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RESEARCH ARTICLE

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"Rest recharges my energy"; experiences and perceptions of rest in adults with long-term conditions and fatigue in rehabilitation: a qualitative study

Martin Ackah[a], Vincent Deary[b], Ulric S. Abonie[a], Florentina Johanna Hettinga[a,c] and Katie L. Hackett[d]

[a]Department of Sport Exercise and Rehabilitation, Northumbria University, Newcastle upon Tyne, UK; [b]Department of Psychology, Northumbria University, Newcastle upon Tyne, UK; [c]Department of Human Movement Sciences, Vrije Universiteit Amsterdam, Amsterdam, The Netherlands; [d]Department of Social Work, Education and Community Wellbeing, Northumbria University, Newcastle upon Tyne, UK

ABSTRACT

Purpose: To explore and understand the experiences and perceptions of rest among adults experiencing fatigue alongside a long-term condition (LTC) and healthcare professionals (HCPs).

Methods: This qualitative study used convenience and snowball sampling. Semi-structured interviews were conducted with 23 adults with LTCs experiencing fatigue and four HCPs. Data were audio-recorded, transcribed, and analysed using thematic analysis with inductive approach.

Results: Four themes were identified: (1) operationalisation of rest, (2) rest as a practiced skill, (3) rest as a tool for optimising functioning, and (4) barriers. Both participants with lived experience and HCPs viewed rest as reducing activities, connecting with nature, and disengaging from responsibilities. Both groups valued rest for managing energy, symptoms, and activities. Barriers included impact of expectations on persons with LTC, environmental, and interpersonal factors, as well as responsibilities and lack of resting skills. Lived-experience participants noted physical symptoms, while HCPs highlighted "all-or-nothing" thinking as a significant barrier

Conclusion: Rest in chronic fatigue management involved reducing activity, restorative practices, connecting with nature, and disengaging from responsibilities. Identifying truly restorative activities was challenging. Both adults with LTC and HCPs recognised effective rest as a strategic tool for energy management, symptom control, and activity participation.

IMPLICATION FOR REHABILITATION

- Rest is an important component for effectively managing fatigue and optimising activity levels in rehabilitation.
- Rest is a skill that requires practice and experimentation and viewing it as restorative rather than merely inactivity can help patients embrace it as a valuable tool for well-being in rehabilitation.
- Our findings highlight the need to prioritise restorative rest alongside physical activity in fatigue management and interventions like activity pacing.

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Fatigue; long-term conditions; healthcare professionals; rest; qualitative study

Introduction

Fatigue is a prevalent symptom associated with adults with long-term conditions (LTCs) such as multiple sclerosis, rheumatological conditions, long COVID, and stroke [1–5]. Recent systematic reviews and population-based surveys estimate the prevalence of fatigue in adults with LTCs to range from 25% to 78% [1–4,6]. Fatigue is associated with adverse effects on physical and mental health, contributing to limitations in daily activities, reduced quality of life, increased risk of mortality [7–9] and important predictor of healthcare utilisation [10,11]. Despite the debilitating symptoms of fatigue, a systematic review of clinical guidelines and fatigue management interventions identified limited recommendations for managing fatigue [12] and limited evidence supporting the effectiveness of pharmacological treatments in reducing fatigue in LTCs [13].

Promoting an active lifestyle and activity management may contribute to fatigue management and the prevention of further health deterioration [14,15]. Activity pacing is a potential strategy to promote an active lifestyle by reducing fatigue and enhancing physical activity in adults with LTCs [15]. This self-regulatory strategy involves for example segmenting daily activities into manageable components to prevent symptom exacerbation while supporting gradual and sustained increases in activity in rehabilitation [15–18]. Two recent systematic reviews show activity pacing may reduce fatigue in adults with LTCs [19,20], though evidence remains inconsistent [18–20]; it shows promise in reducing symptoms, increasing activity, and improving well-being [17,19,20]. Additionally, alongside distributing activities throughout the day, optimal rest is a key element in fatigue interventions like activity pacing to manage fatigue and optimise health [21,22].

CONTACT Katie L. Hackett kate.hackett@northumbria.ac.uk Department of Social Work, Education and Community Wellbeing, Northumbria University, Coach Lane Campus, Newcastle upon Tyne NE7 7XA, UK

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Rest is broadly conceptualised as a deliberate reduction in physical, cognitive, or emotional activity that supports recovery, energy conservation, and restoration of function [23,24]. It involves both passive and active strategies, including mental disengagement, low-energy activities, and opportunities for reflection, solitude, and emotional replenishment [23]. A conceptual analysis further characterises rest as a multidimensional construct with physical, mental, and spiritual dimensions [25]. Within rehabilitation contexts, rest has been increasingly recognised as a crucial element in managing fatigue and promoting overall well-being, particularly for adults living with LTCs [26]. In a productivity-driven society, rest is vital for restoring balance and supporting sustainable health practices [27,28]. It is important to highlight that rest follows a non-linear relationship with health outcomes, as both too little and too much rest can harm health [23]. However, when balanced appropriately, rest may support activity by providing periods of restoration and recovery, making it easier to facilitate daily activities and performance, a concept central to activity pacing interventions [29–35].

Despite its relevance, rest remains inconsistently operationalised, under-explored, and poorly reported in rehabilitation research, with a recent review revealing that intervention studies often describe it only in terms of physical rest, active rest, or relaxation activities [21,23]. A review further noted a lack of focused inquiry into how adults with LTCs and fatigue operationalise rest in daily life [23]. As a result, the existing literature emphasises the importance of establishing a clear understanding of rest in rehabilitation [33,36]. Moreover, various barriers may affect the operationalisation of rest and its outcomes within rehabilitation settings. These barriers may include physical, environmental, psychological as well as social factors, such as the individual's mindset or support systems [37]. Despite these challenges, the subjective experiences of key stakeholders remain underexplored in relation to the concept of rest within rehabilitation contexts. These findings highlight the importance of understanding how rest is perceived and practiced, particularly among adults with LTCs, to inform more effective self-management strategies such as activity pacing.

