CLINICAL RESEARCH STUDY

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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 characterized 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 minimize the risk of symptom exacerbation, commonly known as "post-exertional malaise". A recent systematic review highlighted significant shortcomings in activity pacing interventions for ME/CFS, noting that they lacked rigor, 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.

METHODS: Eight individuals with ME/CFS participated in six 1-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 emphasized 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.

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INTRODUCTION

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a chronic disease that does not have a 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 or post-exertional neuroimmune exhaustion. We have consistently used PEM throughout this article, as it remains the most widely recognized term in the literature.[4-9] PEM, which can last from hours to several days or even weeks, is considered one of the most disabling symptoms experienced by this patient group.[5,6,10] 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]

CLINICAL SIGNIFICANCE

- Participants called for early support, healthcare provider training, and public education to combat stigma and misconceptions around ME/CFS.
- Moreover, participants called for 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.

At present, there is no cure or established pharmacological treatment for PEM, necessitating the development of effective symptom management strategies. This challenge is partly due to the limited understanding of the mechanisms underlying 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 PEM involves activity pacing, which is integrated into the daily routines of individuals with ME/CFS to minimize the frequency and severity of PEM episodes.[14] Activity pacing is characterized 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 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 National Institute for Health and Care Excellence (NICE) guidelines for individuals with ME/CFS no longer recommend cognitive behavioral therapy or graded exercise therapy.[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 PEM.

However, the most recent Cochrane review reported low certainty of evidence when comparing 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; standardized 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 empirical research available was insufficient to confidently support the NICE guidelines, and more high-quality RCTs are needed before any definitive analysis can be made.[23] Furthermore, our recent scoping review revealed activity pacing interventions lack methodological rigor, were rarely longer than a month, and were based on no methodological guidelines or behavior 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 for future research to address these challenges.

METHOD

This qualitative study utilized six 1-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 traveling. Each session used a comment/mood board to facilitate reflection, and discussions were based on predefined question cards shared in advance. Workshops 1 and 2 explored perspectives on existing energy management techniques, participants' experiences in utilizing these methods, and their evaluations of effectiveness. The aim was to understand current practices and perspectives on what worked and what did not. Workshops 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. Workshops 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 written responses 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 2 weeks. Once the signed consent forms were received, a Doodle poll was sent to schedule six 1-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 2 weeks. Upon receiving the signed consent forms, participants were sent a document containing all the questions for the co-production workshops 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 analyzed 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 excerpts). 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 emphasized 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.

Table 1 Interview Excerpts for Theme; Navigating ME/CFS

Individuals Living with ME/CFS	Healthcare Professionals
Pacing is the key, but it's really difficult when you've got lots of things going on. So pacing is the key, but it is the difficulty about how you do it well and how you do it well so that you can improve without doing the boom and bust, which I seem to never learn about —Penelope, living with ME/CFS	Energy management can include determining a baseline, which is probably the most difficult thing to do, due to living an everyday life and unexpected factors (physical, emotional, social, and cognitive things). It often involves stopping some aspects of life. Once a baseline is identified activities can be added very gradually and if symptom-free for a period of time something else can be added. This is often a very slow progression. —Nicole, Psychotherapist, ME/CFS and long COVID service
I've spent an absolute fortune on, you know, different things over the years. Nothing, nothing helps and for me, it pacing, pacing might work 1 day, but it doesn't work with another. And so for me, pacing does nothing works for me —Mila, living with ME/CFS	I personally think if you say to someone you need to use energy management it can be perceived as being easy and it is not. I think it is often just perceived that it is physical activity when it is every type of activity. People can think rest is watching TV, scrolling on the phone, etc. and this is not the case—it is something that activates the parasympathetic nervous system. What works for one works for others—this is very individual and people can't compare themselves to other people. People often look at recovery as returning to the life they led before when this potentially is not achievable as they were leading a life that is not sustainable —Emma, Occupational Therapist, ME/CFS and long COVID service
My doctors were useless and even though there was a support service and she'd had a letter about it, it was ages before she actually and it was through talking to other people. You know, being sort of harangued by family in various people about you know what? What I could do about this and that I found out that there was a service and got referred to it and then they I learned about the post-exertional malaise and you sort of start to put things together when you're when you're working and trying to manage [umm] and you just feel dreadful all the time, it's quite difficult to and you can constant boom and bust. [umm] It's quite difficult to unpick it all, and that's what the support service helped me do, and that's how things sort of changed —Sarah, living with ME/CFS	I don't think they have changed. I think I have expanded my knowledge and am more able to work/support people in adapting techniques such as pacing/energy management skills. I think there is more awareness and more training amongst professionals in this area now —Nicole, Psychotherapist, ME/CFS and long COVID service
Having a supportive family who understand and "get it" is everything. I'm thankful for that which keeps me positive -Louisa, living with ME/CFS)	N/A
Overrules your life. Everything is about will I be able to do that. What the consequences have been able to do that what? What can I fit in? How did? How's it affecting us? Can I go to that? Can we go to this? Is that wise? Is it not wise? Can I go out Friday morning? Well, I need to wait till Friday morning to 10:00. O'clock in the morning or 9:00 o'clock in the morning to see. Different things like that so. It really becomes. —Alexander, living with ME/CFS	N/A

