Managing Energy, and Shaping Care: Insights from Adults with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Through Co-Production Workshops

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Abstract

Background: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a complex, debilitating condition characterised by severe fatigue that is not relieved by rest and is often exacerbated by physical or mental activity. A key challenge for individuals with ME/CFS is energy management and to date, the only recommended strategy is "activity pacing." This approach involves balancing activity and rest to avoid overexertion and minimise the risk of symptom exacerbation, commonly known as "post-exertional malaise"(PEM). A recent systematic review highlighted significant shortcomings in activity pacing interventions for ME/CFS, noting that they lacked rigour, were brief, and did not follow guidelines or integrate recommended technology, limiting their relevance for modern energy management. To address these gaps, the present study aimed to explore ME/CFS patients' and health practitioners' perspectives on approaches to energy management, how their understanding of energy management has evolved over time, and their recommendations for future interventions concerning energy management.

Method: Eight individuals with ME/CFS participated in six one-hour long online co-production workshops with two researchers, with the option to provide input through written responses. Additionally, three health practitioners shared their perspectives via email. Thematic analysis of the data identified several key recommendations for improving ME/CFS care.

Results and conclusions: Workshops highlighted the need for early support, healthcare provider training, and public education to combat stigma and misconceptions around ME/CFS. Participants emphasised patient collaboration, research-informed practices, rigorous research, multidisciplinary teams, and the integration of technologies like mHealth, along with a comprehensive approach including sleep, diet, and psychological support for better symptom management and activity pacing.

Keywords: Myalgic encephalomyelitis, chronic fatigue syndrome, energy management, recommendations, co-production workshops, attitudes, beliefs, experience, future interventions, health professionals

Introduction

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a chronic disease that does not have an universally agreed case definition, cause, diagnosis or treatment [1] and is estimated to affect up to 390,000 people in the United Kingdom with a population prevalence of 0.6%[2]. Disease symptoms are often broad, marked by wide range of patient reported symptoms such as heart palpitations, muscle or joint pain, severe fatigue, cognitive dysfunction, unrefreshing sleep, neuroendocrine and immune alternations [3].

Individuals with ME/CFS experience worsening of their ME/CFS symptoms (people with ME/CFS often describe this as a 'relapse' or 'crash') following physical or mental exertion, referred to as post-exertional malaise (PEM) or post exertional symptom exacerbation (PESE) or post-exertional neuroimmune exhaustion (PENE), we have consistently used post-exertional malaise (PEM) throughout this paper, as it remains the most widely recognised term in the literature [4–9]. Post-exertional malaise (PEM), which can last from hours to several days or even weeks, is considered one of the most disabling symptoms experienced by this community [5,6,10]. Post-exertional malaise (PEM) is strongly associated with a significant decline in quality of life in ME/CFS patients, as it limits the ability to carry out daily activities, imposes substantial restrictions on social and familial interactions, and it is linked to mental health comorbidities, including depression and anxiety, and often results in severe employment and financial challenges[9,11–13].

At present, there is no cure or established pharmacological treatment for post-exertional malaise (PEM), necessitating the development of effective symptom management strategies. This challenge is partly due to the limited understanding of the mechanisms underlying post-exertional malaise (PEM), as empirical evidence remains sparse and largely anecdotal while identification of a reliable biomarker has remained elusive. The most widely adopted strategy for managing post-exertional malaise (PEM) involves activity pacing, which is integrated into the daily routines of individuals with ME/CFS to minimise the frequency and severity of post-exertional malaise (PEM) episodes [14]. Activity pacing is characterised by encouraging patients to engage in activities within the constraints of their illness, promoting a balance between activity and rest to prevent symptom exacerbation[14–16]. The core principle of activity pacing is the "energy envelope" theory, which suggests that individuals should limit their energy use to their perceived available energy in order to stay within physical and mental limits [17].

In practice, activity pacing involves individuals identifying a level of activity that prevents the onset of post-exertional malaise (PEM). This involves balancing their current energy expenditure with the demands of the past few days and anticipating the energy requirements of the near future to avoid triggering a significant exacerbation of fatigue and other symptoms [18,19]. Activity pacing is a primary management strategy for ME/CFS, with the highest level of patient adherence and the most widely reported benefits from patients[20]. As of the 2021 update, the NICE guidelines for individuals with ME/CFS no longer recommend cognitive behavioural therapy (CBT) or graded exercise therapy (GET)[21]. Instead, activity pacing is the sole management strategy endorsed [21]. Thus, energy management or ‘activity pacing’ remains the only management strategy for people with ME/CFS and involves regulating and planning activity to avoid post exertional malaise (PEM).

