

# Experiences of a cognitive behavioural therapy (CBT) intervention for fatigue in patients receiving haemodialysis

Frances Waite MSc<sup>1</sup> | Joseph Chilcot PhD<sup>1</sup>  | Rona Moss-Morris PhD<sup>1</sup>  |  
Ken Farrington MD, FRCP<sup>2,3</sup> | Federica Picariello PhD<sup>1</sup> 

<sup>1</sup>Health Psychology Section, Psychology Department, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK

<sup>2</sup>Department of Renal Medicine, Lister Hospital, Stevenage, UK

<sup>3</sup>University of Hertfordshire, Hertfordshire, UK

## Correspondence

Federica Picariello, PhD, Health Psychology Section, Psychology Department, Institute of Psychiatry, Psychology, and Neuroscience, King's College London, 5th Floor, Bermondsey Wing, Guy's Campus, London Bridge, London SE1 9RT, UK.  
Email: federica.picariello@kcl.ac.uk

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## Abstract

**Background:** A feasibility randomised-controlled trial found that a cognitive-behavioural therapy intervention for renal fatigue has the potential to reduce fatigue in patients receiving haemodialysis, but uptake was low.

**Objectives:** Nested in the randomised-controlled trial (RC) qualitative interviews were undertaken to understand the acceptability of renal fatigue, the facilitators of, and barriers to, engagement, and the psychosocial processes of change.

**Design:** The trial included 24 participants at baseline. Semi-structured interviews were conducted with nine participants from the intervention arm ( $n = 12$ ). Approach Interviews were carried out immediately following treatment (3 months post-randomisation). Data were analysed using inductive thematic analysis.

**Findings:** Five main themes were formulated. The overarching theme was a sense of coherence (whether the illness, symptoms and treatment made sense to individuals), which appeared to be central to acceptability and engagement. Two themes captured the key barriers and facilitators to engagement, cognitive and illness/treatment burdens and collaboration with the therapist. Participants described changes related to their activity, thoughts and social identity/interactions, which shaped perceptions of change in fatigue. Lastly, participants discussed the optimal delivery of the intervention.

**Conclusions:** This study revealed the importance of patients' understanding of fatigue and acceptance of the treatment model for the acceptability of and engagement with a cognitive-behavioural therapy-based intervention for fatigue. Overall, there was an indication that such an intervention is acceptable to patients and the mechanisms of change align with the proposed biopsychosocial model of fatigue. However, it needs to be delivered in a way that is appealing and practical to patients, acknowledging the illness and treatment burdens.

## KEYWORDS

cognitive behavioural therapy, dialysis, fatigue, kidney failure, quality of life

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## INTRODUCTION

Patients receiving haemodialysis experience high symptom burden with fatigue being reported as one of the most common and disabling (Bonner et al., 2010; Murtagh et al., 2007). It is estimated that between 42% and 82% of patients experience persistent fatigue (Artom et al., 2014) which can significantly impact upon the quality of life and daily functioning (Picariello et al., 2018a; Rezaei et al., 2020). Furthermore, among patients receiving haemodialysis (HD), fatigue is associated with increased risk of cardiovascular events (Koyama et al., 2010) and mortality (Bossola et al., 2015; Jhamb et al., 2011; Picariello et al., 2019). Given this, the importance of interventions designed to reduce fatigue and its impact should be a research priority, which has also been identified by the Standardized Outcomes in Nephrology-Hemodialysis (SONG-HD) initiative (Tong et al., 2017).

The complex aetiology of fatigue in kidney disease is yet to be fully defined, but is likely to involve an interaction between biological, psychological and social factors (Artom et al., 2014; Bossola et al., 2011; Chilcot et al., 2016; Gregg et al., 2021; Picariello et al., 2017c, 2020). Currently, there is no consistent treatment model of fatigue in patients receiving dialysis.

