

1 **Managing Fatigue Transdiagnostically: A Qualitative Study Among People With Chronic**
2 **Conditions on Optimising Daily Activity**

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21 Word count: 4990

22 Article Category: Research Article

23 **Managing fatigue transdiagnostically: a qualitative study among people with chronic**
24 **conditions on optimising daily activity**

25 **Abstract**

26 **Purpose:** To explore fatigue and physical activity behaviour experiences and management, with
27 an emphasis on activity pacing among adults with chronic conditions.

28 **Materials and Methods:** Semi-structured interviews were conducted with 15 adults with chronic
29 conditions and the symptoms of chronic fatigue who had either received or not received fatigue
30 management advice. Interviews were audio-recorded and transcribed verbatim, then analyzed
31 using reflexive thematic analysis.

32 **Results:** Participants reported barriers to fatigue management such as overactivity, mental health
33 issues, and workplace challenges. Additionally, they highlighted rest, restful activities, and
34 supportive social environment as facilitators of effective fatigue management, along with the
35 importance of nutrition and physical activity. In some cases, there were conflicting experiences
36 with social environment and physical activity. Activity pacing was identified as a promising solution
37 and participants recommended several strategies for future consideration.

38 **Conclusions:** Participants identified fatigue as a significant denominator in daily living and
39 recognized the importance of activity pacing in fatigue management. Through reflective
40 processes, they uncovered crucial factors for effective fatigue management, highlighting a
41 multidimensional, interdisciplinary, and tailored approach to activity pacing as a promising
42 solution. Further research should explore clinicians' perspectives of a multidimensional fatigue
43 management approach to further support optimal intervention design.

44 Implications For Rehabilitation

- 45 • Fatigue was perceived commonly across various chronic conditions, extending beyond
46 mere tiredness and diminishing individuals' capacity to perform daily activities.

- 47 • Rehabilitation professionals might incorporate activity pacing strategies tailored to each
48 individual's needs to effectively manage fatigue across chronic conditions.
- 49 • A multidimensional approach, including physical, psychological, and social interventions,
50 is suggested for comprehensive fatigue management in rehabilitation.
- 51 • Facilitating rest and fostering a supportive social environment might be integral
52 components of rehabilitation process to enhance the effectiveness of fatigue management

53 **Keywords:** fatigue, physical activity, chronic disease, rest, social support

54

55 **Introduction**

56 Living with chronic conditions profoundly impacts daily life, with fatigue as a common and
57 debilitating symptom(1). Fatigue is associated with decreased health-related quality of life
58 (HRQoL), functional limitations, depression, and reduced physical activity(PA)(2). Notably, it
59 significantly affects social life, leisure, and work participation in chronic conditions(3,4). Despite
60 being a common symptom across chronic conditions, research often focuses on fatigue-per-
61 condition, overlooking comorbidity (individuals with multiple conditions)(1); therefore, the
62 effectiveness of specific interventions in isolation can be limited. Although, current research
63 targets fatigue and its associated factors as specific to individual chronic diseases, it is possible
64 that these factors are generic and consistent across various chronic conditions(5). Thus, adopting
65 a transdiagnostic approach to study fatigue across chronic conditions can provide insights for
66 effective management strategies and could address common mechanisms(5). This valuable
67 approach emphasizes the importance of symptom-dependency and disease-independency(6),
68 identifying common underlying causes that contribute to fatigue across various conditions.
69 Understanding these common factors can lead to the development of interventions that are
70 broadly applicable(5,7). Moreover, a transdiagnostic approach could enhance treatment

71 efficiency by targeting symptoms that are prevalent across various conditions(5), which is
72 particularly valuable when underlying causes remain undetermined or poorly understood.
73 However, compared to the traditional condition-specific approach, a transdiagnostic approach
74 might present challenges, particularly in the complexity of designing such interventions. This
75 would require robust methodologies and comprehensive understanding of the multidimensionality
76 of fatigue to ensure that such interventions can be efficient and effective. While transdiagnostic
77 approaches have shown promise in addressing mental health disorders(8), limited evidence
78 exists for their application in fatigue management(6,9,10). Given fatigue's substantial burden,
79 developing optimal management strategies is imperative to enhance HRQoL in chronic
80 conditions.

81 Fatigue management interventions can be categorized into three groups: exercise,
82 psychological/behavioural, and educational(11). Strong evidence supports the use of both
83 exercise-based interventions and cognitive-behavioural therapy for alleviating fatigue in chronic
84 conditions(6,11,12). For example, a systematic review of randomised control trials demonstrated
85 that physical activity interventions are moderately effective in reducing fatigue among adults with
86 chronic conditions(6). Similarly, another review found that moderate-intensity exercise training
87 programs lead to small-to-moderate improvements in fatigue and energy levels in chronic
88 conditions(13). Psychological/behavioural interventions, such as cognitive-behavioural therapy,
89 have also demonstrated benefits. Reviews have reported positive effects on fatigue reductions in
90 individuals with multiple sclerosis and cancer survivors following psychological/behavioural
91 interventions(14,15). Educational interventions have shown promise as well. One study found that
92 an educational intervention significantly reduced fatigue and increased increasing activities of
93 daily living in patient with systemic lupus erythematosus(16). However, the evidence base for
94 these intervention categories remain mixed. A review investigating the impact of exercise,
95 rehabilitation, and behavioural interventions on fatigue in multiple sclerosis reported inconclusive

96 results(17). Therefore, further research should be done for the development of interventions
97 targeting alleviating fatigue and enhancing HRQoL in chronic conditions. This inconsistency
98 highlights the need for further research to develop and refine interventions tailored to fatigue
99 management and enhancement of HRQoL in chronic conditions.