However, the most recent Cochrane review reported low certainty of evidence when comparing post-exertional malaise (PEM) treatments [22]. In terms of activity pacing effectiveness, we recently conducted a meta-analysis which included five intervention studies, of which only two were RCTS[23]. Meta-analyses revealed a positive effect of energy management on physical function (k=4; standardised mean difference [SMD]=0.15, 95% CI=-0.39, 0.68), pain (k=4; SMD=0.11, 95% CI=-0.32, 0.10;), and fatigue (k=4; SMD=1.09, 95% CI=-2.38, 0.21)[23]. The level of empirical research was insufficient to confidently support the NICE guidelines, with more high quality RCTs need before there is any definitive analysis[23]. Furthermore, our recent scoping review revealed activity pacing interventions lack methodological rigour, were rarely longer than a month, and were based on no methodological guidelines or behaviour change principles[24]. Interventions lacked integration of technology and self-monitoring devices (outlined as future research necessities in the NICE guidelines (2019 update)[24]. Thus, studies provided limited applicability for the 21st century[24]. Accordingly, we conducted six participatory co-production workshops aimed at exploring ME/CFS patients' and health practitioners' perspectives on energy management, and how their understanding of energy management has evolved over time. These workshops focused on sharing perspectives about energy management, identifying energy management challenges, and collaboratively developing strategies and recommendations to address these challenges.

Method

This qualitative study utilised six one-hour online co-production workshops involving eight individuals living with ME/CFS and two researchers. Additionally, three health professionals (Functional Medicine Medical Doctor, Physiotherapist and Occupational therapist in ME/CFS and long COVID service) provided written responses to the same questions discussed in the workshops. Using thematic analysis, we identified key themes and sub-themes from the workshop transcripts.

Energy management co-production workshops

Workshops focused on sharing perspectives, identifying energy management challenges, and collaboratively developing strategies and recommendations. The workshops were conducted online to include participants with varying severities of ME/CFS, particularly those who are mobility impaired with difficulty travelling. Each session used a comment/mood board to facilitate reflection, and discussions were based on predefined question cards shared in advance. Workshop 1 and 2 explored perspectives on existing energy management techniques, participants’ experiences in utilising these methods, and their evaluations of effectiveness. The aim was to understand current practices and perspectives on what worked and what did not. Workshop 3 and 4 focused on identifying the specific challenges individuals with ME/CFS faced when trying to implement energy management. Discussions aimed to uncover barriers to effective energy management and explore potential improvements to enhance the applicability and usability of these techniques. Workshop 5 and 6 focused on collaboratively developing recommendations or interventions tailored to the energy management needs of individuals with ME/CFS.

Participants and Recruitment

Following ethical approval (approved by the Health and Society at the University of Salford, application ID: 14720), eight participants (five females and three males, median age 54) were recruited and two researchers (two females, median age 27) took part in the six online co-production workshops. Three health practitioners, Functional Medicine Medical Doctor, Physiotherapist and Occupational therapist in ME/CFS and long COVID service (all female, median age 47) provided a written response to the workshop questions. All participants with ME/CFS met the inclusion criteria: adults living with ME/CFS and have access to internet enabled device to join online co-production workshops. Individuals with ME/CFS from previous studies[25–29] who had expressed interest in future research were contacted by email. Those who were interested received a participant information sheet and consent form. Participants who did not submit the completed consent form were followed up after two weeks. Once the signed consent forms were received, a Doodle poll was sent to schedule six one-hour long co-production workshop sessions based on participants' availability. Health practitioners involved in our previous studies[23,24,30] helped distribute information about our study through word of mouth, and some practitioners contacted us directly to express their interest. Interested individuals were provided with a participant information sheet and a consent form. Participants who did not return the completed consent form were followed up after two weeks. Upon receiving the signed consent forms, participants were sent a document containing all the questions for the co-production workshop to complete.

