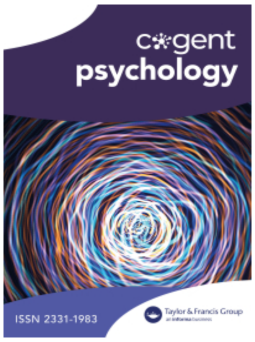

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Exploring barriers and facilitators to effective self-management in individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: an Interpretative Phenomenological Analysis

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ABSTRACT

The present study explored the lived experiences of individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome to identify barriers and facilitators to effective self-management. Five female participants (mean age; 33.2 ± 13.00 years) with a formal diagnosis of ME/CFS, were recruited via social media. Semi-structured interviews were conducted and analysed using Interpretative Phenomenological Analysis. Barriers to self-management were identified as one key theme, comprising two sub-themes: i) navigating competing and cyclical symptom burdens and ii) the need for self-advocacy. Facilitators of self-management were identified under two main themes: adapting to manage symptoms, with sub-themes of i) navigating symptom management through trial and error and ii) growing confidence over time, and social and practical support, which included i) family and partner support and ii) workplace flexibility. Key barriers included the physical, emotional, and social toll of symptoms, while facilitators such as trial-and-error, growing confidence, and social and workplace support were crucial. Although self-advocacy is essential, it emerged as both a necessary and burdensome strategy. To improve the quality of life of individuals with ME/CFS, there is an urgent need to reduce the reliance on extensive self-advocacy which may help to alleviate this burden by making healthcare systems and support structures more responsive, accessible and patient-centred.

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Introduction

Myalgic Encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), is a debilitating condition with an unknown aetiology and no established cure (Nacul et al., 2020). In the United Kingdom (UK), the lifetime prevalence of ME/CFS is estimated to be as high as .92% for females and .25% for males, suggesting that approximately 390,000 individuals are affected (Ponting & Samms, 2024). Despite being a significant public health concern, research on its causes, progression and treatment has yielded inconsistent results, leading to ongoing debate and uncertainty (Arron et al., 2024; Melby & Nair, 2024; Rogers, 2024). Although the World Health Organisation (WHO) recognised ME/CFS as a neurological disease in 1969, its diagnosis remains challenging due to the absence of validated biomarkers (Lim & Son, 2020).

ME/CFS manifests through a variety of symptoms, including fatigue, post-exertional malaise, pain, sleep disturbances and cognitive impairments such as memory and concentration difficulties (Deumer et al., 2021). The severity of symptoms can vary greatly, with some patients able to manage their condition while continuing to work, while others are severely affected and bed bound (Friedman et al., 2021). As no cure currently exists for ME/CFS, treatment primarily focuses on symptom management. This approach is informed by healthcare professionals' advice, which acknowledges that each patients' experience of the illness is unique. Current management strategies include energy management, pacing, graded exercise therapy, cognitive behavioural therapy and various lifestyle changes (Rowe, 2023; Sanal-Hayes et al., 2025).

One of the most common forms of treatment is self-management, where patients are encouraged to regulate their energy levels to avoid exacerbating symptoms (Duda et al., 2023). Self-management is

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This article has been corrected with minor changes. These changes do not impact the academic content of the article.

defined as *people taking responsibility for their own health and wellbeing, as well as learning to manage any long-term illnesses* (Davies, 2010, pp.1). Research has shown mixed evidence that effective self-management, utilising cognitive, emotional and behavioural strategies can help individuals with chronic conditions maintain a good quality of life (Pinxsterhuis et al., 2015; Schulman-Green et al., 2012). That said, with respect to ME/CFS, self-management can reduce symptom severity, particularly when supported by healthcare advice and education (Rowe, 2023). However, the literature also highlights challenges in adhering to self-management practices. Bayliss et al. (2014) identified that attitudes of healthcare professionals, particularly when adhering to a biomedical framework, can impede effective self-management. Indeed, a significant proportion of UK general practitioners (GPs) lack confidence in diagnosing ME/CFS. Bowen et al. (2005) measured the attitudes of 811 GPs in England and found that 8% did not feel confident in diagnosing ME/CFS and 28% did not recognise ME/CFS as a clinical condition. This lack of confidence in diagnosis and treatment advice leads to dissatisfaction among patients, contributing to disengagement from medical care (Duda et al., 2023; Melby & Nair, 2024).

The biomedical model of health, which focuses solely on biological changes and the absence of disease, has been criticised for its reductionist approach, especially in cases like ME/CFS, where no clear biomarkers exist (Brenu et al., 2011). This model's limitations in addressing the complexity of ME/CFS may explain why many healthcare professionals continue to struggle with the condition's diagnosis and management. In contrast, the biopsychosocial model (Engel, 1977) incorporates biological, psychological and social factors, offering a more holistic approach to understanding ME/CFS. This approach acknowledges that social and psychological influences are integral to patients' health and well-being. When healthcare providers adopt a biopsychosocial perspective, patients are more likely to feel validated and supported, fostering better self-management and improved patient-practitioner relationships (Kusnanto et al., 2018).

Chronic conditions like ME/CFS are often better managed when patients have positive relationships with their healthcare providers, characterised by effective communication and support (Vainauskienė & Vaitkienė, 2021). Patients who are actively involved in their care and decision-making, especially through enhanced self-management programmes, report improved symptom management and enhanced emotional support (Bartlett et al., 2020; Lee et al., 2021). Research highlights persistent barriers to the effective diagnosis and management of ME/CFS. Bayliss et al. (2014)conducted a meta-synthesis of 21 qualitative studies, revealing that, for over two decades, health professionals have reported a limited understanding of ME/CFS, often influenced by constraints of the biomedical model. This has led to scepticism among some GPs about the conditions' existence, contributing to delays in diagnosis and inconsistent management. However, GP's who adopt a broader, multifactorial understanding of ME/CFS demonstrate more positive attitudes, collaborate effectively with patients and employ therapeutic skills that promote self-care. Adding to this, Broughton et al. (2017) conducted a thematic analysis of interviews with patients treated at NHS specialist ME/CFS services and highlighted the unique role of these services in improving patients' quality of life. Participants reported that these services provided validation of their experiences, practical support and better therapeutic outcomes, which were often absent before referral. Positive relationships with clinicians, flexibility in treatment plans and a supportive environment emerged as critical factors facilitating improvement. However, patients also emphasised challenges before accessing these services, including a lack of societal understanding and validation of their condition, and concerns about managing life after discharge from specialist care. Taken together, these findings illustrate the significance of specialist services in bridging gaps in support and treatment for individuals with ME/CFS.