100 Clinical guidelines advocate for incorporating PA into daily routines, recognizing its potential to
101 enhance overall health(18). While PA encompasses all movement, including incidental activities
102 like walking to the store, exercise is a subset of PA and refers to structured and planned physical
103 activity with the goal of improving fitness(19). Despite the benefits of PA(20), sustaining
104 engagement is challenging in chronic conditions. High-intensity exercise, may lead to adverse
105 physical and affective responses, potentially causing a “crash” and exercise fear-
106 avoidance(21,22). Reviews have demonstrated that cognitive-behavioural therapy and
107 psychoeducation are beneficial for improving exercise and movement fear avoidance and self-
108 efficacy across various chronic conditions(23–25). Relatedly, behavioural activation, an approach
109 of activity scheduling in mental health treatment, aims to enhance psychological well-being by
110 promoting increased engagement in valued and enjoyable activities and ultimately alleviating
111 fatigue(26,27). Moreover, activity pacing (AP), such as breaking down tasks and resting, could
112 enhance daily activity participation, alleviate fatigue, improve function, and reduce
113 disability(28,29). Activity pacing involves strategically managing all forms of physical activity,
114 including both structured exercise and daily activities, to help individuals with fatigue maintain a
115 sustainable level of engagement. In the realm of fatigue management and overarching goal of
116 enhancing the HRQoL, a recent conceptual model highlights the multidimensionality of AP(10). It
117 emphasizes physiological, psychological, and environmental factors in disease management,
118 promoting sustained PA and alleviating fatigue. Therefore, understanding these factors is crucial
119 for an AP multidimensional fatigue management approach.

120 The development of a multidimensional intervention to enhance HRQoL requires patient
121 engagement as it is crucial for quality care(30). First, it is important to derive insights from patients'
122 experiences, forming a contextual foundation for interventions and deepening the understanding
123 of fatigue, its impact on daily life, and patients' needs(31). Those who have undergone fatigue
124 management programs can provide insights into lacking aspects or favorable elements. Similarly,
125 individuals experiencing fatigue but not participating in such programs could offer perspectives
126 on their daily experiences and unmet needs. To our knowledge, three studies have interviewed
127 adults with chronic conditions on their AP views(32–34). Individuals with chronic conditions
128 identified AP as a multidimensional strategy involving task breakdown, planning, prioritizing, and
129 goal-setting, helping alleviate symptoms(32). Individuals with rheumatic disease reported
130 requiring AP to self-manage daily life(33). Stroke survivors expressed the need for AP instruction
131 to manage fatigue and sustain PA in the long-term(34). Cross-sectional findings suggested that
132 without AP interventions, people with chronic conditions lack a clear strategy to manage fatigue
133 and enhance PA and HRQoL(35–37), linking the potential inappropriate use of AP as a response
134 to fatigue instead of anticipating it, to low PA levels(37). These findings offer initial insights, but
135 further evidence is essential for developing optimal AP interventions in chronic conditions.

136 Given the early promise and importance of a transdiagnostic approach to fatigue, its
137 multidimensionality, and the potential of AP, this interview study aims to explore in-depth the
138 experiences of fatigue and its management, including the role of AP amongst adults with chronic
139 conditions. We sought to gain insight into how these individuals experience fatigue and its daily
140 impact. Our primary objective was to gain a comprehensive understanding of the multidimensional
141 aspects of fatigue management. This aids in better supporting the design of an optimal AP
142 intervention to enhance HRQoL through promoting sustained PA engagement and alleviating
143 fatigue.

144 **Methods**

145 **Ethical approval and informed consent**

146 Ethical approval was obtained from the HRA and Health and Care Research Wales REC 4 (IRAS
147 ID: 313465) and Northumbria University's Ethics Board (reference number: 3396). Participants
148 received verbal and written information regarding study purposes, and procedures, and provided
149 written informed consent prior to participation. This study reports based on the criteria of the
150 Consolidated Criteria for Reporting Qualitative Studies(38).

151 **Participants**

152 A constructivist approach was used in this qualitative study, which aimed to further understand
153 experiences, thoughts, and perceptions on AP, fatigue management, and PA among adults with
154 chronic conditions who experience fatigue. Two sub-groups of adults with chronic conditions were
155 recruited: 1) individuals who had received fatigue management advice and 2) individuals who had
156 not received such advice. This approach was used to explore a broad range of experiences,
157 perspectives, and ideas. Group 1 participants were recruited either from an NHS clinic
158 specializing in fatigue management or from the community via social media groups and condition
159 support groups. Group 2 participants were recruited the same way either from the waiting lists of
160 the NHS clinic or from the community. It is important to note that participants from the two sub-
161 groups did not differ in any other way; aside from whether they had received fatigue management
162 advice or not. Purposive sampling was used to ensure a heterogeneous sample based solely on
163 the presence or absence of such advice.

164 **Procedure**

165 Participants recruited from the NHS clinic were provided with an information sheet by the
166 clinicians and if they were interested, they contacted the first author via email. Participants were
167 recruited from the community through relevant social media groups and the university (including
168 students and staff). The study advertisement was shared, and they were directed to an online

169 information sheet. If they indicated interest, they emailed the first author and received more
170 information with a consent form. A convenient time and date for the participant was scheduled.
171 Participation was voluntary and uncompensated.

172 **Data collection**

173 The interviews were conducted by the first author, a female PhD candidate in public health with
174 prior experience and training in conducting interviews. The author had limited interactions with
175 the participants via email before the interviews. The participants were informed that the
176 interviewer was a PhD researcher and that this project was part of a PhD research project.
177 Throughout the interviews, the interviewer made field notes, both during and after the sessions.
178 Only the interviewer and the participant were present during the interview. Data collection took
179 place from June 2023 until July 2023. All interviews were conducted using the Microsoft Teams
180 platform.