## LITERATURE REVIEW

A recent scoping review of fatigue interventions across long-term physical conditions ( $N = 52$ ) found little support for pharmacological treatments, while exercise and cognitive-behavioural therapy (CBT) appeared effective in reducing fatigue (Hulme et al., 2018). The potential of psychosocial interventions for fatigue management in kidney disease has also been substantiated by a recent meta-analytic review (Picariello et al., 2017b). However, studies included in the review were found to be of low quality and most of the interventions were designed to improve quality of life or reduce psychological distress rather than treat fatigue.

Recently we developed a CBT for renal fatigue (BReF) intervention which was informed by theory, namely the Common-Sense Model of Self-Regulation (CSM-SR; Leventhal et al., 1997, 2003, 2016) and the cognitive-behavioural (CB) model (Wessely et al., 1998); existing evidence from other long-term conditions (White et al., 2011; Moss-Morris et al., 2012) and studies conducted to better define the contribution of cognitive and behavioural factors to fatigue in kidney failure (Chilcot et al., 2016; Picariello et al., 2017c, 2018a, 2020). The CSM-SR is a dominant theoretical framework for understanding how patients' lay perceptions of an illness (illness perceptions) and emotional responses guide-coping behaviours, as part of self-regulation of health and illness (Hagger et al., 2017). Illness perceptions consist of the following dimensions: (1) identity (how symptoms are experienced and attributed to the illness); (2) cause (beliefs about causes of the illness); (3) timeline (beliefs about the duration of the illness, cyclical, acute or chronic); (4) consequences (beliefs about the impact of the illness), (5) control/cure (beliefs regarding the controllability/curability of the illness, further split into personal and treatment control), and (6) coherence (understanding of the illness). An integrated approach is critical when the management of a

symptom is in conjunction with self-management demands of the illness more generally, while the CB model acknowledges the interrelationships between cognitions, emotions, behaviours, and physiology (Hudson et al., 2016). The biopsychosocial cognitive-behavioural model of fatigue arising from these theoretical underpinnings and evidence suggests ways in which these factors impact on physiological and disease-related processes, and therefore can lead to the exacerbation and perpetuation of fatigue (Picariello et al., 2017c; Van Kessel & Moss-Morris 2006). In summary, using CBT principles, the BReF intervention targets patients' thoughts, emotions, and behaviours related to fatigue.

In a subsequent feasibility randomised-controlled trial (RCT) there was indication that BReF was beneficial when compared to a wait-list control, revealing moderate to large treatment effects for fatigue severity ( $g = 0.81$ , 95% CI:  $-0.67, 2.29$ ) and fatigue-related functional impairment ( $g = 0.93$ , 95% CI:  $-0.26, 2.12$ ) (Picariello et al., 2021). Despite a high rate of retention (75%; 18/24), issues with uptake were evident through a consent rate of 16.6% (53/320). These findings illustrate the need to further understand participants' experiences with the intervention from approach to treatment completion before pursuing a large efficacy trial.

Accordingly, and in line with the MRC framework for developing and testing complex interventions (O'Cathain et al., 2019a; Skivington et al., 2021), nested qualitative interviews were conducted as part of the RCT with the aim of understanding participants' experiences of the BReF intervention to inform modifications for enhanced acceptability and engagement. Even though there is growing qualitative evidence on the experience of fatigue across LTCs (Whitehead et al., 2016), qualitative studies that focus on fatigue treatment experiences are generally scarce (Gottberg et al., 2016; Picariello et al., 2017a). In contrast to pharmacological interventions, interventions like CBT or exercise require both time and effort from patients. Not surprisingly, drop-out is a pertinent issue of CBT, where, according to a meta-analysis of drop-out from CBT across a range of mental health disorders, 15.9% of patients would not start treatment, while 26.2% of patients dropped-out during treatment, with higher attrition rates among patients with diagnosed depression (Fernandez et al., 2015). Similarly, according to a systematic review of CBT for fatigue in multiple sclerosis, session adherence varied from 4.3% to 100% across trials (Van Den Akker et al., 2016). Given the complex and multifactorial nature of acceptability (Sekhon et al., 2017) and a multitude of factors that may facilitate or impede engagement with CBT, coupled with the complex needs of the dialysis population, building an in-depth understanding of patients' experiences of treatment was deemed essential. The main research question of the nested qualitative interviews was: *How do people on haemodialysis engage with, and perceive, a cognitive-behavioural intervention (BReF) for fatigue?* with the following sub-questions mapped onto Sekhon et al. (2017) acceptability framework:

- (1) What were participants' attitudes towards, and understanding of, the intervention? (seeking to explore affective attitudes, ethicality, intervention coherence).
- (2) What were participants' experiences of the feasibility of the intervention? (seeking to explore burden and opportunity costs).

- (3) What were participants' experiences of the perceived effectiveness of, and change following, the intervention? (seeking to explore perceived effectiveness).
- (4) What were the perceived facilitators of, and barriers to, engagement with the intervention? (seeking to explore burden and self-efficacy).

## MATERIALS AND METHODS

### Design

As reported elsewhere (Picariello et al., 2018b, 2021), a two-arm parallel feasibility RCT was conducted which included nested qualitative interviews. Participants were randomised (1:1 ratio) to either the intervention arm (BReF) or a wait-list control arm. The primary outcomes of the trial were related to feasibility, including recruitment and retention rates and willingness to be randomised. In addition, self-reported outcomes were also collected including fatigue severity (Chalder Fatigue Questionnaire; CFQ; Chalder et al., 1993). The CFQ consists of 11 items scored on a 4-point SSS, with total scores ranging from 0 to 33 using continuous scoring. Higher scores indicate higher fatigue severity. Assessments were conducted at baseline (before participants were randomised,) and at follow-up (3 months post-randomisation, representing end-of-treatment).

Of 320 patients who were approached 53 were screened for fatigue and subsequently 24 were randomised (12 per arm, see RCT paper for full details; Picariello et al., 2021). One participant was lost at follow-up in the intervention arm, and five participants were lost in the control arm. The rate of retention at follow-up was 75% (95% CI: 53.29–90.23). Participants in the intervention were interviewed immediately after completion of the 3-month post-randomisation questionnaire. The current study reports the findings arising from the nested in this trial qualitative interviews.

The study received ethical approval from the London Bridge NHS Research Ethics Committee (17/LO/1406). Informed consent was obtained from all participants. All participants were assigned an identification number (ID) and all collected data, audio-recordings, and interview transcripts are identified by the ID number. Any identifiable information was removed from interview transcripts. Data were stored in a secure restricted access digital folder. Consent forms containing identifiable information are stored separately from non-identifiable data. Optional consent was sought for the use of quotes arising from the qualitative interviews.

### Participants

Participants were eligible to take part in the trial if they were aged 18 or over, had been receiving haemodialysis treatment for at least 90 days, were experiencing clinical levels of fatigue ( $\geq 18$  using the CFQ). Participants were excluded if they had any known cognitive impairment, a severe mental health disorder, were failing on dialysis

and approaching end of life, receiving psychotherapy, participating in any other intervention. Participants in the intervention arm were supposed to be purposively selected to take part in the interviews based on prespecified criteria outlined in the study's protocol (Picariello et al., 2018b) but given the smaller sample size, a decision was made to invite all the participants who received the intervention. All participants consented to be interviewed; however, two were subsequently unreachable or hospitalised during the data collection window, leading to nine participants being interviewed.