Therefore, our study addresses this gap in knowledge and aims to investigate and understand the experiences and perceptions of rest among adults with LTCs who experience fatigue, along with healthcare professionals (HCPs) who support these individuals in managing their fatigue. Empirical research has demonstrated that fatigue across diverse LTC is associated with shared transdiagnostic traits and processes [38,39]. Transdiagnostic models offer theoretical and clinical advantages over condition-specific approaches by enabling adaptable, scalable, and evidence-based rehabilitation interventions [13,40,41]. A recent study by Barakou et al. employed a transdiagnostic approach to investigate how adults with LTCs manage daily activity in the context of fatigue [26]. In line with this perspective, the present study includes multiple LTCs, thereby aiming to provide a more holistic and inclusive understanding of rest within rehabilitation. Moreover, the inclusion of HCPs as pivotal stakeholders in rehabilitation is essential, particularly given their extensive experience with a broad range of patient needs and conditions. HCPs' insights may provide an important lens through which the experience and perception of rest can be better understood and contextualised within clinical practices. Additionally, their insights could be important for comprehensive understanding of rest, aiding in the development of patient-centred, evidence-based rehabilitation practices.

Taken together, given the conceptual complexity of rest and the subjective nature of individual experiences [42–47], this study adopts a qualitative design to address this under-researched issue and explore how adults with LTCs and fatigue perceive and experience rest within the context of rehabilitation. A qualitative approach is well-suited to capturing the nuanced and varied understandings of rest, as well as the contextual and personal factors that may influence its practice and implementation in rehabilitation [48]. This study is guided by the following research questions: How do adults with LTCs and HCPs understand and describe rest? What resting strategies support fatigue management and participation in daily activities? How does effective rest contribute to these outcomes? What barriers limit optimal rest for adults with LTCs?

Methods

Study design

The methods and results of this study are reported in adherence to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines [49].

Participants and recruitment

The participants were adults with LTCs with symptoms of fatigue and HCPs working with LTCs with symptoms of fatigue. The participants were selected through convenience and snowball sampling. They were recruited through patient organisations and support groups (Long covid support group-UK, Sjogren's Syndrome-UK, Multiple sclerosis-UK, Fibromyalgia support-UK, Versus Arthritis-UK) *via* emails and social media (Facebook and Twitter (now known as X). The inclusion criteria for patients were adults with LTCs with symptoms of fatigue (Fatigue Severity Scale ≥ 4) [50]. A mean score of 4 or higher on the Fatigue Severity Scale indicates the presence of clinical fatigue [17]. Additionally, the patients must be fluent in English and be aged 18 years and above. Potential patient participants who showed interest in the study were contacted and assessed using the fatigue severity scale [50]. Moreover, HCPs involved in the management of adults with LTCs with fatigue were recruited in the UK through professional networks using a snowball sampling approach, to provide additional insights into the concept of rest within the context of rehabilitation. Eligible participants were given participant information sheets explaining the study's objectives, rationale, and potential advantages. After consent was obtained, the participants were sent Microsoft Teams invites at a mutually agreed day and time.

Data collection

Semi-structured interviews were used to examine and gain participants' perceptions, understanding, and experiences of the concept [51]. Semi-structured interviews are effective in qualitative research, offering flexibility to explore participant experiences deeply while ensuring consistency and rich, contextual data, unlike unstructured interviews, which may lack focus and clear direction [52]. We developed an interview guide (see Supplementary File 1) informed by our literature review and multi-disciplinary experts (the research team). This guide utilised standardised prompts and probes to elicit comprehensive information and clarified points as needed during the interviews [53]. The interview guide was piloted with an adult with LTC (specifically, long COVID) and a post-doctoral student to assess the appropriateness of the questions and to provide initial recommendations regarding the feasibility of the interview guide. These pilot interviews led to adjustments being made to the interview guide before its

implementation in the main study. Key adjustments to the interview guide included simplifying the wording of questions to enhance clarity, as well as incorporating probes to encourage more detailed and nuanced responses. Additionally, certain questions were restructured and merged to improve the overall flow and minimise redundancy. These modifications were made to facilitate an in-depth examination of both patient and HCPs perspectives on rest with regards to fatigue and activity management.

One-on-one interviews were conducted *via* Microsoft Teams by the first author (MA), a physiotherapist with six-years clinical experience and a PhD student who had not personally experienced chronic fatigue. The study participants were not previously acquainted with the researcher, allowing him to maintain an outsider perspective [54]. To help participants feel comfortable and open during the interviews, each session began with reassurance regarding confidentiality. Participants were informed that their responses would be anonymised throughout the analysis and reporting process. They were also assured that there were no right or wrong answers, which aimed to create a safe space for them to share their experiences and perceptions of rest candidly.

Participants were primarily asked about various aspects of rest in the context of managing their fatigue and activity. They were asked to describe their understanding of rest with questions such as, "How would you describe rest in the context of managing your fatigue and activity?." They were also asked about the implementation and strategies of rest with questions like, "How do you rest?." The importance of rest was explored through questions such as, "How important is rest in managing your fatigue and activity?" and "How does feeling well-rested affect your fatigue and activity levels?." Additionally, participants discussed the barriers and challenges to obtaining quality rest, with questions like, "What are some of the challenges that prevent you from obtaining high-quality rest?."

Similarly, the HCPs were asked about strategies they used to restore their patients' energy. They were prompted with questions such as, "What are some things that you recommend to your patients with fatigue to manage their fatigue or restore their energy?." They were also asked about their understanding of rest in relation to fatigue management, with questions like, "How would you describe rest in the context of fatigue and activity management?." They were asked about rest advice in clinical environment with a question like "How do you give advice about rest to your patient?." Finally, they were asked about the challenges that prevent their patients from resting, with questions such as, "What are some of the challenges your patients face that prevent them from resting?."

Data collection was done concurrently with data analysis and continued until data saturation was achieved [55]. The data collection took place between April 2023 to August 2023.

Data analysis

All interviews were audio-recorded with Microsoft Teams and transcribed verbatim with online transcription software (Otter.ai) and diligently cross-checked by the first author. The data were cleaned by removing any personally identifiable information, then exported into a qualitative management software, NVivo12 (QSR International, Doncaster, Australia). MA engaged with the data through iterative readings of each transcript to have overall sense of the data [56,57]. The analysis involved inductive orientation [58]. The initial phase of the coding process employed an inductive approach, focusing on the concept of rest and its associated attributes. This method involved identifying and categorising data based on emerging patterns and meanings without preconceived notions. During this stage, the coding was systematically organised into clusters based on shared meanings and relationships among the concepts related to rest. The preliminary coding clusters were reviewed and discussed with experienced team members. This collaborative review process took place through two organised meetings conducted *via* Microsoft Teams. These meetings facilitated a thorough discussion of the codes and clusters, allowing team members (VD-health psychologist, KH-occupational therapist, and FH-human movement scientist, UA-physiotherapist) to provide feedback and insights, which contributed to refining the clusters into more coherent themes. To ensure "trustworthiness" [59] of the data and analysis, the initial themes were discussed with two adults with LTCs and with symptoms of fatigue (Participants 1 and 14) and their feedback was incorporated.