Few studies have utilised Interpretative Phenomenological Analysis (IPA) to explore the self-management experiences of individuals with ME/CFS. Arroll and Senior (2008) used IPA to examine how individuals make sense of their symptoms and diagnostic experiences, identifying six themes including: the nature and progression of symptoms, disruption to daily and occupational life, symptom frequency, influence of external information, the diagnostic process and treatment experiences. Crucially, receiving a diagnosis of ME/CFS did not signify resolution, highlighting the ongoing complexities of the illness. Extending this work, Brooks et al. (2014) explored both patient and significant other perspectives, revealing that social interactions - especially with healthcare professionals and the wider community - shape illness beliefs and dyadic coping. Their findings point to the value of including significant others in treatment and support interventions. Recent research has focused on lived experiences in specific populations. Waite and

Elliot (2021) found that students with ME/CFS faced stigma and delegitimisation within university settings, which negatively affected self-esteem. Over time, some participants developed greater acceptance and improved well-being. Wilde et al. 2020) explored how men with ME/CFS cope with identity threats related to masculinity. Their study identified three themes: loss of masculine identity, marginalisation attached to ME/CFS and masculinity and coping with dual identity. Men with ME/CFS navigated personal, social, and cultural contexts by adapting their perceptions and performances of masculinity. Similarly, Snell et al. (2024) highlighted how stigma and lack of recognition from healthcare professionals contribute to a loss of identity for men with ME/CFS. Taken together, both studies demonstrate the intersection of illness and masculinity. These findings suggest that gender-sensitive, empathetic approaches in ME/CFS care are essential to help men navigate these complex identity issues.

While thematic analysis (TA; [Clarke & Braun, 2017])is well-suited for identifying common patterns across participants' accounts, IPA offers a complementary but distinct value: it enables a detailed, idiographic exploration of how individuals interpret and make sense of their experiences within their unique contexts. This is particularly important in conditions such as ME/CFS, which are characterised by high heterogeneity in symptom presentation, illness trajectory, and personal coping strategies. Understanding how individuals make meaning of the barriers and facilitators to self-management is critical, as these meanings shape behaviour, engagement with care and emotional well-being. Moreover, ME/CFS is often poorly understood and medically contested, which can lead to experiences of stigma, disbelief, and invalidation. IPA can surface how such social and contextual factors intersect with personal illness narratives, offering insights that are vital for designing person-centred interventions that resonate with patients' lived realities. While TA can effectively identify what the common barriers and facilitators are, it does not capture the subjective meanings individuals attach to these experiences - meanings that profoundly influence how people with ME/CFS navigate and manage their condition. IPA, therefore, provides the depth necessary to explore these interpretative processes. Considering the above, the present study aimed to explore: *How do individuals with ME/CFS experience barriers and facilitators to effective self-management of their condition?*

Materials and methods

The present study recruited five participants through opportunity sampling, aligning with the idiographic approach of IPA. All participants were female [(F); 100% of the cohort; mean age ± SD, 33.2 ± 13.00 years old, age range, 22–50]. The duration of ME/CFS symptoms ranged from 6 to 14 years (mean ± SD, 10.4 ± 3.58 years). All participants had a confirmed diagnosis of ME/CFS. Eligibility criteria included: i) being ≥18 years old, ii) fluency in English, iii) residency in the UK, and iv) having a formal diagnosis of ME/CFS.

Recruitment and ethical approval

Participants were recruited via advertisements shared on ME/CFS-focused forums on social media platforms, including Facebook and X (formerly Twitter). Ethical approval for the study was granted by the Health, Psychology, and Social Care Research Ethics Committee of the University of Derby, UK (approval number ETH2324-3086). The study adhered to the British Psychological Society (2021). All participants provided written and oral informed consent before participating.

Demographic information

Participants completed a brief demographic questionnaire administered via Qualtrics (XM, Provo, UT). This questionnaire gathered essential information, including age, sex ethnicity and ME/CFS symptom history. For an overview of participant demographics and ME/CFS history please see Table 1 below.

Interview schedule

The interview schedule was designed to explore participants' lived experiences with ME/CFS, with a specific focus on their self-management behaviours and interactions with healthcare systems. Semi-structured interviews were chosen to balance structure and

Table 1. Overview of participant demographics and ME/CFS history.

Participant	Pseudonym	Age, years	Ethnicity	Time since ME/CFS diagnosis, years
1	Amelia	44	White British	6
2	Becky	50	White British	14
3	Caroline	22	White British	8
4	Stephanie	22	White British	10
5	Victoria	28	White British	14

flexibility - allowing for consistency across participants while providing space to pursue individual narratives in depth (Smith & Osborn, 2015). This approach was particularly suited to the idiographic focus of IPA, as it encouraged participants to reflect on their personal meaning-making processes in relation to their illness.

The development of the interview questions was informed by a comprehensive review of the literature on ME/CFS, particularly studies highlighting the challenges of managing fluctuating symptoms, limited access to effective treatments and complex experiences with healthcare providers. Emerging themes from this literature - such as pacing, stigma, diagnostic delays, and the emotional burden of self-management - were used to shape the key areas of inquiry. The open-ended, non-leading questions were designed to explore perceived barriers and facilitators to self-management (including personal, social and systemic influences). All interviews were conducted by the first author (MR), who was trained in qualitative interviewing and familiar with the IPA approach.

Analytic method

IPA was used to analyse the data due to its suitability for exploring individual, subjective experiences and for generating rich, reflective insights into participants' meaning-making processes (Larkin & Thompson, 2011). The method's emphasis on flexibility and rapport-building made it especially appropriate for exploring sensitive topics such as the challenges of managing ME/CFS.

In keeping with IPA's theoretical underpinnings, the study adopted an interpretative, phenomenological approach. This allowed for a close, idiographic analysis of participants' lived experiences while recognising the active role of the researcher in interpreting these accounts - a process known as the double hermeneutic. That is, participants make sense of their own experiences, and the researcher, in turn, seeks to make sense of those interpretations. Rather than suggesting that themes passively 'emerge', we acknowledge that they are constructed through a dynamic and iterative interpretative process. While the interview schedule was informed by prior literature to provide focus, the analysis remained grounded in participants' accounts. The researchers engaged reflexively with the data, drawing on both the participants' narratives and their own critical perspective to develop themes that illuminate how individuals navigate the complex realities of living with ME/CFS.

This interpretative work was conducted within a critical realist framework, which recognises that while participants' experiences are deeply subjective and context-bound, they are also shaped by broader, often invisible structures and mechanisms (Hood, 2016). Thus, the analysis sought not only to represent personal meaning-making but also to consider how these narratives are situated within wider socio-medical contexts.