### Overview of BReF intervention

Participants in the intervention arm received a CBT-based self-management intervention targeting fatigue with therapist support. The development of the CBT-based intervention was systematic, based on the findings of reviews and qualitative and prospective studies, with substantial input from 10 patient and public representatives and a multidisciplinary team of health psychologists, clinical psychologists, and nephrologists. A self-management manual was provided to participants alongside a task workbook which helped participants to track their behaviour and set goals. The manual consisted of 10 chapters, accompanied by a task for each session (see Table 1 for a content summary). This was accompanied by three to five sessions with a therapist (one was a researcher with a background in health psychology, CBT training and experience in working with fatigued patient groups and the other was a health psychologist working in a renal setting). The first and last therapy sessions were in-person and lasted an hour, and the ones in-between took place on the phone for 30 minutes. Face-to-face sessions were in most instances held in a private room at the participant's home although, in some situations, it was necessary they took place while participants were on dialysis. The number of therapy sessions participants received depended on their level of engagement and personal model of fatigue. The programme comprised of two units: a basic unit (level 1) and an advanced unit (level 2). For the basic unit, participants covered four chapters from the manual, three of which were accompanied by a therapy session, and one was selected according to the participants' needs and covered without therapist support. Participants who engaged well in the first two sessions were provided with the opportunity to undertake level 2, which involved covering two additional chapters with the therapist over the phone focused on cognitive restructuring. The wait-list control arm continued receiving routine treatment, including any medical treatments for fatigue, and received the manual without therapist support after their participation was completed.

### Procedure for the qualitative interviews

Semi-structured, one-to-one interviews were conducted between May 2018 and February 2019 either in-person ( $n = 2$ ) or on the phone ( $n = 7$ ), with a researcher who was independent of designing or running the intervention. The interview schedule (available in Supporting Information Material 1) focused on participants'

**TABLE 1** Summary of the content of the BReF manual (Picariello et al., 2018b)

Chapter	Content	Between sessions task
Renal fatigue explained	Understanding renal fatigue and alternative explanations Assessment of fatigue and personal model of fatigue	Fatigue self-monitoring
Finding balance in activities and rest	Patterns of rest and activity and their effects on the body Planning activity and rest Exercise	Activity difficulty task Activity and rest goal sheet
Improving sleep	Sleep hygiene Maladaptive sleep patterns Improving sleep	Sleep, activity and rest goal sheet
Learning to relax	Diaphragmatic breathing Progressive muscle relaxation (PMR) Relaxation training: Step-by-step	Relaxation diary
Coping with emotions	Strategies to cope with negative emotions Self-assessment of negative emotions Expressing emotions	Coping with negative emotions goal sheet
Managing stress	General tips to reduce the impact stress on life Managing controllable and uncontrollable stressors Mindfulness	Managing stress goal sheet
Making use of social support	Creating a support network Disclosure versus keeping it to self Social comparisons	Social support goal sheet
Becoming aware of your thinking	Common unhelpful thoughts Identifying unhelpful thinking	Thought record
Changing your thinking	Identifying alternative thoughts	Alternative thoughts goal sheet
Preparing for the future	Sustaining and building on improvements Developing future goals Tips for everyday life	Long-term goals worksheet

Abbreviations: BReF, cognitive-behavioural therapy for renal fatigue; PMR, progressive muscle relaxation.

experiences of taking part in the study and receiving the intervention, other treatments they have tried to manage fatigue, their expectations about their future energy levels and how to improve the intervention for future use. The duration of the interviews ranged from 19 to 68 minutes (mean = 48 min, s.d. = 14.32). Interviews were digitally recorded, anonymised, and transcribed verbatim by the interviewers. Qualitative guidelines (Elliott et al., 1999; Yardley, 2000) informed the study procedure.

## Analysis

Qualitative data were analysed using reflexive inductive thematic analysis, a qualitative method used for identifying recurrent patterns (themes) in the data bottom-up (driven by the data rather than a pre-existing theory) acknowledging the active role of the researcher in

formulating themes (Braun & Clarke, 2019). This qualitative analysis approach was deemed to be most appropriate given the scope of the work based on existing guidance (Braun & Clarke, 2021). This approach provided flexibility and enabled the researcher to interpret and create an understanding of participants' experiences of the intervention directed by the content of the data (Braun & Clarke, 2014, 2019).