Ethical considerations

Northumbria University Research Ethics Committee approved the study under Reference #3779. Prior to initiating the research, formal permission was obtained from both the leadership of the patient organisations and the managers of the relevant social media groups, such as Facebook communities, to ensure that all necessary approvals were in place. Interested participants were provided with a detailed information sheet outlining the purpose of the study, the nature of their involvement, and any potential risks or benefits. Informed consent was then obtained from each participant, ensuring that they were fully aware of and agreed to the terms of their participation. To uphold the principles of confidentiality and anonymity, each participant was assigned a unique identification number and were used in all documentation and reporting to protect the participants' identities and to maintain their privacy throughout the study.

Results

Participants characteristics

This transdiagnostic and transdisciplinary study examined a cohort of 23 adults with LTC and with symptoms of fatigue. The participants were aged between 30 and 70 years, with a range of experiences related to fatigue ranging from 1 to 30 years. Notably, over three-quarters of the participants were female, and the severity of their fatigue symptoms was reported to range from 4 to 8, as presented in Table 1. The study included four female HCPs involved in managing and researching LTCs and fatigue symptoms in the UK. The HCPs' clinical experience varies from 14 to 30 years (Table 2).

This study explores the experiences and perception of rest among adults with LTC with fatigue, as well as among HCP. Four principal themes were identified: (1) Operationalisation of rest, (2) Strategies for resting, (3) Rest as a tool for optimising functioning, and (4) Barriers to achieving restful experiences. The themes are presented in Table 3.

Main theme 1: The operationalisation of rest

This theme relates to the meaning and understanding of rest from the participants' perspectives. Both persons with LTC and HCPs contributed insights into this overarching theme, which were further categorised into three sub-themes: low energy activity/connecting with nature, detachment and disconnecting, and stopping/slowing down (Table 1).

Table 1. Characteristics of adults with LTCs and with symptoms of fatigue.

Participants ID	Age/years	Primary long-term condition	FSS	Duration of fatigue/yrs.
P1	30–40	Long Covid and Postural orthostatic Tachycardia Syndrome	7	2
P2	40–50	Long Covid	6.4	3
P3	50–60	Long Covid	5.7	1
P4	40–50	Long Covid	6.2	3
P5	50–60	Long Covid	6	3
P6	50–60	Long Covid	7	3
P7	30–40	Long Covid	6	2
P8	30–40	Long Covid	6.7	3
P9	40–50	Chronic Fatigue Syndrome	6.6	13
P10	40–50	Chronic Fatigue Syndrome	5	3
P11	50–60	Long Covid	6	3
P12	50–60	Arthritis and chronic renal conditions	7	3
P13	50–60	Sjögren's Syndrome	7	3
P14	40–50	Multiple Sclerosis	7	3
P15	30–40	Sjögren's Syndrome	6	3
P16	60–70	Hip and knee osteoarthritis	6.5	2
P17	30–40	Multiple sclerosis	5.6	2
P18	50–60	Osteoarthritis	4	2
P19	50–60	Chronic Fatigue Syndrome	7	2
P20	50–60	Rheumatoid arthritis/chronic fatigue	7	2
P21	50–60	Arthritis/Fibromyalgia	8	30
P22	50–60	Multiple sclerosis	4	23
P23	60–70	Sjögren's Syndrome	8	5

FSS = Fatigue Severity Scale.

Table 2. Characteristics of health care professional.

Participants	Gender	Experience at the time of interview	Occupation at the time of interview
HCP1	Female	28 years	Occupational therapist
HCP2	Female	20 years	Occupational therapist
HCP3	Female	30 years	Physiotherapist
HCP4	Female	14 years	Health psychologist

HCP = Health Care Professional.

Table 3. Themes and comparison between adults with long-term conditions and healthcare professionals on rest.

Main theme	Similarities (both patients and HCPs)	Differences (group specific)
1. Operationalisation of rest	Low energy activities and/or connecting with nature Stopping activity Detachment and disconnecting from core activity	HCPs: Intentionality about timing of rest emphasised
2. Rest as a skill to be practiced	Psychological engagement Serene environment	HCPs: Planned and intentional rest Patients: Physical engagement (Light physical activity)
3. Rest as a tool for optimising functioning	Energy management Activity management Symptoms management	No explicit differences noted
4. Barriers to achieving rest	Impact of expectations on persons with LTC. Environmental barriers Responsibilities Lack of skills for resting Interpersonal barriers	HCPs: All-or-nothing approach Patients: Physical symptoms as barrier

HCP = Healthcare Professionals.

Sub-theme: Low energy activities and/or connecting with nature

Persons with LTC emphasised that rest involves activities characterised by low energy engagement, including sitting, lying down, observing nature, reading, sewing, and other leisurely pursuits. For instance, several participants indicated that sitting outside in the garden or watching nature constitutes rest. Adults with LTC described how they operationalised and conceptualised rest.

> Rest is simply sitting and enjoying looking at the garden. Sometimes, because we now live in a bungalow, it's easy to get into the garden, unlike our previous house. Usually, there's a chair by the back kitchen door, so I can go out and just be in nature. That, for me, is a form of rest. [P21]

> We have a little garden outside, in the garden, I have vegetables growing…., and I've got blackberries up there, which I'm watching grow…… just being in nature. [P22]

> My resting activities are what I call low-energy things. Reading is one of them, although I struggle with academic stuff due to my course. Autobiographies or novels with simple plotlines are enjoyable reads, even though I might have trouble recalling details afterward. [P7]

Some individuals reported that sitting down to watch television provided a sense of restfulness. For these individuals, such low-effort activities contribute to their perception of rest.

> Like I can rest and watch TV, and luckily for me, now I'm able to deal with that stimulation and that is relatively restful for me. [P9]

In discussions of low-activity pursuits, such as watching television or reading, not all adults with LTCs align with categorising these activities as "restful." Many adults with LTCs report that such activities, despite their low physical exertion, still demand a degree of cognitive or emotional energy. Consequently, they do not experience these activities as restful in the same way as others might.