The analysis followed the six-step IPA process described by Pietkiewicz and Smith (2014). Each transcript was read and re-read to identify initial interpretative insights (Step 1). Emerging patterns were clustered into preliminary themes through abstraction (Step 2). These were refined and structured into broader thematic categories with relevant sub-themes (Step 3). A detailed table was then constructed linking superordinate and subordinate themes to participant extracts (Step 4). Analytic decisions were documented throughout to ensure transparency and methodological rigour (Step 5), culminating in the final written analysis (Step 6).

Transcription

Participants were given the option to conduct interviews face-to-face or via Microsoft Teams video calls. Two interviews were conducted in person at the University of Derby (Kedleston Campus) within a dedicated interview room, and three were completed via Microsoft Teams. Interview durations ranged from 32 to 84 minutes (mean ± SD, 50 ± 19.7 minutes).

The three online interviews were audio-recorded and transcribed verbatim in real time using Teams, the two in-person interviews were recorded through audio recording and then transcribed using Otter AI. Participants were informed about the recording process beforehand. Transcripts were stored in a password-protected folder, and anonymous labels (e.g. participant one) were used to maintain anonymity. Identifiable information was removed and participants provided consent to use verbatim quotes in the study.

Researcher reflexivity

IPA recognises the active role of the researcher in making sense of participants' experiences, viewing subjectivity not as a limitation but as a lens through which deeper insights can be accessed. It is therefore important to acknowledge the positionalities of the authors and how these may have shaped the research process.

The lead author (MR, female, MSc Health Psychology student) has first-hand experience with ME/CFS given a family history of the condition. This background contributed to a heightened sensitivity to the personal, relational and social complexities of living with ME/CFS, which may have influenced the interpretation of participants' narratives. The corresponding author (DG, male), a lecturer in Health Psychology, brought a complementary perspective shaped by a health psychology lens. This perspective emphasised the interaction between biological, psychological and social factors in understanding participants' experiences, particularly in relation to self-management, healthcare engagement and emotional well-being. Both authors have attended a training workshop focused on using IPA.

These positionalities inevitably influenced the framing and interpretation of participants' accounts. However, the authors actively engaged in reflexive dialogue throughout the research process to critically examine their assumptions and potential biases. These ongoing discussions supported a balanced, collaborative interpretation that aimed to remain faithful to participants' lived experiences, while drawing on the researchers' insights in a transparent and reflective manner. This reflexive approach contributed to the rigour and depth of the analysis.

Procedure

Study advertisements were shared on social media platforms. Individuals expressing interest in the study were directed to a brief Qualtrics (Qualtrics, Provo, UT) survey, which provided information about the study's aims and obtained their consent. The survey also collected participants' email addresses and demographic information. The researcher (MR) subsequently contacted participants to arrange a convenient date, time and preferred format for the interview (face-to-face or via Microsoft Teams). At this stage, the interview schedule was also emailed to participants to provide an overview of the topics to be discussed. Interviews were conducted as scheduled, and participants were debriefed both verbally immediately after the interview and sent an electronic copy of the debrief sheet via email. Each participant was thanked for their time and contributions to the study. MR transcribed the data and then both MR and DG began coding.

Analysis

The analysis examines how individuals with ME/CFS experience barriers and facilitators to effective self-management. Barriers to effective self-management comprised one main theme, including sub-themes of: i) navigating competing and cyclical symptom burdens and ii) the need for self-advocacy. Facilitators of self-management were categorised into two main themes. Adapting to manage symptoms, highlighted the importance of navigating self-management through trial and error i) and growing confidence over time ii). The third theme, social and practical support, included the crucial role of i) family and partner support and ii) workplace flexibility in enabling individuals to manage their condition more effectively. Table 2 below provides a structured overview of the themes and sub-themes that emerged from the data corpus.

Theme 1: barriers to effective self-management

Managing physical symptoms such as pain, sleep disturbances and fatigue emerged as profound challenges for individuals with ME/CFS. The unpredictable and debilitating nature of symptoms such as brain fog, pain and post-exertional malaise (PEM) compounded the difficulties of self-management. Chronic sleep disturbances and exhaustion exacerbated these issues, leaving participants in a persistent state of depletion. While strategies such as pacing, prioritising activities and adjusting work routines provided some relief, these efforts often fell short of mitigating the pervasive impact of symptoms on daily life.

Sub-theme 1: navigating competing and cyclical symptom burdens

Participants' accounts revealed the multifaceted and compounding challenges posed by chronic pain, sleep disturbance, fatigue and cognitive dysfunction, which often reinforced one another in a cyclical pattern. Rather than dealing with isolated symptoms, individuals faced competing and interdependent symptom burdens that complicated efforts to manage their condition and maintain daily functioning.

Table 2. Themes and sub-themes highlighting barriers and facilitators to self-management in ME/CFS.

Theme(s)	Sub-themes(s)
Barriers to effective self-management	• Navigating competing and cyclical symptom burdens • The need for self-advocacy
Adapting to manage symptoms	• Navigating self-management through trial and error • Growing confidence over time
Social and practical support	• Family and partner support • Workplace flexibility

ME, Myalgic Encephalomyelitis; CFS, Chronic Fatigue Syndrome.

Pain was described as both a physical and psychological burden, contributing to emotional distress, fear, and avoidance behaviours that further undermined self-management efforts. Amelia described how pain exacerbated her sleep disturbances, creating a vicious cycle of worsening symptoms:

> Sleep disturbance and pain are my two bigger symptoms, although the fatigue is there. Actually, the pain is far greater in terms of its intrusion. It's the thing that then kind of if I'm already having disturbed sleep being in pain on top of it disturbs it further. So, [I'm] trying to work with the doctors to get a good pain management regime.

Amelia's account emphasises the cyclical and interdependent nature of ME/CFS symptoms, where pain intensifies sleep disruption, which in turn worsens fatigue and cognitive dysfunction. These dynamics pose significant challenges for self-management, as individuals must navigate multiple, compounding symptoms that resist straightforward solutions. Amelia's reliance on *working with the doctors* to find a *good pain management regime* highlights the difficulty of accessing effective treatment options and the need for her to advocate for adequate care while contending with physical limitations.

Stephanie reflected on the psychological impact of pain, describing how the fear of re-experiencing it became a mental barrier to self-management:

> You have the anxiety inside you, and I still get it these days. That's like a mental block. Where you know if you're going to do something that has previously hurt you, you're sort of scared that it's going to affect you again… and I don't want to be in pain again. Like those years are some of the worst of my life. When you know. You [have your] entire independence, and routine, and everything's taken away.