181 Demographic characteristics of the participants were collected virtually via an online
182 demographic's questionnaire. These characteristics, all self-reported (no formal diagnosis
183 confirmation was requested), included age, biological sex, employment status, marital status,
184 chronic condition(s), years of experiencing fatigue, and whether or not they had received fatigue
185 management advice.

186 Fatigue severity was also measured using the Fatigue Severity Scale (FSS) questionnaire(39),
187 which ranges from 1-7 (1= completely disagree; 7= completely agree) and is considered a valid
188 and reliable measurement to determine the impact of fatigue in several patient populations(40–
189 42). A higher score indicates greater fatigue severity, while a score of 4 or greater indicates severe
190 fatigue.

191 **Interview guide**

192 Before data collection, a semi-structured interview guide was developed by the first author, which
 193 included questions to all participants as well as specific questions to each group [individuals who
 194 have received fatigue management (group 1) and those who have not (group 2)]. The interview
 195 guide was not pilot tested and it was developed in consultation with all co-authors following the
 196 project aims based on the knowledge gaps from previous studies on the AP concept(9,10,32). It
 197 was also informed by team members' experiences in undertaking research and practice in clinical
 198 settings (KLH), including fatigue management. The interview guide was also refined in
 199 collaboration with a health psychologist who provided feedback on the structure, interpretation,
 200 and wording of the questions. The semi-structured interviews included open-ended questions,
 201 allowing for the exploration of themes as they arose during the interview. See Table 1 for the
 202 topics covered in the interview.

203 Table 1. Topics covered in the interviews

Questions for all participants	
<ul style="list-style-type: none"> • How would you describe fatigue? • When do you experience fatigue the most? • How do you deal with fatigue? • What are some factors that impact you from pacing your activities during the day? • Does your fatigue impact your physical activity? • How do you plan your activities? • Do you experience any stress/anxiety/depression feelings? • What strategies would you like to be considered in an activity pacing program? 	
Questions specific to each group	
Group 1*	Group 2**
<ul style="list-style-type: none"> • How has activity pacing helped you? • What is the value of activity pacing? 	<ul style="list-style-type: none"> • Do you think activity pacing would be beneficial?

204 *Individuals who have received fatigue management advice, ** individuals who have not received
 205 such advice

206 **Data Analysis**

207 Interviews were audio-recorded with participants' permission, transcribed verbatim automatically
 208 by Microsoft Teams, and were accuracy-checked by the first author. Transcripts were anonymized
 209 for analysis to ensure any personal information was excluded and were not returned to

210 participants for comment or correction. Data were analyzed using reflexive thematic analysis
211 (RTA) to fit the study's exploratory objective of better understanding individuals' experiences and
212 perceptions of fatigue management and AP(43,44). A hybrid approach, incorporating both
213 deductive and inductive methodologies, was employed to harness the advantages of each. This
214 combined approach enhances our understanding of the findings within the context of existing
215 research(45). The deductive element was executed by employing pre-ordinate themes derived
216 from a multidimensional AP conceptual model(10) and relevant literature, while the inductive
217 entailed the initial generation of themes directly from the data.

218 Reflexive thematic analysis is an open-ended and flexible process, devoid of a specific
219 epistemological or ontological framework(44,46). For the current study, the researchers adopted
220 a critical realistic position, acknowledging the active participation of the research team in the study
221 process. A critical realist approach posits that although the world is knowable, there exists no
222 objective reality(47). The research team was aware of the significance of considering individual
223 experiences; therefore, this epistemological stance was chosen as it aligns adequately with the
224 investigation of participant experiences and perspectives concerning the impact of fatigue and AP
225 in daily life. This approach acknowledges that, while direct access to individuals' realities is
226 unattainable, research can provide partial insight, enabling us to make observations that may be
227 transferable to other similar circumstances(48) and inform future interventions. The research team
228 brought together diverse disciplinary and experiential perspectives that informed the study design,
229 data analysis, and interpretation. Our team included clinicians with expertise in physiotherapy
230 (cardiorespiratory rehabilitation) and occupational therapy (fatigue management), bringing
231 valuable perspectives in understanding fatigue management challenged in clinical practice
232 among chronic conditions. Non-clinical expertise covered healthcare & implementation science,
233 social and psychological sciences, human performance and behavior change, self-management
234 of chronic conditions, complex interventions, and mixed-methods research. This variety of

235 expertise allowed us to have a holistic view on both clinical practices as well as research
236 methodologies and theoretical frameworks for understanding behaviour change and intervention
237 development. Throughout the research process, we engaged in critical reflections on how the
238 team's varied perspectives and experiences shaped the interpretations and approach to the
239 research. This reflexive approach ensured that this study was informed by a comprehensive
240 understanding of the multidimensionality of fatigue and pacing in chronic conditions.

241 The analysis was supported using NVivo 12 software and followed the six-phase process outlined
242 by Braun and Clarke(43). Initially, data were collectively analyzed by the first author, using RTA.
243 Early transcripts were independently reviewed by all team members, with initial codes recorded
244 alongside the data in the transcripts. In subsequent team analysis sessions interview transcripts
245 were examined to identify key issues. Discussion and consensus building took place to assign
246 coding labels and construct an analytical map highlighting key themes and connections within the
247 data. Corresponding sub-themes were developed, with participant quotes used to finalize the
248 thematic categories. All quotes in the results section are presented verbatim/direct and descriptive
249 statistics summarise participant demographics.