> I could watch television programs, but they sort of take up energy. [P20]

> Occasionally, I'll watch some TV, but it really isn't restful. [P10]

Similarly, HCPs agreed with adults with LTCs that connecting with nature can be considered a form of rest. They further elaborated on how this concept might be effectively integrated into therapeutic sessions to enhance patient well-being. Additionally, HCPs noted that even sitting down to engage in a quiet activity, or simply taking a moment to enjoy a cup of tea, can also serve as meaningful forms of rest.

> …even just staring at nature, we know that we are, you know, biologically, we are animals, we are moving further and further away from our biology, we need to go and regroup and use the therapy that's out there. So, I'll ask a patient, do you have a garden? Can you go and sit in your garden? Can you look out your window, can you look at the sky, look at the horizon, just stare off into the distance and try and build that up. [HCP3]

> So sometimes it will be sitting down and doing an activity that, you know, it could be having a cup of tea, I mean, it could be sitting down and doing that. [HCP4]

Additionally, HCPs observed that prior to advising patients on rest, it was important to recognise that some patients might be watching television, scrolling on their phones, or reading. HCPs noted that these low-activity behaviours often habituate patients to continuous cognitive engagement, effectively conditioning them for sustained mental stimulation. As a result, these activities are not categorised as rest but rather as forms of cognitive engagement.

> So, before I tell them what to do, they might watch TV, scroll on their phone, read a book, or do a low-level activity, like stepping away from their desk to do some cleaning. They aren't stopping and resting; they're still engaged in an activity. [HCP3]

While the activities described were similar, patients and HCPs differed in how they interpreted these experiences. Patients tended to describe rest as personally meaningful and context dependent. What felt restful varied between patients and included activities like watching TV or reading, even if they were cognitively engaging. In contrast, HCPs emphasised a more clinical view of rest, distinguishing between truly restorative rest and passive behaviours that still involve cognitive stimulation. HCPs were more likely to question whether activities such as scrolling on phones or watching TV genuinely provided rest.

Sub-theme: Stopping activity

Both HCPs and adults with LTCs with fatigue reported that rest involved stopping activities. For adults with LTCs and fatigue, rest is synonymous with "doing nothing," which may involve lying down, sitting with feet elevated, or deliberately minimising exposure to external stimuli.

> *Rest is stopping completely*……just stop and do nothing for 10 to 15 minutes to half an hour effectively is what I class as rest. [P7]

> Obviously, like I said, that physical rest, I can stop myself from moving. I can force myself to sit in a seat. [P9]

Similarly, the HCPs reported that rest involves not only ceasing physical activities but also creating a sense of calm by remaining still and maintaining a relaxed state.

> Sitting down for 10 or 20 minutes, you know, and sitting very still and relaxed. [HCP1]

> Sitting still and resting, as we have historically viewed rest. [HCP3]

Despite some differences in their phrasing, both groups agreed that rest requires stillness, whether it's through consciously doing nothing or remaining still to cultivate calmness. Both patients and HCPs recognised that a key aspect of rest is the ability to stop physical activity and remain in a relaxed state.

Sub-theme: Detachment and disconnecting from core activity

Rest, as reported by both adults with LTCs and HCPs, may extend beyond the mere reducing of physical activity or reduction in movement. They described rest as an intentional process involving a mental disengagement from primary, often cognitively or emotionally demanding activities. This process requires redirecting attention to alternative activities or mental detachment, which was identified as an important component in restorative mental rest.

Adults with LTCs characterised rest as.

> It's [rest] about being able to switch off completely and turn your mind, your brain, off. [P18]

> Just sitting and not actively engaging your mind. [P17]

HCPs echoed this understanding, observing that effective rest requires patients to "mentally switch off" to gain the mental reprieve needed to cope with fatigue.

> They [patients] need to mentally switch off to get the mental rest that is required, [HCP2]

> They [patients] need to be mentally able to switch off as well. [HCP1]

Together, both patients and HCPs viewed rest as requiring mental detachment, not just physical stillness, to achieve true and restorative rest.

Sub-theme: Timing of resting

Additionally, most HCPs emphasised the importance of timing and intentionality in rest. They observed that many patients with LTCs tend to rest only when really exhausted preparing for sleep or find it difficult fitting rest into daily routine.

> So, when I ask patients how they rest, some people respond by saying things like, "What I do…when I'm really exhausted…. or they might say things like, "Well, when I'm sleeping' or "over the weekend. [HCP1]

> You know, it's really hard to know where to fit rest in, especially when you speak to people who are working or have a young family. They are just busy, busy, busy, and often don't know where rest can fit in. [HCP4]

Main theme 2: Rest is a skill to be practiced

Both patients and HCPs provided insight into how they achieve rest in their daily lives. The findings of this main theme are presented under the following sub-themes: physical activity engagement, psychological activity engagement, and looking for/creating a serene environment (Table 1).

Sub-theme: Physical engagement

For adults with LTCs and symptoms of fatigue, one skill and strategy for achieving rest involves engaging in gentle physical activities. They reported incorporating various forms of light exercise, such as slow walking, stretching, and other mild exercises, into their routines to facilitate rest. Furthermore, some adults with LTCs reported strategies involving engaging in occupational activities within their home setting. They reported working with their hands provided some form of rest.

> What helps, well, actually helps you to be able to rest, sort of, and to actually rest better is to actually do some form of exercise. And then you find that it's easier to rest because I think your body then feels more, you know, more ready for just, you know, sitting and switching off your mind. [P17]

> I also have a workshop, and doing engineering work there is nice for me. It helps me rest in a funny way. However, I haven't been able to do that for a long time, which affects my mind. But I know that when I can do it, I find it very restful. [P22]

Sub-theme: Psychological engagement

In addition to mild and slow physical activities, adults with LTC reported that psychological and relaxation techniques, such as meditation and listening to soothing music, played a key role in helping them rest both physically and mentally.