Stephanie's account highlights how the anticipation of pain leads to avoidance behaviours, creating a self-reinforcing barrier to engagement in daily activities. The *mental block* reflects the profound fear and anxiety associated with pain, which can prevent individuals from pursuing potentially beneficial actions. The loss of *independence* and *routine* further illustrates the cascading effects of pain on physical, psychological and social well-being, compounding the difficulties of regaining a sense of control.

In addition to pain, participants described how sleep disturbances and fatigue created a constant struggle to balance activity and rest. Sleep problems and exhaustion disrupted routines, impaired decision-making and diminished the energy needed to implement coping strategies, adding to the competing burdens of daily life.

Amelia shared the social and professional repercussions of brain fog linked to sleep disturbance:

> The sleep disturbance impacts… my brain fog stuff. It was really embarrassing when I first got unwell and I'd sort of never had brain fog before, you know, I was working in a job that was, it was a lot of thinking. It was lots of kinds of legal stuff and quality. So, it was very detail orientated and there were days at work where I was slurring my speech and I couldn't find the right word and people I'd worked with for over a decade, you know, took me to one side and said, 'Are you drunk?'

This quote highlights the far-reaching consequences of cognitive dysfunction on professional identity and self-management. The embarrassment and misunderstanding associated with brain fog undermined Amelia's self-confidence and made it more difficult to seek support or accommodations. Such experiences of stigma and diminished self-efficacy further complicated the already significant challenges of managing symptoms and maintaining occupational roles.

Becky described the disproportionate physical toll of even simple tasks:

> Every day is a bigger challenge just to get through the day. I can get up easy enough. But just by doing the simplest tasks, it wipes me out. So, it's just a challenge to get through it really each day. Things like having a shower, washing my hair, that wipes me out for ages, makes me very breathless.

Becky's account emphasises the profound physical limitations imposed by ME/CFS. The significant energy cost of basic self-care activities left little capacity for other tasks or management strategies. Being *wiped out for ages* and *breathless* illustrates how the demands of daily functioning can deplete vital reserves, forcing individuals to prioritise survival over long-term planning or symptom improvement, contributing to a sense of defeat and helplessness.

Despite these challenges, some participants described proactive strategies to mitigate symptom burden where possible. Victoria explained how she adopted pacing to better manage her limited energy:

> I've learned to pace my diary, prioritising important things and outsourcing what I can, but I know I'll always be tired.

While pacing offers a structured way to manage energy expenditure, Victoria's recognition that she will *always be tired* captures the persistent and often unrelenting nature of ME/CFS symptoms. Even with adaptive strategies, the ongoing experience of fatigue can sap motivation and create emotional barriers to sustained self-management. Nevertheless, pacing and prioritisation reflect the resilience and resourcefulness individuals employ to navigate their complex and overlapping symptom burdens, even when full relief remains out of reach.

Sub-theme 2: the need for self-advocacy

Healthcare interactions and the need for advocacy emerged as vital elements of symptom management for participants, many of whom faced challenges in gaining recognition, proper diagnoses and treatment. Several participants described being dismissed or disbelieved by healthcare providers, making persistent self-advocacy necessary to secure appropriate care.

Caroline reflected on the challenges of not being taken seriously by healthcare providers in the early stages of her illness:

> Before I was referred to the paediatrician when I was going to the GP, it was kind of when I was saying about them saying, 'Oh, it's just teenage growing pains'. It was kind of like it obviously didn't help me because there was obviously something more than just teenage growing pains so it was kind of like I wasn't taken seriously so therefore I couldn't get any help for it until I really pushed to get referred elsewhere.

Caroline's experience highlights the emotional toll of being dismissed by healthcare professionals. The phrase *just teenage growing pains* exemplifies the trivialisation of her symptoms, which led to delayed diagnosis and treatment. Her frustration is palpable, as she emphasises how difficult it was to get appropriate help until she *really pushed* for a referral. This demonstrates the critical role of self-advocacy, especially when healthcare providers fail to acknowledge the seriousness of ME/CFS. Her persistence in seeking a referral highlights the broader issue of systemic dismissal faced by patients with chronic illnesses.

Caroline elaborated on this experience further:

> I just went to the GP two or three times within the space of about five or six months, and I just kept being told like, 'Oh, it's just growth pains, like you're young, you're a teenager, whatever. It was only after a certain while I was like, 'It's not normal for me to have CFS, it's not normal for me to feel like this all the time. So, we pushed for a referral at the hospital to which I got, I was under a paediatrician for a year before I got diagnosed.

Caroline's frustration with being repeatedly dismissed by her GP reveals the emotional and psychological impact of not being taken seriously. Her realisation that *it's not normal for me to have CFS* marks a pivotal moment of self-awareness and advocacy. Her determination to push for a referral illustrates the vital role of self-advocacy in securing proper care when medical professionals lack awareness of the complexities of ME/CFS. This experience illustrates the importance of patients' persistence in navigating the healthcare system, as well as the need for greater education and responsiveness from healthcare providers.

Amelia shared her experience of seeking a second opinion from a private GP to secure a referral:

> I also paid to get a private GP opinion, who then said I can't… I can't help because it's too complicated and I can't take you on a regular basis. But what you do need is you need a referral, emergency referral through to endocrinology. So, it took to get back to the point where I am now, which is where we should have been, the formal complaint, a private GP and that private GP then sent in a referral to my GP for the hospital to say she needs to see an endocrinologist. This isn't normal.

Amelia's pursuit of a second opinion and eventual referral to endocrinology highlights the difficulties faced by individuals with ME/CFS in accessing appropriate care. Despite being told her condition was *too complicated* for the GP to handle, Amelia's persistence - paying for a private consultation and filing a formal complaint - led to the necessary referral. This experience outlines the emotional and financial toll of navigating a healthcare system that often fails to adequately address the complexities of ME/CFS. It illustrates the systemic barriers patients must navigate and the essential role of self-advocacy in overcoming these obstacles.

Stephanie also shared the impact of dismissive attitudes from healthcare providers, reflecting on a negative experience with a consultant:

> The advice from the consultant, which I won't speak highly of. But again, his advice was, 'It is in your head'. So that wasn't any real self-management. So, when you have got that lack of information and suggestions from healthcare professionals, it is hard to self-manage because I wouldn't even know what self-management was. It wasn't until recently when I've had more open conversations. My self-management was just making it out of bed and just being able to actually be normal for a day. Just leaving the house.

Stephanie's experience further illustrates the harmful effects of dismissive healthcare interactions. The consultant's suggestion that her condition was *in* *your head* minimised the seriousness of her symptoms, leaving Stephanie without guidance on how to effectively manage her condition. Her reflection that she *wouldn't even know what self-management was* highlights how critical information and support from healthcare professionals are to the process of self-management. Stephanie's description of self-management as *just making it out of bed* elucidates the overwhelming challenges of navigating daily life with ME/CFS when the healthcare system offers little support. It is clear healthcare professionals should not only acknowledge the physical reality of conditions like ME/CFS but also provide actionable advice and support that empowers patients to manage their health.