250 **Results**

251 **Sample characteristics**

252 In total, fifty-two participants were invited for the interview, with fifteen of them agreeing to
253 participate in the study. Thirty-five potential participants did not respond to the invitation email and
254 two declined participation due to experiencing brain fog. No more potential participants were
255 invited when the point was reached where fewer insights were being generated from the
256 interviews and we had confidence that the dataset was sufficient to address the research aim.
257 Fifteen participants were recruited, of which twelve (80%) were females and nine (60%) had
258 received fatigue management advice. Nine participants self-reported having comorbidities, while

259 two self-reported CFS/ME, and four participants with Sjögren's syndrome, aplastic anemia,
 260 antiphospholipid syndrome, and bronchiectasis, respectively. All participants self-reported
 261 experiencing fatigue for a duration over two years. Twelve out of the fifteen participants reported
 262 significant severe fatigue (median FSS score = 5.88). The three participants who did not report
 263 severe significant fatigue, all belonged to group 2 (those who had not received fatigue
 264 management advice). The interviews took an average of 25 minutes (range 8-42 minutes).
 265 Participants' characteristics are shown in detail in table 2.

266 Table 2. Participants' characteristics at the time of the interviews

Participant (P)	Biological Sex	Age	Fatigue management advice Group 1: Received Group 2: Did not receive	Employment status	Marital Status	Chronic Condition	Experience of fatigue	Fatigue Severity Scale Score
103-P1	Female	54	1: Received advice	Part-time	Separated	CFS/ME*, Irritable bowel syndrome	Over 2 years	6.55
105-P2	Female	23	1: Received advice	Student	Single	Antiphospholipid Syndrome	Over 2 years	5.66
107-P3	Female	18	1: Received advice	Not employed	Single	CFS/ME*	Over 2 years	6.66
108-P4	Male	46	1: Received advice	Full-time	Married	Bronchiectasis	Over 2 years	6.55
111-P5	Male	31	1: Received advice	Full-time	Married	CFS/ME*	Over 2 years	5.55
112-P6	Female	52	1: Received advice	Student	Cohabiting	Aplastic Anemia	Over 2 years	6.22
115-P7	Female	56	1: Received advice	Retired	Separated	CFS/ME*, Brittle Asthma, Widespread Autonomic Failure, Restless Legs, Osteoarthritis, Postural Orthostatic Tachycardia Syndrome	Over 2 years	7.00
118-P8	Female	57	1: Received advice	Part-time	Divorced	Chronic Vertiginous Migraine, Orthostatic Headache, Postural Orthostatic Tachycardia	Over 2 years	4.22

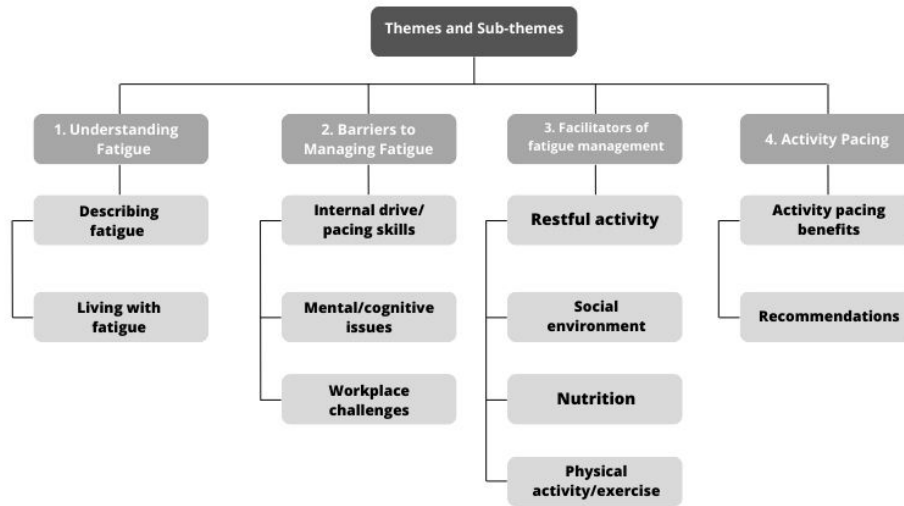
						Syndrome, Cerebrospinal Fluid Leak, CFS/ME*, Postural Orthostatic Tachycardia Syndrome		
119-P9	Male	64	1: Received advice	Retired	Married	Fibromyalgia, Cirrhotic Liver (Fatty Liver Disease), Type 2 Diabetes, CFS/ME*, Hypertension, History Of Depression	Over 2 years	6.66
302-P10	Female	35	2: Did not receive	Not employed	Married	Hypermobile Spectrum Disorder, Postural Tachycardia Syndrome, Fibromyalgia	Over 2 years	5.88
318-P11	Female	19	2: Did not receive	Student	Single	Ehlers Danlos Syndrome, Postural Orthostatic Tachycardia Syndrome, Fibromyalgia, Chronic Costochondritis, Chronic Migraine, Chronic Gastric Volvulus, Raynaud's Syndrome, Temporomandibular Disorder	Over 2 years	7.00
322-P12	Female	52	2: Did not receive	Part-time	Cohabiting	Aplastic Anaemia, CFS/ME*,	Over 2 years	5.77
324-P13	Female	65	2: Did not receive	Retired	Cohabiting	Blood Clotting Disorder, Sjögren's Syndrome	Over 2 years	3.77
325-P14	Female	28	2: Did not receive	Student	Single	Hypermobility Spectrum Disorder, Chronic Migraines	Over 2 years	2.55
330-P15	Female	60	2: Did not receive	Retired	Divorced	Sjögren's syndrome	Over 2 years	3.11

267 *Chronic fatigue syndrome/Myalgic encephalomyelitis

268 **Themes**

269 Data analysis resulted in identifying four main themes and eleven sub-themes (figure 1);

270 additional supporting quotes can be found in Supplementary Table 1.