The qualitative analysis here complements the quantitative findings of the feasibility trial, and together these findings informed progression decisions and modifications necessary with regard to the intervention and its further evaluation. In consideration of this, data were analysed within a pragmatist epistemological paradigm, for the following reasons: (1) equal value placed on both the quantitative and qualitative data, (2) not constrained by the philosophical discrepancies underpinning quantitative and qualitative research, and (3) focus on practical and actionable results (Bishop, 2015; Frey, 2018).

The data were analysed using NVivo 12, following the six phases outlined by Braun and Clarke (2006). Firstly, the researcher familiarised themselves with the data, then they systematically read each transcript and coded units of meaning which led to the generation of initial codes. Following this, codes that were similar in meaning were grouped together. Once the number of codes had been reduced substantially by amalgamating them, the codes were organised into potential themes and subthemes and were refined in the discussion by the team and applications of the devised themes/subthemes back to the raw data, and a coding manual was developed (see Supporting Information Material 2). Analysis was conducted by a researcher who was independent of designing or running the intervention, but the themes and subthemes were refined collaboratively with the research team. Anonymised quotes are presented in the overview of findings below and they were selected for typicality in illustrating the themes. Participant ID codes refer to gender and age (i.e. M\_32; male aged 32).

## Findings

A summary of key participant characteristics is available in Table 2. An improvement in fatigue was observed among eight participants (points of change range 4.40–21), while one participant reported a one-point deterioration in fatigue. Five main themes were formulated through the thematic analysis (Table 3) and are discussed in more detail below. Figure 1 is a thematic diagram of the identified themes and subthemes and their inter-connections.

## Themes

### Coherence of fatigue and intervention

Participants spoke about the causes for their fatigue, relating their understanding and experiences back to the biopsychosocial

view of fatigue adopted in the intervention. This was closely linked to their understanding and acceptance of the treatment model. The sense of coherence in relation to the understanding of fatigue and intervention was an overarching theme here that grounded all the other themes described below, shaping participants' perceptions of acceptability, experience of barriers and facilitators, and how they engaged with the intervention. Lack of coherence between the perceived causes of fatigue and the treatment model could undermine acceptability of and engagement with the intervention, establishing it as a key and superseding construct.

#### *Understanding the causes of fatigue*

Participants spoke about their understanding of the causes of their fatigue and how this aligned with the biopsychosocial approach to fatigue presented in the intervention. For some participants, there was a clear alignment between their experiences and the biopsychosocial approach presented in the intervention, indicating coherence:

Everything that was happening to me I was noticing in the book [intervention manual] (M\_32\_Fatigue Improved).

Others described re-evaluating the factors responsible for their fatigue and adjusting their understanding of fatigue as a result of the intervention:

That's partly what was making me feel fatigued, was the negativity so, if I could have more positive thoughts and more goals and aims then I would have a little bit more energy (F\_80\_Fatigue Improved).

This illustrates how participants were able to increase a biopsychosocial understanding of the causes for their fatigue through participating in the intervention.