Overall, the need for self-advocacy is a double-edged sword: while it facilitates care and treatment when the healthcare system fails, it is also a burden that patients should not have to carry, and it can exacerbate feelings of frustration, isolation and helplessness.

Theme 2: adapting to manage symptoms

Living with ME/CFS necessitates continual adaptation, as participants learn to respond to the fluctuating and often unpredictable nature of their symptoms. This theme explores the evolving strategies individuals use to self-manage their condition - developed not through clinical guidance, but through lived experience, trial and error and increasing self-awareness. Adaptation often requires participants to relinquish previously valued roles and activities, recalibrate their expectations and refine their approaches to physical and emotional boundaries over time. The process is inherently dynamic, shaped by moments of hope, frustration, acceptance and small, hard-won victories. This theme is explored through two sub-themes: navigating self-management through trial and error and growing confidence over time.

Subtheme 1: navigating self-management through trial and error

Participants described an experimental, non-linear path to self-management. Early attempts were often driven by hope and frustration, with recurring setbacks acting as turning points for learning. Through repeated experiences, participants gained insight into their limits, reshaped expectations, and cultivated more sustainable practices. These narratives reflect not only behavioural adjustments but also deeper emotional and identity shifts that accompanied the process of adaptation.

Amelia's account foregrounds the painful but pivotal shift towards acceptance of her condition's constraints:

> To function now and work full time, I've just cut a lot of things out of life. So, I've given up all of my hobbies that have any sort of physical nature. I had a period where I was starting to feel that I was kind of going into remission and foolishly because I'm an idiot, I decided that I was going to prove that I was better and that, you know, my health wasn't going to rule me. I took up running, which was a really sensible thing to do [sarcastic]. Don't do that anymore.

There is a clear tension in Amelia's narrative between her desire for normalcy and the realities of chronic illness. Her reflection on taking up running reveals a lingering need to test the boundaries - to *prove* she is not ruled by ME/CFS - which speaks to the threat the condition poses to her autonomy and identity. The use of sarcasm and self-deprecation *because I'm an idiot* softens the emotional weight of the loss but also reveals a sense of regret and perhaps shame around her earlier resistance to self-limiting behaviours. Yet, this attempt led to an important shift. Letting go of physically demanding hobbies, though described as a loss, is also positioned as a functional and deliberate choice - *to function now and work full time*. Amelia's account effectively captures the complex emotional labour of adaptation, where acceptance is not passive resignation, but an active recalibration of priorities grounded in lived experience.

Becky reflects on the shift from uncertainty to self-trust, drawing attention to the emotional payoff of consistent pacing:

> At first I wasn't very confident because I was like what's going to actually cure feeling like this but then I feel like over time of like I say resting and not pushing myself too far seeing that progress of oh my I'm actually feeling better it's encouraged me to do more.

Becky's narrative highlights the emergent nature of confidence in self-management. Initially, she frames her approach with scepticism and doubt - *what's going to actually cure feeling like this* - suggesting a desire for a more immediate, curative solution. Her use of *over time* and the casual, conversational tone *like I say* reflects a gradual, embodied learning that is not linear or prescribed, but routed in personal discovery. The moment of realisation - *oh my*

I'm actually feeling better - marks a turning point where internal evidence, rather than external instruction, fuels motivation. Consistency in rest and pacing eventually reconfigures her expectations from cure-seeking to progress-tracking, allowing self-management to become a source of empowerment rather than frustration.

Caroline offers a practical and emotionally attuned perspective, grounded in bodily awareness:

> When I need to slow down and stop, I slow down and stop. Like, I try not to get to that point where I'm sort of burnt out because that obviously makes me feel a lot worse. So, when I can feel myself getting to that point where I'm like, I need to stop, I will take a couple of days just to do nothing.

Caroline's approach demonstrates a proactive orientation towards self-care, rooted in a close attention to bodily signals. Her repetition of *I need to stop* reflects both urgency and assertiveness - she positions herself as someone who listens to and honours her own needs. The deliberate choice to *do nothing* for a few days' challenges common cultural values around productivity, suggesting a redefinition of rest as therapeutic and necessary. Her language is calm and measured, indicating that this self-awareness has become integrated into her way of life, rather than something she continues to struggle with.

Caroline later builds on this, offering a gentle and realistic framework for moving forward after setbacks:

> Don't sort of try to run a marathon after you've been in bed all day the day before. If it means just getting up and walking up the road, you've done something… I think that's definitely helped me to get to where I am now with managing it and not pushing myself too far. It's those baby steps. If I've had a bad day, yeah, it's fine to have a bad day. But then when I come back from having a bad day, it's those baby steps to come back from it.

Here, Caroline's use of metaphor - *don't try to run a marathon* - illustrates the unrealistic expectations she once held and now actively resists. Her validation of small efforts (*you've done something* and her normalisation of *bad days* reflect a shift in mindset away from self-criticism and towards self-compassion. The repeated emphasis on *baby steps* conveys both the fragility and sustainability of progress, grounded in day-to-day decision-making. Thus, symptom management is not just behavioural, but cognitive and emotional, involving a reworking of what counts as success, progress and ultimately care.

Sub-theme 2: growing confidence over time

Over time, participants described a growing sense of confidence in managing their ME/CFS, shaped by accumulated experience, personal insight and emotional maturation. This confidence did not emerge uniformly or easily but evolved through moments of trial, reflection, and reframing. Participants articulated an increasing ability to read their bodies, make proactive decisions, and adapt flexibly to the unpredictability of symptoms. The growing trust in their own knowledge and instincts became a form of empowerment, enabling not only more effective self-management but also a shift in how they related to their illness and others.

Amelia spoke about how her confidence in self-management shifted in response to worsening symptoms:

> The minute that I start to kind of decline and any sort of self-management becomes more challenging and so it's kind of much more about battening down the hatches and waiting for the storm to pass. Because it's the only way to do it, really.

Amelia's use of the storm metaphor - *battening down the hatches* - conveys a sense of powerlessness in the face of symptom deterioration, but also a certain emotional preparedness. Rather than resisting or denying the downturn, she frames her approach as protective and strategic. The phrase *the only way to do it* reflects a form of acceptance grounded in lived experience. Here, confidence does not mean always being in control but knowing when to step back and ride out the harder phases. This is a mature, embodied insight, showing an evolution from striving to fix the problem to acknowledging the wisdom in stillness.