Data collection and analysis

All workshops were recorded and transcribed verbatim. The transcripts from all workshops, along with health practitioners' responses to the questions, were analysed using a thematic analysis approach to identify key themes and subthemes[31].

Results

In the following sections, we present the three themes that emerged from our analysis: (1) Navigating ME/CFS (2) Adapting to ME/CFS (3) Building a Supportive Framework for ME/CFS. These themes elucidate participants' perspectives, understandings of and recommendations for future research projects concerning energy management. We include excerpts from the interviews to illustrate these themes (please see tables), followed by a discussion on the implications of our findings for co-production and research practice.

Navigating ME/CFS

This theme captures the journey of individuals with ME/CFS as they navigate activity pacing strategies, face frustration and disillusionment, combat early misconceptions, and rely on support systems to manage and live with the condition (see table 1 for interview extracts). Participants identified activity pacing as a vital strategy for managing ME/CFS, describing it not as a cure but as a tool to prevent deterioration and enable small functional improvements. They emphasised that effective energy management requires a holistic approach, addressing physical, cognitive, and emotional demands. However, participants expressed frustration and disillusionment with the complexities of activity pacing, highlighting its challenges due to the complexity of balancing daily activities and the unpredictability of physical, emotional, social, and cognitive daily life demands. Early intervention for ME/CFS and proper activity pacing were seen as crucial for preventing long-term deterioration. Many participants regretted pushing themselves too hard in the early stages of their illness, often influenced by societal and medical pressures. Misconceptions about ME/CFS further underscored the need for better awareness and education. Social support emerged as essential, with participants valuing the practical and emotional help provided by family, friends, and partners who truly understood their condition. Finally, participants shared how living with ME/CFS necessitates a constant evaluation of energy levels, requiring them to carefully balance activities and anticipate potential consequences, profoundly reshaping their daily lives.

Adapting to ME/CFS

This theme reflects the evolving journey of individuals with ME/CFS, highlighting the learning curve, the impact of healthcare professionals, the development of personal strategies, the role of technology in energy conservation, and shifting attitudes toward the condition (see table 2 for interview extracts). Participants stressed that pushing through exertion, especially on “crash” days, worsens symptoms, and early recognition of this is critical for better management or recovery. Many described humiliations when healthcare professionals, lacking understanding, offered misguided advice on activity pacing or hesitated to diagnose ME/CFS, leaving patients feeling dismissed and pressured to overexert. Discussions highlighted the benefits of heart rate regulation strategies and medications which improve physical capabilities. Participants emphasised the value of tools like heart rate trackers to monitor exertion, though some found proactive use challenging.

Despite some progress in awareness, participants noted persistent public misunderstandings and shared feelings of isolation, even within their own families.

Building a Supportive Framework for ME/CFS

This theme emphasises the importance of training healthcare providers, early support, and fostering collaboration between patients, providers, and multidisciplinary teams. It highlights the need for research-informed practices and the integration of technological aids to develop effective interventions for ME/CFS management (see table 3 for interview extracts). Many noted that current healthcare training is insufficient, leading to widespread misconceptions that ME/CFS is merely a symptom of chronic fatigue, rather than a complex illness with underlying physical factors. Participants called for healthcare providers to demonstrate greater respect and empathy, improve communication, and acknowledge the limitations of existing knowledge about ME/CFS. Participants advocated for individualised care that empowers patients to explore various management strategies tailored to their specific needs. They also emphasised the necessity for ongoing research to both develop new medications and repurpose existing treatments, highlighting the critical role of innovation in improving patient outcomes. Participants stressed the importance of cooperation among healthcare professionals, patients, and specialists from diverse fields, including dietetics, physiotherapy, and immunology. There was a strong call for the establishment of interdisciplinary teams that fully comprehend the complexities of ME/CFS. Participants highlighted the value of wearable devices, such as fitness trackers, for monitoring objective metrics like heart rate variability (HRV) and step counts, which assist in energy management and activity pacing strategies. There was a strong advocacy for repurposing existing medications and utilising straightforward technological interventions, such as mobile apps, to empower patients in self-managing their condition. Additionally, the importance of personalised approaches was underscored, with education on dietary choices, sleep management, and nervous system regulation seen as crucial components of effective care.