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280 Figure 1. Thematic Themes and Sub-themes

281 **Theme 1 – Understanding Fatigue**

282 Participants described their fatigue and experiences of living with it. This theme provides a
 283 concise overview of common key perceptions of fatigue transdiagnostically across various chronic
 284 conditions that are well documented in the literature, though usually separately for specific
 285 conditions. This was expressed through two sub-themes: (1) describing fatigue and (2) living with
 286 fatigue.

287 **Describing fatigue**

288 All participants similarly articulated their experiences of fatigue, using common language. The
 289 experience of fatigue was commonly characterized as extending beyond tiredness and
 290 diminishing the capacity to perform activities while a participant described fatigue as a “complete
 291 drain of energy...very different to being tired. It's like somebody stuck a syringe in you and sucked
 292 all the energy out”(P1). Some participants described fatigue as an “almost invisible condition”(P5),
 293 acknowledging that it is frequently overlooked.

294 **Living with fatigue**

295 Participants expressed the impact of fatigue in their lives by explaining that their lives have
296 significantly changed due to the fatigue. One participant said that the “fatigue has shrunk his
297 world”(P9). Some also mentioned feeling isolated at home, identifying fatigue as a key challenge
298 for their daily lives not just during the activity, but also after. One participant mentioned that if she
299 goes out of the house for any activity “I do know if I go out anywhere and do anything the next
300 day, I'll know about it”(P15). Additionally, several participants said that they experience fatigue
301 the most when they do not pace, highlighting pacing as a strategy for managing fatigue. Some
302 participants also explained the importance of accepting fatigue to slowly build up from it.

303 **Theme 2- Barriers to Managing Fatigue**

304 The management of fatigue in everyday life captured three important barriers that prevented
305 participants from effectively managing their fatigue. This was conveyed through three sub-
306 themes: (1) internal drive/pacing skills, (2) mental/cognitive issues, and (3) workplace challenges.

307 Internal drive/pacing skills

308 Some participants reported a tendency to exceed their limits when doing an activity, leading to
309 exacerbation of fatigue. One participant said, “The fatigue was so bad because I've done too
310 much”(P7). Another participant was experiencing difficulties slowing down and said “I just need
311 to learn to slow down, can't I? Can't do it. I'm finding it very hard to slow down”(P13). Others
312 explained that it is hard to stop an activity once initiated because they enjoy doing the activity
313 while others experience feelings of guilt if they slow down during the day.

314 Mental/Cognitive issues

315 Most participants articulated the prominence of mental and cognitive challenges. Participants
316 mentioned anxiety as a primary concern stemming from fatigue. More specifically, many
317 expressed anxiety when they are outside of their house as they fear that if fatigue occurs at that
318 time and they feel bad and crash, they will be stuck. One participant said, “You get to point where

319 you're anxious to leave the house because you think you're not gonna get back”(P1). This anxiety
320 limits them and makes them cautious about doing things even taking their dogs on a walk as
321 another participant explained.

322 Likewise, some participants associated stress with fatigue, noting its energy-draining effect.
323 Furthermore, several participants pointed to brain fog as a prominent symptom going along with
324 fatigue. Participants explained that some days brain fog is bad that they cannot have
325 conversations, find the right words, remember names or things. It prompts them in general, to
326 think slower.

327 Workplace challenges

328 Some participants identified significant impediments to effective management, specifically
329 attributing challenges to the workplace environment. Some articulated that the demands of their
330 work depleted their energy levels and made them more fatigued, and, in some cases, it was not
331 possible to keep the work up resulting in giving up their jobs or opting for early retirement. One
332 participant explained: “I lost my job, and I was off for good”(P8).

333 **Theme 3- Facilitators of fatigue management**

334 The participants delineated a range of factors that augment their approach to fatigue management
335 and, by extension, contribute positively to their HRQoL. This overarching theme describes four
336 sub-themes: (1) restful activity, (2) social environment, (3) nutrition, and (4) PA/exercise.

337 Restful activity

338 Rest was perceived as a way of managing fatigue by most participants. Many participants
339 explained that they incorporate frequent rest breaks throughout the day as a beneficial way of
340 fatigue management, considering rest as an integral component of a pacing strategy. However,
341 some participants emphasized their reluctance to engage in prolonged periods of rest, expressing

342 that extended inactivity tends to worsen fatigue. Therefore, many participants articulated the
343 usefulness of engaging in restful and mindfulness activities. A participant mentioned, “I know it’s
344 very important to find relaxing time basically and trying do like meditation like very restful
345 stuff”(P2). Besides meditation, relaxation exercises were also mentioned as a restful activity and
346 a helpful way of promoting calmness and mitigating the daily impact of fatigue.

347 Social environment

348 The participants described the impact of their social environment on fatigue management and
349 effective pacing, reporting diverse and conflicting experiences. Some participants described
350 receiving support from close family and friends recognizing their effort to understand fatigue “My
351 husband is very supportive. And my mom is starting to understand”(P10). Conversely, others
352 highlighted challenges in garnering understanding from their social circles “Sometimes people
353 just don’t get it and they just don’t understand”(P12), particularly when individuals lacked personal
354 experience with fatigue. Experiences were reported by a few participants where friends failed to
355 comprehend the experience of fatigue, leading to the perception of laziness in cases of non-
356 participation in certain activities. Notably, age emerged as a variable influencing the
357 comprehension of fatigue, with a few older participants expressing a greater sense of
358 understanding amongst their similar-aged peers. In contrast, younger participants faced
359 challenges in fostering empathy, as friends could not relate to their fatigue experience.

360 Nutrition

361 Several participants emphasized the significance of a healthy diet in their well-being and reported
362 improvements in how they felt. A participant said “I know that diet is a really big part. I’ve found it
363 very helpful”(P4). Another participant described how a healthy balanced diet and eating different
364 types of foods from every nutrition group specifically many fruits and vegetables and drinking
365 water have helped her with her energy levels and managing fatigue. Another participant explained

366 that slow-card diet and the FODMAP (Fermentable Oligosaccharides, Disaccharides,
367 Monosaccharides, and Polyols) are ways of trying to manage fatigue more effectively. Overall,
368 participants mentioned they changed their diet after conducting online research on fatigue to try
369 and improve overall health and effective condition management.