> I meditate in the afternoons. It helps me rest. [P12]

> Meditation is good, and I practice breathing techniques, including the Wim Hof method. These methods help me a lot. [P13]

> Sometimes, I go into deep meditation using a technique called progressive muscular relaxation… it guides you to completely relax every muscle in your body, and I practice it often. I use it to fall asleep at night, but it's also beneficial to do during the day. [P2]

HCPs echoed these sentiments, recognising the importance of psychological engagement strategies for rest. They reported frequently recommending specific tools, such as apps, to support their patients in integrating these practices into their daily routines. Importantly, HCPs collaborate within a multidisciplinary team

to implement effective psychological strategies aimed at promoting rest. This collaborative strategy involves engaging with team members who possess specialised skills in delivering these strategies effectively. For instance, practitioners skilled in techniques such as relaxation exercises, meditation practices, and guided relaxation sessions play a crucial role in this context.

> I suggest using apps. There are apps out there that will teach you how to meditate. They have different features like sleep stories, relaxation stories, mindfulness sessions (which last about 10 minutes), breathing exercises, and masterclasses explaining the value of rest. [HCP, 3]

> I work with my colleagues, including a psychologist and a physiotherapist, and it may be that the physiotherapist is particularly skilled in relaxation techniques and even meditation-based practices with clients. Sometimes, a guided relaxation session can be very helpful, especially for individuals who struggle… [HCP 1]

Sub-theme: Environment

The surrounding environment was reported to play a crucial role in promoting rest for adults with LTCs. Many reported intentionally seeking or creating quiet and calming spaces to support restful experiences. Methods to achieve such environments included quieting and darkening rooms, as well as minimising noise and light disturbances. Additionally, some participants reported that spending time outdoors, such as sitting on a comfortable bench in a park and appreciating the natural scenery contributed to their sense of restful experiences.

> Small things like shutting the curtains to make the space dark and blocking out light and noise as much as possible help too. [P8]

> I usually put an eye mask and earplugs in, so I try to block out noise and light. [P3]

> We have a small garden, which is nice. Sometimes, I go out to spend time there. [P22]

Similarly, HCPs reported advising patients to establish calming environments to enhance restfulness. They recommended creating spaces with minimal visual and auditory distractions, recommending adjustments such as dimming lights, reducing ambient noise, and incorporating soothing elements, such as soft lighting or natural sounds. For patients whose home environments may not easily support these changes, HCPs sometimes suggested alternative settings that naturally offer quieter atmosphere.

> … an alternative environment, or, you know, try wearing noise-cancelling headphones. [HCP 1]

Sub-theme: Planned rest into daily routines and providing support to patients

Additional perspectives from HCPs on optimising rest in adults with LTCs emphasise the importance of planned rest and the integration of regular rest periods into daily routines. Several HCPs advised patients to engage in consistent and intentional rest to prevent fatigue. Some reported that rest is more than merely taking breaks; it requires a shift in mindset from pushing through to adopting a deliberate and planned rest.

> You should rest regularly to avoid reaching the point of exhaustion and ensure that you are always using the right energy pathway. [HCP3]

> I think one important aspect of rest is that it should be planned rather than simply pushing through. [HCP4]

Moreover, some HCPs reported that supporting patients to communicate their needs both at home and in the workplace, could be important in optimising rest and preventing daily disruptions.

> Sometimes, it's about supporting them in communicating their needs to others so that they are not interrupted. [HCP1]

Together, the theme of "rest as a skill to be practised" highlights both similarities and differences between patients and HCPs. Both adults with LTCs and HCPs emphasise the importance of psychological engagement (e.g. meditation and breathing exercises) to promote optimal rest. HCPs provide tailored support and utilise technology to enhance resting practices. However, there is a notable difference in how these strategies and skills are framed. While adults with LTCs often incorporate light activities (e.g. physical engagement) into their daily routines to aid rest, HCPs take a more formal and collaborative approach, focusing on planning and support to optimise rest.

Main theme 3: Rest as a tool for optimising functioning

This theme sheds light on rest as a strategic tool for achieving functional outcomes in the lives of adults with LTC with fatigue. It reveals that rest is not simply a break from activity but a crucial element in managing health and well-being. The main theme is presented under the following sub-themes: improving energy, managing activity, and reducing symptoms of fatigue.

Sub-theme: Energy management

Adults with LTC highlighted that rest is vital, and it is a core part of managing their conditions. They reported that rest enables them to recharge their energy, which is depleted by the condition and rigours of daily activity. Additionally, they expressed that although they do not feel great going into rest, after resting, their energy level is partially replenished, enabling them to function at a pre-morbid level.

> So, rest recharges my energy. I've heard someone use an analogy of a battery, and it's like they've taken away my original battery and given me a totally tiny battery that is much, much smaller than my previous one. But I can recharge that battery enough through rest to function for a short while and to do some tasks before the next rest. [P11]

> I don't feel great going into a resting period, but then, after lying down for an hour or two, I feel like my energy is filled up a bit. It's as if I've been refilled somewhat, and I can then get up again, maybe fix myself some lunch or get food for the children. Yes, its [rest] kind of recharges my battery a little, but only up to a level where, you know, I'd say I'm at about 10 to 15% of a normal person. [P6]

Similarly, some HCPs noted that fatigue is a significant symptom of LTCs. However, fatigue can be broken down into different dimensions, including physical, mental, emotional, and spiritual fatigue. As a result, they assess these areas to identify where the patient is expending more energy or where their energy is depleted then they can top that energy up.

> It [fatigue] can be broken down into different areas: physically, mentally, emotionally, and spiritually. Examining which aspects of these areas' patients are investing their energy in and where their energy is depleted, you can then focus on how to replenish that energy through rest. [HCP2]

Additionally, the HCPs perceived that prioritising regular rest may allow patients to utilise the appropriate energy pathways, promoting a balanced and sustainable energy level throughout the day. They perceived that when individuals engage in regular rest, they minimise the risk of "dipping into their body's adrenaline reserves" which are associated with the fight-or-flight response [HCP 3].

Sub-theme: Activity management

Adults with LTC indicated that rest plays a crucial role in helping manage and engage in daily activities. For many, rest was not merely a break, but an essential strategy that enabled them to perform even the most basic tasks of daily living. Without sufficient rest, activities such as cooking, walking, and other simple routines would be challenging or even impossible to undertake. Thus, rest served as a preparatory phase that facilitated activity engagement. Participants illustrated this, sharing.

> I need to allow myself to rest and take breaks to be able to engage in any activity. [P19]

Rest was integrated into the participants daily schedule as a necessary part of maintaining functionality. Without this careful management of rest, even minimal activities would be unmanageable.