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 excerpts). 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 that improve physical capabilities. Participants emphasized 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.

Table 2 Interview Excerpts for Theme; Adapting to ME/CFS

Individuals Living with ME/CFS	Healthcare Professionals
The big revelation was how harmful any exertion on "crash" days is the impact on my body was massively higher for the same activity on an easier days. I think for someone recently ill it could be a game-changer and give them a good chance of recovery within the first 3-4 year window that there seems to be. —Anne, living with ME/CFS	N/A
There's just a lack of complete lack of understanding and also a willing a lack of willingness to understand. I think from a lot of the medical profession, but long COVID has changed that to a certain extent. —Penelope, living with ME/CFS	As a healthcare provider I feel I am able to support people with energy management techniques, giving them the confidence and skills they need to experiment and often try new things, add tools to their toolkit in self-managing their condition. —Nicole, Psychotherapist, ME/CFS and long COVID service
Keeping the heart rate lower by altering how I exert myself allows me to do far more and avoid the worst of the PEM. Beta blockers helped massively in this (although that's not why they were prescribed) but I realize they help minimize the time in the damaging anaerobic and aerobic states. I was bedbound to housebound before them and it allowed me to get up to my present level of abilities (around 4000 steps in a day and an average of about 4-5 "useful" hours). This has been the major factor in allowing me to increase my abilities and improve my functioning and quality of life. Although it's pharmaceutical I'd class beta blockers as an energy management technique. Hugely beneficial—but there will be even better drugs, like ivabradine, which further helps avoid the zones that trigger PEM. Also very important is learning the symptoms and pain which are signs of over-exertion and acting on them by resting before the damage is done. This has been hugely hampered by prophylactic painkiller use in me. I can only take pain relief reactively. I crash hugely and repeatedly when the pain signals are lessened because I just can't judge when to moderate my activities. I've had years-long relapses from (well-intentioned) prescriptions for constant pain relief. Sadly I think the pain needs to be there to work as a warning. A simple technique to eke out a little extra useful activity is to switch between the physical and mental exertion. Both are taxing, of course, both require resting afterward, but a switch can help to do a little more in the day than otherwise. Even a 10 minutes rest during mental or physical activity, ideally feet up, can help a lot to limit PEM. Realize too that mental exertion uses a huge amount of energy. It is probably a bigger factor in school children or those with desk jobs than physical exertion. And one will have an impact on the other—the inflammatory pain still reaches all over the body from mental exertion. —Christopher, living with ME/CFS	N/A
I do have an I have a tracker that is designed for ME and for long COVID. It's very early days for me, but there is that tech there. But what I have come across, you know what I have discovered so far has impressed me, so I'm hoping it will give me just a bit a bit more warning of when I'm overexerting myself. I've got a reasonable understanding now after all these years. But I'm hoping it will give me a bit more heads up, especially the cognitive, especially the cognitive exertion, which is maybe not quite as easy to quantify as the physical exertion. XX works in real-time by helping patients avoid these zones and using heart rate variability and resting heart rate to give a warning for the day ahead if PEM is bad. I truly believe it would be a game changer for those in the early days of the illness possibly enabling them to	I think heart rate variability for everyone with ME/CFS would be an incredible tool. —Isla, Functional Medicine Medical Doctor

Table 2 (*Continued*)