370 Physical activity/Exercise

371 The participants had diverse experiences with PA and/or exercise. Some individuals underscored
372 the importance of exercise for managing chronic conditions, noting that it contributed to an
373 improved overall sense of well-being. For instance, one participant observed an improvement in
374 energy levels and brain fog symptoms, remembering a bit more, after starting a gym-based
375 exercise routine. Another participant mentioned that cycling makes her feel great and she loves
376 the fact that she can push herself and increase her distance every time while she does not feel
377 so fatigued afterwards “I feel great. I absolutely love it. I feel great after I've done it and I'm so
378 glad that my partner introduced me to cycling... I can push myself further and I don't feel so
379 fatigued after”(P13). A further participant described some different exercises that have slowly
380 improved his fatigue including nerve gliding and stretching exercises, yoga poses, and a light
381 strengthening program. Other specific activities such as core exercises and Pilates were cited as
382 beneficial by some participants. Conversely, other participants mentioned that the day after the
383 gym is the worst regarding fatigue or that they know that after a walk or any house chore, they
384 will suffer from fatigue and pain. A participant specifically said, “Any kind of exercise or anything
385 like that just completely knocks me out, causing me a lot of pain”(P3). Notably, another participant
386 mentioned yoga as an exhausting activity.

387 **Theme 4- Activity Pacing**

388 Many participants elaborated on the benefits of incorporating AP as an approach to fatigue
389 management. One participant explained his frustration that all research is on pacing and fatigue

390 management but nothing on supplements or vitamins that could boost energy levels or
391 pathophysiology of fatigue. Based on their experiences, participants articulated recommendations
392 for key components necessary for an optimal pacing intervention. This thematic analysis yielded
393 the development of two sub-themes: (1) AP benefits and (2) recommendations.

394 Activity pacing benefits

395 Most participants elucidated AP as a conscious strategy for achieving more during the day. Those
396 without AP advice expressed a belief that pacing advice from professionals could potentially help
397 them with doing more on regular basis. A participant specifically said “Activity pacing I think will
398 allow me to get my life back to a point where it’s enjoyable and not anxiety driven and not having
399 to cut things out”(P12). However, some participants were familiar with pacing from researching
400 online and described that they incorporated it in some form. Similarly, participants who had
401 received fatigue management advice from pacing and fatigue management clinics conveyed a
402 positive impact, attributing significant help in managing fatigue symptoms and daily
403 responsibilities through pacing. A participant mentioned “It (AP) can control it (fatigue) more than
404 anything else”(P9). However, a few participants expressed sentiments of constraint,
405 acknowledging the necessity of pacing whereas they would prefer to have a normal life without
406 having to think about pacing.

407 Recommendations

408 Participants described several important approaches that they deemed imperative for inclusion in
409 a pacing intervention. Specifically, most participants emphasized the significance of a
410 multidimensional approach and the implementation of tailored pacing approaches to address the
411 diverse needs of individuals “It (a pacing intervention) needs a multidimensional team definitely.
412 You need specialists in each different area to work in a team with their evaluation of a patient to
413 develop a good plan for fatigue management”(P6). Some participants highlighted the benefits

414 derived from healthcare professionals, including occupational therapists, physiotherapists, and
415 psychological support. Furthermore, a few participants reported the importance of sleep therapy
416 as sleep problems are a major issue and dietary advice for future interventions. Additionally, most
417 participants expressed a desire for group support, seeking a sense of community for sharing
418 feelings, experiences, and practical tips. Also, several participants endorsed the practice of
419 maintaining a diary as a valuable management strategy, aiding in daily planning and prioritization.

420 **Discussion**

421 This qualitative study provides insights into patients' perspectives on the impact of fatigue on daily
422 life and explores the potential of developing AP as an effective fatigue management approach for
423 adults with chronic conditions. The findings significantly contribute to multidimensional guidance
424 on fatigue management. Our interviews analysis showed that participants share similar
425 experiences of fatigue impact in daily life, leading to a diminished capacity to perform activities.
426 Divergent experiences were reported in social support and PA, but many found value in using AP
427 to manage fatigue effectively, emphasizing its multidimensional importance.

428 This study adopted a transdiagnostic approach, interviewing adults with various chronic
429 conditions, either having received or not having receive fatigue management advice. A key finding
430 was that all participants perceived fatigue similarly, describing it as energy-draining, invisible, and
431 distinct from tiredness, significantly impacting their lives. While prior studies focused on specific
432 conditions like rheumatoid arthritis, chronic heart failure, and chronic obstructive pulmonary
433 disease(49–51), our findings align with and underscore that fatigue is pervasive across diverse
434 chronic conditions(1). Low perceived fatigue has been associated with enhanced HRQoL in
435 chronic conditions(52). The implication is that transdiagnostic fatigue management could
436 potentially enhance HRQoL, particularly in situations where the root condition's causes are
437 unknown(6,10).

