repeatedly throughout the day (usually on a smartphone) to collect detailed information about an individual's fatigue in daily life. Using EMA alongside activity monitors (for example a Fitbit) provides a digital solution to some of the issues encountered with traditional clinical assessment approaches and may better inform the use of fatigue management strategies (Huguet et al 2015; Lenaert et al 2020).

Methodology

The study was approved by the University of Southampton, Environment and Life Sciences Faculty ethics committee (ERGO no: 76333). The study design was a qualitative usability enquiry into the usefulness and usability of fatigue tracking data for people living with fatigue and for occupational therapists. Two people living with brain injury provided feedback on the design of the study, the data collection methods and the data analysis and writing up of the study. We recruited people with acquired brain injury and self-reported fatigue as well as occupational therapists with clinical experience of brain injury fatigue.

Recommendations

- With the increased digitalisation of healthcare, understanding how people with brain injury engage with and use digital technology and information must be central to the development and implementation of digital tools.
- Further research and stakeholder mapping is needed to understand and address the challenges experienced by occupational therapists in developing their digital capabilities and using digital tools to support their practice.
- Using a strengths-based approach and occupational lens to understand post brain injury fatigue may support service users to live well with fatigue but further research is needed to evidence this.
- Further research is needed to investigate the effectiveness and impact of real time tracking of fatigue and activity as an adjunct to fatigue management.

Conclusion

Tracking fatigue and activity in real-time may be a useful addition to fatigue management approaches, particularly for promoting self-awareness of fatigue triggers in relation to valued occupations. However, implementation of such data driven approaches in occupational therapy practice may be limited by resource constraints and the need to further develop therapists data literacy skills.

Publications

Manuscript in preparation: Exploring the usefulness of real-time digitally supported fatigue monitoring in for fatigue management: perspectives from Occupational Therapists and Brain Injury Survivors. L. Ezekiel, Wilding, H. Dearling, J. Collet, JC, Dawes, HD

This study, conducted in 2022-2023, received funding via a Research Career Development Grant from the Royal College of Occupational Therapy Research Foundation

Grant holder: Dr Leisle Ezekiel

Copyright © 2024 Royal College of Occupational Therapists & University of Southampton

Acknowledgements

We would like to thank the research participants for making the study possible. We also acknowledge the help and support from our public patient involvement group and the support from School of Health Sciences at University of Southampton.

References

- Andelic N, Røe C, Brunborg C, Zeldovich M, Løvstad M, Løke D...von Steinbuechel N (2021) Frequency of fatigue and its changes in the first 6 months after traumatic brain injury: results from the CENTER-TBI study. *Journal of Neurology*, 268(1), 61–73. <https://doi.org/10.1007/S00415-020-10022-2>
- Cumming TB, Packer M, Kramer SF, English C (2016) The prevalence of fatigue after stroke: A systematic review and meta-analysis. *International Journal of Stroke: Official Journal of the International Stroke Society*, 11(9), 968–977. <https://doi.org/10.1177/1747493016669861>
- Huguet A, McGrath PJ, Wheaton M, MacKinnon SP, Rozario S, Tougas ME, Stinson JN, MacLean C (2015) Testing the Feasibility and Psychometric Properties of a Mobile Diary (myWHI) in Adolescents. *JMIR Mhealth Uhealth* 3(2), e39. <https://doi.org/10.2196/mhealth.3879>
- Lenaert B, van Kampen N, van Heugten C, Ponds R (2020) Real-time measurement of post-stroke fatigue in daily life and its relationship with the retrospective Fatigue Severity Scale. *Neuropsychological Rehabilitation*, 32(6), 992-1006. <https://doi.org/10.1080/09602011.2020.1854791>