Becky reflects a more proactive and reflective stance, emphasising planning and body-awareness:

> We've just got to pace it all out and I have to plan very carefully of what I'm doing. I think it's about learning about your own body, your own capabilities. Not one person's the same. It's trying to understand what will take you over that edge from not doing too much to doing too much, knowing your limitations.

This narrative centres on *individualised learning*, with Becky highlighting the importance of self-tailored strategies. Her emphasis on *learning about your own body* suggests a deepening relationship with herself - she is not simply managing symptoms but understanding the nuances of her limits. The contrast between *not doing too much* and *doing too much* evokes a delicate balance, and her ability to identify this edge signals confidence in her self-knowledge. Becky's reflections suggest that growing confidence involves moving from generic advice to personally meaningful insight - what works for others may not work for her, and she's come to own that distinction.

Caroline described how changes in her condition shaped the evolution of her self-management:

> I feel like it's obviously my self-management has evolved with my symptoms… back then it was a lot worse now I'm like a lot more active, so I feel like with knowledge with me knowing that I am going to get better and obviously showing that I have gotten better it's changed the way that I manage my symptoms.

Caroline's reflections are future-oriented and hopeful. She expresses a belief in her own progress - *I have gotten better* - which has in turn transformed how she approaches self-management. There is a sense of feedback between improvement and agency: her symptoms have lessened, and this has not only allowed for more activity but also deepened her confidence and adaptability. Caroline's narrative demonstrates how positive change reinforces commitment to self-care practices and renews the emotional energy needed to continue adapting. It also reflects a shift from reacting to symptoms to actively shaping her daily life around changing capacities.

Stephanie offered a broader perspective, linking emotional growth and social support with increased confidence:

> So, as I've got older. I think there's definitely a lot more of a confidence within me. Because when you're in that situation, where you're just very mentally down and you're in a lot of pain, you just don't know where to go. So, as I've got older, and sort of, more mature… I've grown out of it to an extent. Within sort of doing research and having these conversations it's given me confidence. To speak about it more and to actually open up to people who I know will listen. In terms of self-management, I think with my support group, at the moment I don't do it [engage]… And I'm a lot more determined, and sort of willing, to try things that I wouldn't have done previously, because I either didn't have the support or I just really wasn't in a good mental place to go ahead.

Stephanie's account brings attention to the emotional and interpersonal dimensions of growing confidence. Her reflection on becoming *more mature* suggests that this process is not just medical or behavioural but tied to broader identity development. Confidence, for her, is situated within relational contexts - *conversations*, *support group*, *people who I know will listen* - showing that feeling heard and understood accelerates change. She contrasts her current openness and willingness to try new strategies with a time when she felt emotionally depleted and unsupported. The shift from isolation to connectedness seems central to her sense of agency, highlighting the interdependence of emotional resilience and practical self-management.

Theme 3: social and practical support

For individuals living with ME/CFS, social and practical support emerged as a vital resource in navigating the complexities of daily life with a chronic, fluctuating condition. Support from family members and partners provided more than just physical assistance - it fostered emotional stability, validation and a sense of security that many participants relied on, particularly during times of relapse or uncertainty. Practical adjustments at home and work also played a key role in enabling participants to preserve energy and maintain a sense of agency. Together, these support systems enhanced individuals' capacity for self-management, helping them to balance illness with other aspects of life.

Sub-theme 1: family, partner and community support

Participants consistently highlighted the importance of emotionally attuned and practically responsive support from close relationships. These relationships helped buffer the psychological strain of illness and offered meaningful assistance with everyday tasks, making self-management more feasible.

Amelia offered a powerful reflection on her home life, illustrating both emotional and practical support in the context of an ongoing partnership:

> And I'm lucky that, like I say, the support network I've got at home certainly is strong enough so that the kids are now older. My husband's really supportive. They [family] worry about me kind of more than I worry about myself most days and I will be my harshest critic.

Her statement highlights not only the reliability of her support network but also an emotional dynamic in which others' concern acts as a protective mirror to her own internal harshness. The phrase *they worry about me more than I worry about myself* suggests a deep emotional investment from her family, which may serve as both a source of comfort and accountability. This dynamic subtly reflects the tension between internal self-critique and external care, highlighting how meaningful relationships can mediate internalised pressures.

Amelia also reflected on her partner's unflagging support:

> Family wise, I'm incredibly fortunate as well. My husband is an absolute legend and he doesn't bat an eyelid at it, and I always feel really guilty because although we've both got senior jobs, he's the primary earner. He works incredibly long hours. So, he just sort of 13-hour days Monday to Friday and then comes home and [does] all the housework.

Here, Amelia expresses a strong sense of gratitude and guilt, capturing the emotional complexity of receiving care while feeling unable to reciprocate in the expected ways. Her use of the phrase *absolute legend* conveys deep admiration, while the routine nature of her partner's contributions - *he doesn't bat an eyelid* - suggests a normalisation of caregiving within their relationship. This highlights how emotional and practical support can be seamlessly integrated into everyday life, though not without emotional cost for the recipient.

Becky reflected on the value of shared labour and understanding from those around her:

> It is family and friends helping me do stuff around the house so that frees me up just to rest in between and doing little jobs. Friends by being understanding of that I can't go and do loads of things and energy limited and stuff like that. So, I'm quite lucky that I've got a good support network.

Becky's account highlights how small, practical actions – 'helping me do stuff around the house' - can have a significant impact, enabling her to rest and preserve energy. Her appreciation of friends' *understanding* reveals how emotional support is not always explicit but often conveyed through quiet acceptance and flexibility. The phrase *I'm quite lucky* emphasises the precariousness with which such support is held - participants often knew how different things might be without it.

Victoria offered insight into how social understanding intersects with emotional well-being and symptom management:

> They're very cool people [network around them] and they're very supportive people and I think how well I feel and how well managed my symptoms are… Spending a lot again on like my psychological thoughts on things. So, for example, if there's a guilt tag to something I will like, it will drain me and I think when I can like when I reliably know my friends, I can say can we just not and they'll be like, yeah, yeah, of course. Like, are you OK? And their response comes from a place of love and support rather than inconvenience.

Victoria's account reveals how the psychological experience of support - particularly the removal of guilt - can be just as vital as practical assistance. Her example of *can we just not* shows how being able to assert boundaries without fear of burdening others allows her to protect her energy and emotional stability. This deep mutual understanding, grounded in *love and support rather than inconvenience,* creates a psychosocial environment where self-management becomes more sustainable.

Stephanie reflected on the steady, enduring role her family played through different phases of her illness:

> My family. They have seen me through it. So, it is not really any change with that. They have just seen me sort of get better and grow out of it. But they have also supported me during setbacks, because these days I still have issues.