438 Participants identified various pacing-related barriers hindering effective fatigue management
439 throughout the day, including a tendency to overexert themselves in activities, leading to
440 heightened fatigue later and prolonged rest. Overactivity, contributing to a boom-and-bust cycle,
441 is recognized in adults experiencing fatigue(10,28,53). A cross-sectional study found that low PA
442 levels were associated with higher engagement in pacing, suggesting that individuals with multiple
443 sclerosis with low PA levels and unfamiliar with pacing advice may inappropriately use AP(37),
444 which could lead to such overactivity/underactivity responses. Targeting self-regulation and
445 promoting small personal goals, as previously reported by patients with multiple sclerosis and
446 stroke survivors(54,55), could prove valuable for managing fatigue through AP, lessening
447 overactivity. Goal-directed AP interventions are also suggested to improve sustained PA
448 engagement(35). A tailored AP approach is discussed in the literature as potentially beneficial for
449 avoiding overactivity and underactivity, along with developing a measure to detect such
450 activities(28). This could provide valuable insights to tailor AP interventions. Overall, the reported
451 behaviours in this study underscore the significance of AP. Implementing an effective pacing
452 strategy could enhance daily productivity in chronic conditions

453 Anxiety, a key issue identified by participants, aligns with the literature's high prevalence of
454 anxiety, stress, and depression in chronic conditions(56). Anxiety may act as a barrier to engaging
455 in activities outside the home, fearing sudden and significant fatigue, hindering their return as
456 reported. Therefore, psychological support is vital for mental health in fatigue management.
457 Furthermore, finding a balance between work, rest, and daily responsibilities proved challenging
458 for many participants, especially considering the exacerbation of fatigue symptoms by a heavy
459 workload. They often encounter problems in obtaining and maintaining employment(57),
460 potentially leading to reduced work prospects and job loss, as mentioned by some participants.
461 Recognizing the vital role of employment in well-being(58), further research and policy
462 implications are essential to support these individuals in the workplace. Overall, reported barriers

463 emphasize the need for a multidimensional approach to effective fatigue management.
464 Implementing appropriate pacing in chronic conditions could mitigate fatigue and psychological
465 distress, enhancing physical functions and potentially fostering sustained engagement in PA.

466 Furthermore, participants highlighted the significance of incorporating rest breaks and engaging
467 in restful activities like meditation, or PA such as Pilates or yoga, as part of AP. Although not
468 specified in much detail, literature acknowledges rest as a component in the multidimensional AP
469 conceptual model(10). Tailoring rest breaks in AP, considering individuals' needs and preferences
470 for duration and type (active or passive), can potentially enhance HRQoL. Rest is vital for
471 individuals with chronic conditions, aiding stress reduction and addressing sleep issues(10). It
472 should be an integral aspect of AP, contributing to more effective pacing behaviour. Participants
473 also emphasized the impact of the social environment on effective fatigue management.
474 Consistent with prior studies in chronic conditions, this suggests that intervention strategies
475 should encompass the social environment(59), involving partners, family members, and friends,
476 crucial for disease management(60,61). Involving them in behaviour change interventions is
477 important(59) for enhancing their understanding of fatigue. Also, the social impact of exercise can
478 influence motivation and self-efficacy, inspiring sustained PA in chronic conditions(62). The social
479 environment's role in pacing is acknowledged and discussed in sport and exercise context(63)
480 but healthcare literature lacks a comprehensive discussion(10). Examining social support within
481 an AP framework may provide valuable insights into its impact on HRQoL and pacing behaviour
482 in chronic conditions.

483 Many participants emphasized the importance of a healthy diet in disease management.
484 Appropriate energy intake may assist individuals with chronic conditions in effectively pacing their
485 activities and achieving more. Therefore, nutrition guidance could play a central role in fatigue
486 management interventions(64). Literature also highlights the benefits of PA in mitigating
487 fatigue(6). Studies on exercise experiences in chronic conditions reveal participants' appreciation

488 for the enjoyment and social benefits of group exercise(65,66). Our findings align with these
489 results, emphasizing the significance of engaging in group exercise for managing fatigue,
490 potentially improving both physical and psychological aspects. Moreover, stroke survivors with
491 high PA levels have reported low perceived fatigue and risk of overactivity(67); while a PA lifestyle
492 was associated with low perceived fatigue(67). Variations in PA experiences are anticipated due
493 to condition-related limitations, potentially leading to negative affective responses and
494 underactivity. These Individuals tend to be less active due to limitations related to their conditions
495 as it could cause them significant fatigue and pain. Conflicting experiences regarding exercise
496 support have been documented in literature(66). Considering the advantages of PA, individuals
497 with chronic conditions need guidance and support from healthcare professionals for PA
498 participation. They should recommend tailored PA/exercises based on individual's capabilities,
499 needs, and goals to avoid worsening symptoms. Self-regulation is important in managing fatigue
500 through both PA and exercise as a subset of PA(19). Whether individuals with chronic conditions
501 engage in daily tasks like cleaning or participating in a structured exercise like Pilates, the ability
502 to regulate and plan the efforts is essential. By integrating education on activity pacing into both
503 PA and exercise programs, individuals might better manage their fatigue and improve their ability
504 to cope with daily life demands. Thus, activity pacing is not restricted to the context of structured
505 exercise but includes all activities throughout the day. Further research is needed to determine
506 the most effective types of PA/exercise for fatigue management(6).

507 Activity pacing was perceived as a valuable fatigue management strategy, to alleviate fatigue and
508 enhance daily productivity, aligning with prior studies(34,54) and addressing reported fatigue
509 barriers. While some view it as a forced practice, consistent with prior study on chronic obstructive
510 pulmonary disease(68), its inherent value was recognized. Psychological support can foster
511 acceptance of a new lifestyle among individuals with chronic conditions, diminishing the
512 perception of AP as an obligatory task and positioning it as a beneficial lifestyle adjustment,

513 potentially improving overall HRQoL. Moreover, participants provided suggestions aligned with
514 fatigue management, addressing barriers, and sharing personal AP strategies. They underscore
515 the importance of a multidimensional and tailored AP approach, offering recommendations for
516 physical, functional, emotional, and mental well-being. This highlights the need for a collaborative,
517 interdisciplinary approach to fatigue management. Specifically, various health professionals,
518 including physicians, physiotherapists, occupational therapist, (clinical and health) psychologists,
519 sleep therapists, and nutritionists can play a key role in holistically supporting individuals with
520 fatigue and physical activity promotion. The recent Delphi-based consensus guidelines also
521 highlight essential competencies for all health professionals in movement behavior change
522 support(69) along with the integration of physical activity promotion into routine clinical practice,
523 as advocated by the World Health Organization's Global Action Plan on Physical Activity(70). By
524 embracing these competencies and collaborating effectively, healthcare teams can provide
525 tailored and comprehensive movement behavior change and efficient fatigue management
526 support to individuals experiencing fatigue and ultimately enhance their HRQoL. Our findings
527 contribute to refining AP models and frameworks for fatigue management practice. Further
528 research is recommended to explore the feasibility and effectiveness of multidimensional and
529 interdisciplinary interventions in chronic conditions.