> I use a rest routine to prioritise trying to get maybe 20 minutes' work done in the morning and so and then of course I need to rest again after that. So yes, I rest. I mean, I rested before I spoke to you. I was lying on the couch until 3:50pm, and I'll have another rest after talking to you…… I could not manage any activity at all if I wasn't resting carefully. [P11]

Furthermore, one HCP highlighted that patients can only function optimally when they prioritise adequate rest [HCP1].

Sub-theme: Symptom management

Furthermore, participants acknowledged that adequate rest reduces fatigue symptoms. Rest was viewed not merely as a passive activity but as a proactive tool that helped participants manage their energy levels and avoid severe exhaustion. They also noted that without sufficient rest, they could reach a point of complete breakdown, leading to debilitating fatigue.

> When I've had enough rest, the fatigue is lower……. I think if I didn't get enough rest, I would probably just at some point shut down, and you know, you would reach a point where you completely burn out, and then you would be extremely fatigued. [P17]

It was noted that incorporating regular rest periods and dividing tasks into smaller, manageable steps helps participants better navigate their fatigue and maintain balanced energy levels throughout the day. "Pre-emptive rest" was highlighted as being particularly important in this context.

> I think the biggest help with fatigue, if I'm being honest about it, is this pre-emptive rest and breaking down my tasks, using time wisely. I believe those are the things that make the biggest difference. [P21]

> I think last year I wasn't resting and pacing. I felt more fatigued, or I felt fatigued all the time, whereas now I think with the rest and pacing I can have periods of lesser fatigue. [P10]

Collectively, both patients and HCPs expressed similar perspectives regarding the importance and objectives of rest. They emphasised that incorporating rest periods and breaking tasks into more manageable segments can significantly enhance individuals' ability to manage and reduce fatigue. This strategy not only facilitates greater control over energy levels but also improves their capacity to engage in daily activities.

Main theme 4: Barriers to achieving restful experiences

This overarching theme explores the barriers that prevent participants from resting. The participants highlighted various barriers preventing them from achieving the required amount of rest. The barriers were presented under the following sub-themes: psychological, environmental, responsibilities, physical symptoms of the conditions, social and relational, and lack of skill for resting.

Sub-theme: Impact of expectations on persons with LTC

HCPs perceived that expectations of the patients and the people around them could serve as potential barriers to the participants' ability to rest effectively. These expectations may come from multiple sources, including co-workers, supervisors, or the individuals themselves:

> …expectations are a huge influence on people. It might be the expectation of their coworkers, their boss, or themselves. For people who are at home, it might be the influence of their peers or family, especially if they were brought up in cultures with strong work ethics, where they are expected to just fight through it. Some patients feel as though they appear lazy to an outsider or to someone who doesn't understand their condition. [HCP3]

The HCPs added that some patients' personal beliefs, for example that rest is something that needs to be "earned", or that rest is only permissible once tasks are finished, can be internal barriers:

> they don't feel it's justified to rest. So, there's sort of beliefs around the importance of keeping going, or the, you know, the importance of getting everything done. [HCP4]

Adults with LTCs with fatigue expressed that sometimes their mind may be flooded with thoughts which can interfere with their ability to rest or switch off effectively.

> Occasionally, I have a lot of thoughts, so I have to make a conscious effort to practice mindfulness and clear those thoughts, as they can be distracting me from resting. [P3]

> I think sometimes it can be hard to switch off and switch off your mind and you know and because your mind in a way sometimes wants you to keep thinking about things and it's hard sometimes to try and switch off. [P17]

Additionally, the presence of worries and concerns. For example, thoughts about work or fears about returning to a normal routine were also highlighted.

> Another barrier, I suppose, is the worries and concerns on my mind, such as work-related issues. I also wonder if I will ever be able to get back to normality again. [P18]

All the HCPs noted that patients often feel compelled to complete their activities before taking a rest. This tendency results in a strong emphasis on getting things done, leading to a sense of urgency that pushes them to continue working even when they may need a break. Additionally, the HCPs expressed that many patients express that they feel a compulsion to finish tasks before allowing themselves to rest, which can lead to fatigue and decreased well-being. Additionally, some HCPs mentioned that patients often believe that taking breaks will hinder their productivity.

> It's like, "Oh, I have to do this. And if I don't finish it, I'm not going to be able to." This could be a critical inner voice, or it might be a feeling or compulsion that they need to finish the activity first. [HCP1]

> I get the impression that they [patients] are very wired and habituated to activity, and that they don't feel particularly efficient. There are also many cognitive factors at play, leading them to think, "Well, I'm not getting as much done, so I have to be on the move all the time. [HCP3]

Sub-theme: Environmental barriers

An important barrier perceived by the participants to effective daily resting was related to the environment. These barriers included noise, excessive screen time, and being away from home:

> I think too much screen time could also be a problem. You know, spending excessive time looking at screens can interfere with rest because it interferes with that part of the brain related to rest. So, I do try to reduce screen time as well like later on so that it's, you know, easier to then rest as well. [P17]

> being away from home and or being away from family's house as you know like for example, going on a long journey driving or on public transport being away for some kind of event away from home and interferes with your ability to rest. And so therefore, you know, you, you do these things less often and you do these things with concern because, you know, for example, if you're sitting on a very busy train and you know you can't stretch out or lie down, or even stretch your legs out, or you know, so that these things are a challenge to do. [P16]

Health professionals perceived that both the physical and social environments could serve as barriers for individuals with long-term conditions to take rest breaks, particularly when engaging in activities of daily living such as shopping:

> It can even be environmental. For example, during the pandemic, shopping in town became a real problem for some people. We had patients who struggled because chairs and benches were removed or taped off, preventing people from resting. At one point, it was even illegal to sit and rest on a park bench. So, when people had to go out and do their shopping, it became a massive problem because they couldn't take a rest break in the middle of the activity; there was nowhere for them to sit. [HCP1]

Sub-theme: Responsibilities

Some adults with LTCs reported that caregiving and work responsibilities may create substantial barriers for them to rest. Sometimes the constant need to manage the diverse needs of their family members often leaves them with little time and energy. Some also expressed frustration over the impact of family and work commitments on their well-being and ability to rest.