Discussion

This study explored ME/CFS patients' and health practitioners' perspectives on energy management, how their understanding of energy management has evolved over time, and their recommendations for future interventions concerning energy management. Participants with ME/CFS expressed frustration over the lack of support during crucial stages of their treatment. Many recalled being told to "push through" symptoms rather than being encouraged to rest or pace. As of the 2021 update, the National Institute for Health and Care Excellence (NICE) guidelines no longer recommend CBT or GET for ME/CFS, endorsing activity pacing as the sole management strategy[21]. Activity pacing involves regulating and planning activities to prevent post-exertional malaise (PEM) and remains the primary approach for managing ME/CFS. Most participants reported that their understanding of ME/CFS came through trial and error, with little guidance from healthcare professionals. This lack of support reflects the broader issue of poor recognition of ME/CFS by both healthcare providers and the public. Some participants pointed out that there is still scepticism regarding the legitimacy of ME/CFS as a genuine physiological disorder [32,33] which further exacerbates the stigma faced by those affected [34,35]. Consequently, individuals living with ME/CFS emphasised the need for increased education for both healthcare professionals and the public as a crucial intervention in improving awareness and reducing stigma surrounding the condition.

The workshops revealed a strong consensus between individuals with ME/CFS and health practitioners on the need for early, individualised support from healthcare practitioners with participants advocating for increased research to integrate evidence-based practices into ME/CFS treatment. They emphasised that timely, informed care could greatly improve outcomes and stressed the importance of collaboration among patients, healthcare providers, and multidisciplinary teams to ensure comprehensive care and effective communication. Participants also expressed frustration with the complexity of activity pacing, as daily energy levels fluctuate due to various factors, including prior activity. They acknowledged its importance, and highlighted the need for personal adjustments to make activity pacing more manageable. Technological aids, such as smartwatches and HRV tracking, were identified as valuable tools for identifying post-exertional malaise (PEM)patterns and determining when rest is necessary. Participants recommended integrating such technology with personalised adjustments as essential for future interventions, underscoring the need for a more tailored approach to managing the condition. This aligns with findings from our recent scoping review which highlighted that activity pacing interventions often lack methodological rigour, are typically short in duration, and fail to adhere to standardised guidelines or behaviour change principles[24]. Moreover, these interventions seldom incorporate technology or self-monitoring devices, despite the updated NICE guidelines (2019) recognising them as research priorities[21].

Mobile health (mHealth) platforms, such as apps, are well-documented as effective tools for enhancing self-efficacy and health-related knowledge in managing chronic conditions[36–39]. Research on conditions like long COVID similarly highlight the positive impact of mobile apps in monitoring health behaviours and facilitating self-management[40]. A recent study by our group found that the *PaceMe* app significantly improved energy management for individuals with long COVID by enhancing their knowledge and understanding of the condition [40]. This increased awareness and boosted confidence in managing daily activities, helping to prevent post-exertional malaise (PEM) and other symptoms[40]. Participants described the app as a “crutch” and a “lifeline,” providing both practical symptom management tools and emotional reassurance[40]. The app also fostered autonomy and a renewed sense of control over their condition[40]. Participants in the present study also suggested expanding mHealth platforms to include features for tracking sleep, diet, and providing tailored health messages specific to

ME/CFS. Some participants further proposed exploring existing medications as potential interventions for energy management.

Strengths and Limitations

The study design, which involves co-production workshops provides participants with abundant opportunities to share their perspectives in detail and communicate their priorities regarding future interventions and care. While the study offers a valuable longitudinal insights and perspectives of individuals with ME/CFS and health practitioners in relation to energy management, these insights are limited by the current state of research in the field. Participants highlighted the importance of activity pacing as a management strategy but noted that research examining its outcomes remains limited. They emphasised that advancing this area requires greater focus from researchers and funding bodies.

Conclusion

This study explored the experiences and understandings of individuals with ME/CFS and health practitioners about energy management, how these perspectives have evolved, and their recommendations for future interventions. Workshops highlighted the need for early support, increased education for healthcare providers and the public addressing stigma and misconceptions about ME/CFS, and individualised care. Participants emphasised importance of collaboration between patients, research-informed practices and multidisciplinary teams. They advocated for integrating technologies like mHealth and adopting a comprehensive approach that includes sleep, diet, and psychological support to improve activity pacing and symptom management.

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