530 **Strengths and limitations**

531 The sample's diversity enhances the transferability of findings to various clinical settings. As we
532 recruited from clinical and community settings, there is transdiagnostically representation from
533 adults with various chronic conditions. This is important, as many studies exploring fatigue and
534 AP in chronic conditions focus exclusively on one condition, despite knowledge that fatigue is a
535 common symptom across chronic conditions(1). Our sample is also demographically diverse in
536 age, employment status, and marital status. Furthermore, the richness of the data obtained from
537 these semi-structured interviews with participants and by the interviewer's in-depth understanding

538 of the course and their immersion within the study, both of which add depth and breadth to the
539 feasibility data, supports credibility. Additionally, in this study, all participants identified fatigue
540 similarly, which adds to the confirmability of the findings by ensuring that the results reflect the
541 participants' experiences rather than the researchers' biases. This approach facilitates broader
542 application in treating symptoms, even when causes are unknown. Moreover, exploring patients'
543 perspectives as a first step may facilitate the identification of key themes to be considered by
544 health professionals in delivering future care and support.

545 The limitations included that the sample consisted of more females. Despite the study recruiting
546 for both females and males, most of the sample was females. Considering research suggests that
547 conditions with fatigue as a symptom have a female preponderance(71), this may not be
548 surprising; however, it would still be interesting for future qualitative research to explore both
549 females' and males' experiences of fatigue and AP and identify any similarities or differences
550 between the groups and enhance the confirmability of findings across genders. Moreover, while
551 common barriers and facilitators to managing fatigue were identified across the diverse sample,
552 it is essential to recognize that these generalizations may not capture the unique experiences of
553 every individual. The diversity of the sample underscores the need for a tailored approach in
554 clinical practice. Healthcare providers should be receptive to exploring and addressing individual
555 patients' specific barriers and facilitators. This personalized approach is necessary to effectively
556 meet the unique needs of each patient, despite the presence of overarching themes identified in
557 this study.

558 **Implications for Rehabilitation**

559 The importance of fatigue as a common and debilitating symptom beyond specific chronic
560 conditions is often overlooked. This study emphasizes the critical need for a tailored,
561 multidimensional and interdisciplinary approach to AP across chronic conditions, recognizing
562 diverse factors influencing fatigue management and individuals' needs. Encouraging

563 collaboration between healthcare professionals, patients, and their social environment is essential
564 to enhance overall well-being. To translate insights into healthcare improvements, research
565 should explore integrating targeted AP interventions, potentially involving tailored programs for
566 fatigue management, and developing knowledge on rest and to better understand social
567 environment in chronic conditions. Additionally, clinicians are encouraged to use these results for
568 meaningful discussions with colleagues and patients, fostering a collaborative disease
569 management approach. Further research is advised to explore healthcare professionals'
570 perspectives on AP and fatigue management for effective intervention development tailored to
571 individuals' needs.

572 **Conclusion**

573 This study explored fatigue experiences and management in chronic conditions, emphasizing the
574 role of AP. Participants recognized AP's importance in fatigue management. They uncovered
575 crucial factors, highlighting a multidimensional and tailored approach to AP as a promising
576 solution to fatigue management. The findings have potential implications in healthcare practice
577 and research, particularly for clinicians adopting multidimensional and collaborative
578 interdisciplinary approaches to fatigue management. Future research should explore clinicians'
579 perspectives on multidimensional fatigue management, further informing the development of an
580 AP intervention.

581 **Acknowledgements**

582 This work was supported by Economic and Social Research Council funded NINE Doctoral
583 Training Partnership (grant number: ES/P000762/1). The authors greatly appreciate the time
584 given by those who took part in the interviews and the health psychologist (Prof. Vincent Deary)
585 who helped us with the interview guide.

586 **Declaration of interest**

587 The authors report there are no competing interests to declare.

588 **Data availability statement**

589 The datasets generated during and/or analyzed during the current study are not publicly available
590 due to the qualitative transcripts data are confidential, contain personal and sensitive information
591 and thus are potentially person identifiable; the removal of all contextual data as necessary to
592 protect participants' identities makes the transcripts unintelligible. Consent has not been obtained
593 to share this data in a public forum.

594 **Funding**

595 This work was supported by the Economic and Social Research Council funded NINE Doctoral
596 Training Partnership (grant number: ES/P000762/1).

597 **Contributions**

598 Conceptualization: IB, KLH, FJH, TF; Methodology: IB, KLH, FJH, TF; Analysis: IB, KLH, FJH,
599 TF; Writing-Original Draft: IB; Writing-Review and Editing and final approval: IB, KLH, FJH, USA,
600 TF

601 **Declaration of Generative AI and AI-assisted technologies in the writing process**

602 During the preparation of this work, the author(s) used ChatGPT in order to improve the language
603 and readability of the manuscript. After using this tool, the author(s) reviewed and edited the
604 content as needed and take(s) full responsibility for the content of the publication.

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