Steph's description is marked by continuity and quiet resilience. Her family's unwavering presence through both improvement and relapse illustrates the long-term scaffolding that familial support can offer. Her phrase *seen me through it* captures a non-intrusive, witnessing form of care - less about fixing and more about being present, reinforcing the role of family as a stabilising force through the condition's fluctuations.

Sub-theme 2: workplace support and flexibility

Supportive and adaptable working or educational environments were described as vital in enabling participants to sustain both their health and their responsibilities. Given the fluctuating and often invisible nature of ME/CFS, participants reflected on how critical it was for workplaces and institutions to accommodate their variable energy levels, cognitive difficulties and the need for rest.

For Amelia, negotiating flexibility with her previous employer was transformative:

> They [previous workplace] were really good because I was able to manage to negotiate an annualised hours contract. As long as I worked the right number of hours in 12 months, it didn't matter if I had a bad period, and I needed to work shorter days or I needed more flexibility. That was phenomenal and a lot of companies don't do that and at a lot of jobs, it's difficult to do that.

This quote demonstrates how autonomy over one's working pattern - through arrangements such as annualised hours - can empower individuals with ME/CFS to continue working without fear of worsening symptoms. Amelia's experience reflects both appreciation and awareness of how rare such flexibility is, highlighting the structural limitations many face. Her use of *phenomenal* conveys a deep sense of relief and gratitude, suggesting this level of understanding is not only exceptional but vital for long-term sustainability in employment.

Amelia further described how her current employer embeds support into its organisational culture:

> So I've been. I've been really fortunate that I have had employers that that will allow me to put kind of behavioural measures in place, particularly the company I work for at the moment are really, really good because they run an actual health division, it's a massive company…. We have a health division and anybody who's got any sort of disability or kind of neurodivergent or anything like that, you get a disability passport.

This quote illustrates how institutional structures - like a *disability passport* - can formalise support, easing the burden of repeatedly having to explain or justify one's needs. The presence of a dedicated health division, combined with openness to *behavioural measures*, demonstrates a progressive approach where inclusion is systematised rather than optional. For Amelia, this structure seemed to alleviate the emotional labour often associated with self-advocacy.

Stephanie described her workplace's recognition of her limits:

> Work [when asked about any sources of support] by understanding that I can't do too much and I can't push myself too much medically.

Though brief, Stephanie's quote reflects the centrality of being understood. The phrase *can't push myself too much medically* indicates how physical overexertion is not merely tiring but medically significant - potentially exacerbating symptoms. This understanding from her workplace enabled her to feel safe in setting limits, which can be a protective factor in both physical and emotional well-being.

Educational settings, too, emerged as important contexts for support. Caroline reflected on the personalised accommodations she received at college:

> The head of hair and beauty at college. With her personal experiences with it, because I had to retake my Maths and English GCSE, she took a lot of the stress and pressure off me. So, if I couldn't make college, she'd rather me do my Maths work from home and then just make those adjustments and just offer that support.

Here, the tutor's personal experience appears key in fostering empathy and meaningful adjustments. By removing pressure and offering remote alternatives, Caroline was given space to manage her health without falling behind. Her repetition of *just* when describing the tutor's actions suggests that these seemingly simple gestures had a powerful emotional impact - reducing stress and validating her needs.

Caroline also compared her earlier work experience with the support she later received at university:

> When I was working before uni they weren't very supportive but uni are a lot more supportive because I feel like…they know a lot more especially because obviously the field of work that I'm in [midwifery]. They understand about health more than other courses… that's where we kind of come into play with stuff and we go well with me for example when you're having an episode where it's acting up and you'll just be a bit more tired and a bit more blank.

Her reflection suggests that health-related knowledge within certain academic disciplines - like midwifery - can foster more compassionate environments. The difference between *supportive* university settings and unsupportive workplaces suggests a broader need for training and awareness across employment sectors. Caroline's description of feeling *a bit more tired and a bit more blank* captures the subtle cognitive and physical toll of an ME/CFS flare, which may be overlooked by those unfamiliar with the condition. Having educators who *understand about health more* thus becomes a crucial facilitator of effective self-management.

While all participants described the importance of support, their perspectives on self-management and recovery varied. Some, like Amelia and Caroline, expressed a proactive and adaptive stance, engaging creatively with work and education while holding hope for continued improvement. Others, such as Stephanie, conveyed a quieter, more resigned outlook, focusing on stability rather than change. This divergence appeared linked not only to external support but also to internalised illness identities and beliefs about the possibility of recovery. Such differences suggest that self-management is not a uniform process but shaped by emotional, relational and experiential factors that warrant further exploration.

Discussion

The aim of the present study was to explore how individuals with ME/CFS experience barriers and facilitators to effective self-management. The findings highlighted the complex, cyclical and interrelated nature of ME/CFS symptoms and the substantial psychological, emotional and physical demands placed on individuals attempting to self-manage their condition. Chronic pain emerged as both a symptom and a catalyst for psychological distress, with participants illustrating how pain amplified other symptoms (i.e. sleep disturbances and fatigue) and generated anxiety that hindered engagement in everyday activities. These compounding effects often created a sense of entrapment, where managing one symptom inadvertently exacerbated another. From the perspective of Self-determination theory (Deci & Ryan, 1985), such adjustments may challenge individuals' core psychological needs for autonomy and competence. The restriction of daily activities and limitations on personal goals can undermine one's sense of agency, contributing to frustration, helplessness and emotional distress. Similarly, cognitive dysfunction and severe fatigue - extensively reported in the ME/CFS literature (for review see Mohamed et al., 2023) - were described not only as impairments, but as destabilising forces that disrupted identity, independence and routine, all of which participants associated with normalcy and self-efficacy. Basic tasks became disproportionately exhausting, often leaning little energy or cognitive capacity for proactive self-management. While participants displayed resilience and adaptability, their accounts reflected how self-management strategies were often limited by the unpredictable and compounding nature of their symptoms.