Individuals Living with ME/CFS	Healthcare Professionals
make a full recovery in the (approx. 3 years) window where it's most likely to happen. This would condense my decades of learning how to manage activity with this illness into a few days for a new patient. —Christopher, living with ME/CFS	
I feel ill all the time. But people just don't understand. People don't understand even your family like that lady said before, even your family, it takes a long time for it to click that it's really something different. —Alexander, living with ME/CFS	Educating patients about the degree to which this may be useful in their condition. Education clinicians that ME/CFS is a multi-factorial illness which can include immune dysregulation, mitochondrial dysfunction, gut dysbiosis, HPA axis dysfunction. Too many clinicians do not take this condition seriously enough and, from what I have seen, gaslighting is a real issue. —Isla, Functional Medicine Medical Doctor

Building a Supportive Framework for ME/CFS

This theme emphasizes 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 excerpts). 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 individualized care that empowers patients to explore various management strategies tailored to their specific needs. They also emphasized 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 and step counts, which assist in energy management and activity pacing strategies. There was a strong advocacy for repurposing existing medications and utilizing straightforward technological interventions, such as mobile apps, to empower patients in self-managing their condition. Additionally, the importance of personalized 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 NICE guidelines no longer recommend cognitive behavioral therapy or graded exercise therapy for ME/CFS, endorsing activity pacing as the sole management strategy.[21] Activity pacing involves regulating and planning activities to prevent 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 skepticism 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 emphasized 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, individualized support from healthcare practitioners with participants advocating for increased research to integrate evidence-based practices into ME/CFS treatment. They emphasized 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 heart rate variability tracking, were

Table 3 Interview Excerpts for Theme; Building a Supportive Framework for ME/CFS

Individuals Living with ME/CFS	Healthcare Professionals
Subtheme: How to support individuals with ME/CFS When NICE renamed it ME/CFS rather than the previous CFS/ME of the old guidelines, that was a clue things were about to improve. “Chronic fatigue” is a symptom and not an illness—and leads to comments like “oh, i get tired too,” from healthy people. If they could be trained in being able to accept not knowing and still be empathic, communicative, and intelligent, that would be a very big improvement even if they knew absolutely nothing about ME. —Christopher, living with ME/CFS	**Subtheme: How to Support Individuals with ME/CFS** Less gaslighting; giving the patient comprehensive overview of the factors that are known to affect CFS/ME such as viral reactivations, HPA axis, and mitochondrial dysfunction so they know that the symptoms have a biological basis despite normal test results. This should be alongside education about the things that you can do to improve all of these things, eg, foundational diet and lifestyle changes as well as more targeted interventions such as medications supplements which can improve energy, gut health or improve immune function. —Isla, Functional Medicine Medical Doctor
Subtheme: Early support and research-informed practices So they’ve gone to the wrong place, but they’re those of us who, presumably we don’t really know, have got the proper diagnosis, should be sent to a proper support group early on, and they should all be in communication with each other. So with the up to date research so that we can get the help we need. —Penelope, living with ME/CFS	**Subtheme: Early support and research-informed practices** N/A
Subtheme: Collaborations and multidisciplinary teams But it needs a multidisciplinary team where people who really know really, really know about MECFS really know. Multidisciplinary dieticians, physiotherapists, Occupational Therapists, pain specialists, they need to go out and see individual people and listen and after any specialist center where they know everything about ME then everybody’s the same but everybody’s slightly different. —Alexander, living with ME/CFS	**Subtheme: Collaborations and multidisciplinary teams** It needs to be a mix of peers and healthcare professionals with an understanding of the condition. —Nicole, Psychotherapist, ME/CFS and long COVID service
Subtheme: Interventions and integration of technological aids I would say that we want objective measures. As well as just the subjective, so objective measures being you know count the count, the count, the steps in a day, count the symptoms. You know, through an app or something there are there are there is the technology to do that I’m doing that just now we’re XX but there’s fitness trackers. You can design an app relatively easily. I’m imagining for this so use the technology there in an easy simple way for the patient to use to get an objective measure of how anything how any intervention is happening. And also don’t forget that other things are happening in the life, so you need to sort of feed that information in. —Christopher, living with ME/CFS	**Subtheme: Interventions and integration of technological aids** An app would be helpful that gives feedback and support to individuals. —Emma, Occupational Therapist, ME/CFS and long COVID service

identified as valuable tools for identifying PEM patterns and determining when rest is necessary. Participants recommended integrating such technology with personalized 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 rigor, are typically short in duration, and fail to adhere to standardized guidelines or behavior change principles.[24] Moreover, these interventions seldom incorporate technology or self-monitoring devices, despite the updated NICE guidelines (2019) recognizing 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 behaviors 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 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 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 emphasized 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 individualized care. Participants emphasized 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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