> Family and work commitments can make it difficult to listen to your body and act on its needs, as you may feel unable to do so. [P4]

> My family responsibilities include supporting my husband with MS, helping my daughter with her medical condition, and driving my son to work, as he can't drive due to his own challenges. Although we work together as a team, these caring roles can still be a barrier. [P21]

This was also acknowledged by HCPs, who agreed with patients that incorporating rest into their already busy routines can be a significant struggle. They noted that some patients, particularly those with "demanding jobs or young families," often find it difficult to make space for rest amidst the demands of their constantly hectic lives.

Sub-theme: Physical symptoms of the condition

Physical symptoms of LTCs were also reported to prevent some patients from resting effectively. Some patients expressed that symptoms such as fatigue and pain were sometimes extremely distressing.

> You can't ignore the symptoms; they're so distracting and distressing that you can't effectively rest. [P1]

> The biggest barrier for me is pain, pain, and discomfort. [P18]

Sub-theme: Lack of skill for resting

Resting was reported to be very difficult for some participants. Despite their best efforts, they struggled to fully engage in restful activities. Consequently, they often found it challenging to rest. Some admitted they were not good at resting, while others mentioned that rest felt boring and even depressing.

> I'm not very good at resting. [P 10]

> It's so boring, and I hate just lying there. It's not something I've chosen to do; it's not optional. I feel it's forced on me by the condition. It's not a choice I'm making. In fact, I hate doing it. I find it quite depressing just lying there. [P12]

Some HCPs noted that while patients often recognise the need for rest, they typically wait until they feel fatigued before taking a break. Some HCPs also pointed out that patients initially find rest challenging because it may feel as though they are going against their (pre-morbid) active nature

> I asked people, how do you rest? And sometimes people respond, like saying, what I do, or oh, I find that very difficult. For rest, when I'm really exhausted. [HCP1]

> often one of the things they may do is say "I don't rest." [HCP4]

Sub-theme: Social and relational barriers

The study revealed that participants' struggles with rest extended beyond physical limitations, encompassing significant social and relational barriers. Many faced the constant challenge of justifying their conditions to others, as the invisibility of their symptoms often led to scepticism about their experiences. This manifested in perceptions of laziness, further complicating their ability to rest and/or get necessary support.

> I think there is generally a lack of understanding, even among family and neighbours. They see you and think, "Oh, you look well," but they don't understand what you're struggling with. Some people may label you as lazy. I think it's the lack of belief and understanding around the illness that makes it challenging. [P18]

> My family are not supportive because they don't believe I'm ill. [P2]

This perceived barrier of "appearing lazy" [HCP 3] was also highlighted by some HCPs. Such perceptions may create feelings of guilt or shame when patients prioritise rest. The fear of being judged by others can lead these patients to push themselves beyond their limits, ultimately compromising their health and well-being.

Taken together, there were generally shared views and uniquely expressed barriers to rest among the HCPs and patients. The commonly shared perspectives identified by both groups included psychological barriers, environmental factors, responsibilities, a lack of skills, and interpersonal barriers. The physical symptoms associated with their conditions were primarily expressed by the patient participants. Conversely, the concept of the all-or-nothing approach to rest was exclusively expressed by the HCPs. They perceived that patients often feel the need to complete all their activities before taking a break, believing that resting could impede their ability to accomplish more tasks.

Discussion

We conducted the first qualitative study specifically exploring the understanding and experiences of the concept of rest within a

rehabilitation context. Key findings indicated that participants described rest as the cessation of activities, engagement with nature, and detachment from core activities. Both adults with LTCs and HCPs agreed that rest involves stillness and mental detachment, though HCPs highlighted the importance of timing and intentionality in rest for managing fatigue and activity. While both groups acknowledged the roles of psychological engagement and environmental factors in restful strategies, patients favoured light physical activities, whereas HCPs emphasised planned and preventive rest as distinct strategies to optimise rest. Both adults with LTC and HCPs recognised effective rest as a tool for energy management, symptom control, and activity participation. Furthermore, both groups identified barriers to rest, including impact of expectations on persons with LTC, environmental factors, responsibilities, lack of resting skills, and interpersonal challenges. Adults with LTCs specifically highlighted physical symptoms, while HCPs introduced an "all-or-nothing" approach as a unique barrier.

Our findings agree with previous scoping reviews and empirical studies, which have identified rest as both the cessation of activities, engagement in low-energy tasks, coupled with detachment from core responsibilities [23,33,36,46]. However, our findings highlight significant variations in perceptions of restful and genuinely restorative activities among participants. This indicates that rest may require not only deliberate effort but also a nuanced level of self-awareness and adaptability to accommodate individual preferences and needs [33]. This finding corroborates the existing literature, which suggests that the operationalisation of rest may vary from person to person [44–47]. A notable contribution of our study is the recognition of enjoyment from natural environments, particularly sitting and observing nature, as an essential element of rest. These findings were endorsed by both HCPs and adults with LTCs. This highlights the restorative role of "soft fascination" in natural settings, which promotes cognitive ease and restores focused attention, alleviating mental fatigue [24,60,61]. These findings resonate with Kaplan's theory on the restorative effects of nature on cognitive function and well-being, emphasising the importance of environmental context in the resting process [24]. Additionally, our study underscores detachment as a key element of rest, involving disengagement from responsibilities and mentally demanding tasks, allowing for personal reflection [24]. This supports theoretical models linking rest with psychological recovery and improved motivation [62–64]. Taken together, the operationalisation of rest underscored both similarities and differences in perceptions between adults with LTCs and HCPs. While there was consensus on certain restful activities, notable divergence occurred regarding low-energy activities, which engage the mind and may not offer sufficient restorative benefits. HCPs additionally noted that patients often engage in rest reactively, suggesting a need for education on effective rest integration into daily routines. Additionally, we recommend that interventions for adults with LTCs and fatigue be tailored to allow some degree of exploration and experimentation, helping them discover which strategies and restful activities work best for their full restoration.

A key finding of our study is the recognition that rest is a skill requiring intentional learning and practice. This suggests that knowing when to rest, how to approach it, and which activities to engage in for a restorative effect is essential. Our findings reveal a dual reality: while some adults with LTCs face challenges in incorporating rest into their daily routines, others have successfully developed strategies (e.g. mindfulness, meditation, walking) to facilitate rest. Additionally, while some individuals may require longer periods of rest, others may only need brief intervals to achieve full restoration. This disparity is likely influenced by an individual's ability to quickly enter a parasympathetic state [65], a skill that can be learned and developed over time. This highlights the importance of experimenting with different strategies to find the most effective approaches for personal well-being. Although a recent qualitative study reported psychological practices to facilitate rest in chronic conditions [26], the literature surrounding rest strategies specifically tailored for adults with LTCs and fatigue is surprisingly limited. Most existing research predominantly addresses rest strategies in populations without chronic health conditions [47]. Consequently, exploring rest strategies and skills within this context represents a notable gap in the existing literature, and our findings contribute to addressing this void.