Importantly, across all sub-themes, self-advocacy emerged as both an empowering and burdensome necessity. While previous IPA studies have explored how individuals make sense of their symptoms, diagnosis and identity (Arroll & Senior, 2008; Brooks et al., 2014; Waite & Elliot, 2021; Wilde et al. 2020), few have explicitly positioned self-advocacy as a central mechanism of self-management. By positioning self-advocacy as both a necessary strategy and a systemic challenge, this study offers a nuanced extension to existing IPA literature. Participants' experiences, such as being dismissed by GPs (consistent with evidence showing up to half of GPs do not recognise ME/CFS as a legitimate condition, Bowen et al., 2005), as well as navigating private healthcare routes, revealed a systemic lack of recognition and support. The absence of meaningful medical guidance, which may reflect limited GP training and confidence in managing ME/CFS, frequently left individuals without a clear framework for symptom management. This aligns with Bayliss et al. (2014), who noted that medical professionals often adopt a biomedical model, despite its limited relevance to conditions such as ME/CFS. Although a shift towards a more biopsychosocial model (Engel, 1977) is increasingly advocated, its implementation remains incomplete. That said, it is important to note that, while this study is situated within the UK, encouraging progress is being made in the development of multidisciplinary ME/CFS services within some NHS Health Boards. For example, the Derbyshire Chronic Fatigue Syndrome Service, based within Specialist Rehabilitation at Florence Nightingale Community Hospital, integrates the expertise of occupational therapists, physiotherapists, cognitive behavioural psychotherapists, and consultants in rehabilitation medicine. These collaborative, patient-centred approaches represent promising steps towards addressing the multifaceted nature of ME/CFS and alleviating some of the burden placed on patients to self-advocate in the face of structural gaps in care.

While the challenges of living with ME/CFS are substantial, the findings of the present study also highlighted several facilitators that supported participants in managing their condition. A key facilitator was the process of adapting to manage symptoms, which many individuals described as a trial-and-error journey. This aligns with previous research indicating that such a process is central to symptom management in ME/CFS (Edwards et al., 2007). Although initially frustrating, this iterative process allows individuals to discover techniques that worked best for their unique symptoms and limitations. Over time, as confidence in self-management grew, participants reported enhanced ability to regulate their condition. This evolution, based on self-awareness and better understanding of their bodies, highlights the importance of flexibility and patience in managing chronic illness. As individuals became more familiar with their own responses to symptoms, they were able to refine their self-management practices, demonstrating that flexibility is a critical component in adapting to chronic illness. This evolving self-management process echoes findings by Geraghty and Blease (2019), who emphasise the need for a personalised, adaptive approach to managing ME/CFS. However, while the trial-and-error process can lead to self-empowerment, it also points to the need for better support. Individuals could benefit from more structured guidance to help them navigate this complex phase. This might include access to evidence-based resources, continuous feedback from healthcare providers, and peer support networks where individuals can share experiences and learn from one another.

Social and practical support also emerged as a vital facilitator in managing ME/CFS. The role of family and partners was frequently emphasised, with individuals highlighting the emotional and practical assistance provided by loved ones. This support alleviated feelings of isolation and helped individuals manage daily tasks, reducing the overall burden of the condition. Research suggests that social support can act as a buffer against the negative psychological effects of chronic illness, such as depression and anxiety (Cohen & Wills, 1985). The presence of supportive relationships enables individuals to better cope with the challenges of ME/CFS, fostering greater resilience and improving overall well-being. Furthermore, workplace flexibility emerged as a key facilitator for individuals managing ME/CFS. The ability to negotiate adjusted work hours or access remote and hybrid working arrangements enabled individuals to maintain a degree of economic independence and professional identity, while accommodating the unpredictable and fluctuating nature of their symptoms. Flexible work environments allowed individuals to pace their activities, incorporate rest as needed, and avoid the physical and cognitive overexertion that can trigger symptom exacerbation, particularly PEM. This kind of flexibility not only contributed to improved well-being and reduced stress but also played an important role in maintaining a sense of normalcy and purpose - factors known to positively influence mental health and quality of life among people with chronic illnesses. These findings align with the broader literature on chronic illness and employment, which highlights the role of workplace accommodations in reducing disability-related disadvantage and promoting social inclusion (Beatty & Joffe, 2006).

However, despite the benefits highlighted by participants in the present study, ME/CFS results in significant occupational disruption (Bartlett et al., 2022). The stigma associated with the condition, combined with its often-invisible nature, can make it difficult for individuals to advocate for their needs or to have them recognised as legitimate. This highlights the importance of education and policy enforcement in ensuring that workplace rights, such as those outlined in the Disability Discrimination Act 1995 and Equality Act 2010, are meaningfully upheld. As noted by Vink and Vink-Niese (2019), effective implementation of reasonable workplace adjustments is crucial not only for retaining employees with ME/CFS but also for fostering a more inclusive and supportive work environment overall. To further support individuals with ME/CFS in the workplace, organisations might consider proactive measures such as flexible scheduling policies, options for task reallocation, assistive technologies, and management training on chronic illness and disability rights. Moreover, fostering a workplace culture that values empathy and open communication can create a safer space for employees to disclose health-related needs without fear of discrimination or misunderstanding.

Limitations and future research

The present study has certain limitations. Most notably, the sample was entirely female and therefore does not capture the experiences of male patients, whose self-management challenges may differ in important ways. Previous research has highlighted gendered dynamics in the experience of ME/CFS, specifically identity disruption linked to traditional norms of masculinity (Snell et al., 2024; Wilde et al., 2020). However, this study did not seek to compare gendered experiences; rather, it aimed to explore how individuals with ME/CFS experience barriers and facilitators to effective self-management in a broad sense. Given that ME/CFS disproportionately affects women, focusing on a female sample enabled in-depth examination of a group most affected by the condition. Nevertheless, the findings highlight the need for future research to explore how gender shapes the self-management experience, particularly among male and non-binary individuals, and to develop gender-sensitive approaches to care that acknowledge the complex interplay between illness, identity and social expectations. Second, the duration of symptoms varied widely among participants, ranging from 6 to 14 years. This variability could influence individuals' self-management strategies and interactions with healthcare providers. While this heterogeneity may be viewed as a limitation, it also reflects the real-world diversity of ME/CFS experiences and enriches the study's findings by capturing a range of adaptation trajectories. Future research could build on this by recruiting more stratified samples to further clarify how symptom duration and severity impact management approaches and support needs.

Conclusion

This study highlights that individuals with ME/CFS must navigate a challenging landscape marked by competing and cyclical symptom burdens and the constant need to self-advocate. Yet within these challenges, key facilitators emerged. Many participants described how, over time, a process of trial and error enabled them to develop more effective self-management strategies and grow in confidence. Social and practical support - from family, partners, and flexible workplaces - played a crucial role in sustaining these efforts. These findings reinforce the need for earlier diagnosis, genuinely patient-centred care, and greater recognition of the emotional, physical, and social dimensions of the illness. A more holistic, empathetic, and individualised approach to care is essential if we are to meaningfully improve the quality of life for those living with ME/CFS.

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Ethics approval and consent to participate

Ethics approval was obtained from the Health, Psychology and Social Care Research Ethics Committee of the University of Derby (ethics approval no. ETH2324-3086). All participants gave their written and verbal informed consent to take part in the present study.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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Data availability interdependent nature of ME/CFSsymptoms

Data are available from the corresponding author upon reasonable request.

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