Rest was viewed as a strategic tool for managing fatigue, recharging energy, and enhancing daily functioning in rehabilitation for both adults with LTCs and HCPs. This aligns with existing literature, which highlights rest as essential for managing fatigue, pacing activities, managing symptoms, and improving quality of life in adults with chronic conditions [26,66]. A key strategy, "pre-emptive rest," enables people with LTCs and fatigue to anticipate a potential fatigue exacerbation, giving them greater control and efficacy in daily activities. This awareness helps patients make informed decisions about gradually increasing activity levels without aggravating symptoms. This concept aligns with activity pacing, which suggests that integrating rest with activity enhances self-efficacy and symptom control, empowering people with LTCs and fatigue to manage their energy and engage in social, physical, and daily activities [16,17,67]. Consequently, we propose that rest and activity in pacing should not be seen as opposing variables, but rather as interdependent components that work together to facilitate optimal functioning. Taken together, these findings, along with existing literature, indicate that adults with LTCs share an understanding of the restorative potential of rest in rehabilitation. Furthermore, the results highlight that rest is not just a passive state, but an active strategy employed by adults with LTCs to optimise daily functioning and overall well-being [33].

The findings revealed that there were shared views and unique barriers to rest among HCPs and adults with LTCs who experience fatigue. Both identified psychological, environmental, responsibilities, lack of skill for resting, and inter-personal barriers. People with LTCs uniquely highlighted and identified physical symptoms as barriers. Additionally, HCPs drew attention to all or nothing thinking, observing that patients often feel the need to complete all their activities before taking a break. Existing literature corroborates our findings, indicating that environmental disturbances, such as noise and other interruptions, discourage individuals from achieving optimal rest [68]. These findings imply that adults with LTCs may encounter significant obstacles in achieving restful experiences, potentially restricting their capacity to gain the restorative benefits of rest. Additionally, participants perceived rest as a barrier to completing valued activities, raising concerns about not meeting personal standards and resulting in frustration. Prior to their conditions, they derived satisfaction from task completion [22]. Rest, however, may be perceived to disrupt this process, prolonging activity completion and necessitating adjustments to expectations regarding the speed and efficiency of performance. This finding corroborates with finding of Cane et al. [22] which posits that stopping an activity prior to its completion may adversely affect individuals' personal standards and expectations and may indicate difficulties in adapting to necessary changes. An important finding was that adults with LTCs and fatigue often lack both the knowledge and skills necessary to effectively rest or incorporate rest into their daily activities. As a result, participants with this barrier may be reluctant to

incorporate rest between activities, often postponing rest until the last possible moment. This behaviour might result in overactivity, potentially exacerbating their symptoms and necessitating prolonged periods of rest [15,69], a phenomenon linked to physical deconditioning [18,70,71]. We recommend educational programs focused on developing relaxation, mindfulness, and stress management skills to empower personalised rest routines. Providing support systems, such as community resources and caregiver assistance, can further enhance individuals' ability to engage in restorative practices.

Limitations

This study has certain limitations, and readers should interpret the findings with caution. One such limitation is the predominance of female participants. Specifically, the sample included only six male adults with LTCs and with symptoms of fatigue, while all HCPs involved in the study were female. Importantly, the absence of male HCPs means that the study may have missed out on gender-specific insights from these participants, which could have enriched the understanding of how rest is perceived and implemented in rehabilitation contexts. Nevertheless, the finding that a smaller proportion of men participated in this study is consistent with results from prior qualitative research [69].

Another limitation of this study is the sampling strategy, particularly the use of snowball sampling to recruit the HCPs. While this method facilitated the recruitment of HCPs with relevant experiences, it may have introduced bias by relying on participants' networks, potentially limiting the diversity of perspectives and thus reducing the generalisability of the findings. However, the concept of information power suggests that when participants possess rich and relevant information, fewer participants are needed to achieve meaningful insights [72]. Therefore, despite the small number, the depth of knowledge provided by the HCPs contributed significantly to the study's findings.

Future directions

Building on the findings and limitations of this study, we recommend that future research prioritise the recruitment of a more balanced representation of male and female participants, both among persons with LTCs and HCPs. This would ensure the findings reflect a wider range of experiences, improving the applicability and inclusivity of the results.

Although this study used a transdiagnostic approach, expanding the research to encompass a broader range of LTCs, such as Parkinson's disease, stroke, and others, would enhance the generalisability of the findings. This would also offer an opportunity to refine and extend the concept of rest within rehabilitation across different conditions.

Furthermore, the findings suggest that rest appears to be a multidimensional concept. To better understand its role in fatigue and activity management, future studies should develop comprehensive tools, such as inventories or scales, to measure rest more accurately and broadly. These would enable a deeper exploration of the nuances of rest and its impact on energy management, symptom control, and engagement in daily activities.

These efforts would inform the development of tailored rest interventions, integrated into fatigue and activity management strategies, to optimise rest as a central component of self-management for adults with LTCs to improved well-being and rehabilitation outcomes.

Conclusion

The findings demonstrated that participants operationalised rest in terms of activity cessation, engagement with nature, and detachment from core responsibilities. A key insight from this study is the conceptualisation of rest as a skill that necessitates practice and experimentation to determine the most effective approach for each individual. Both adults with LTCs and HCPs acknowledged the value of effective rest as a strategic tool for energy management, symptom control, and engagement in daily activities. Additionally, several barriers to effective rest were identified, including the influence of expectations on individuals with LTCs, environmental constraints, competing responsibilities, insufficient rest-related skills, and interpersonal challenges.

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ORCID

Martin Ackah http://orcid.org/0000-0002-5045-1104
Vincent Deary http://orcid.org/0000-0001-6115-9259
Ulric S. Abonie http://orcid.org/0000-0003-2509-4413
Florentina Johanna Hettinga http://orcid.org/0000-0002-7027-8126
Katie L. Hackett http://orcid.org/0000-0003-0249-9434

Data availability statement

The data are not publicly accessible because they contain information that may compromise the privacy of research participants.

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