**TABLE 2** Participant information

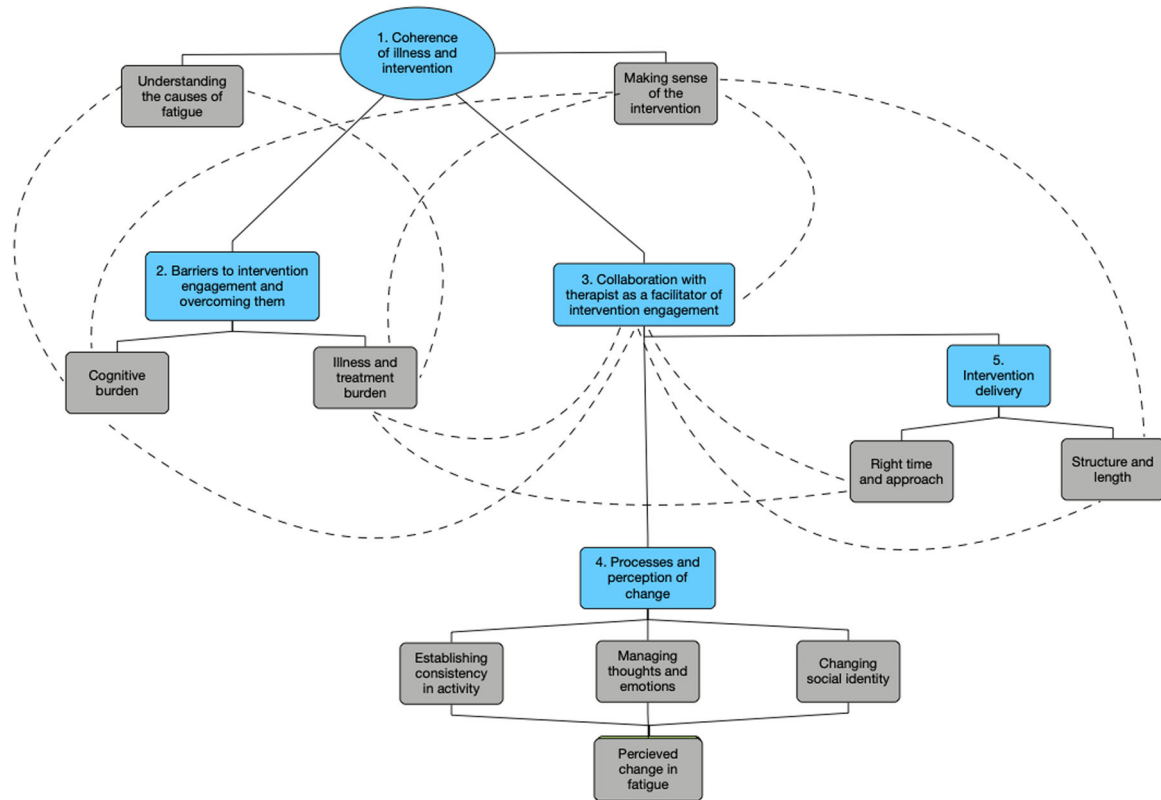
Gender	Age range	Ethnicity	URR baseline (%)	URR post-intervention (%)	Baseline CFQ Score	Months on dialysis	CFQ change score <sup>a</sup>
M	30–44	Asian	76	76	18	18	-12.5
F	45–59	White	80	63	25	14	-12.0
F	30–44	Mixed	68	71	23	24	-4.4
M	45–59	White	55	68	20	48	-7.9
F	60+	White	78	79	19	18	-8.0
M	30–44	White	74	78	27	9	1
M	60+	Asian	78	77	27	72	-14.0
M	60+	White	63	70	22	84	-4.0
F	60+	Black	72	76	26	72	-21.0

Abbreviations: CFQ, Chalder Fatigue Questionnaire; F, Female; M, Male; URR, urea reduction ratio—marker of dialysis adequacy with a recommended target of >65% (Kerr et al., 2005).

<sup>a</sup>A negative score indicates a reduction in fatigue from baseline to follow-up (i.e., improvement).

**TABLE 3** Themes and subthemes

1. Coherence related to fatigue and intervention	2. Barriers to intervention engagement	3. Collaboration with a therapist as a facilitator of intervention engagement	4. Processes and perception of change	5. Intervention delivery
1a. Understanding the causes of fatigue	2a. Cognitive burden	-	4a. Establishing consistency in activity patterns	5a. Right time and approach
1b. Making sense of the intervention	2b. Illness and treatment burden		4b. Managing thoughts and emotions	5b. Structure and length
			4c. Changing social identity	
			4d. Perceived change in fatigue	



**FIGURE 1** Mind map of themes and subthemes. Dotted lines indicate proposed links between the themes and subthemes

In some instances, however, participants held a biomedical understanding of their fatigue that clashed with the biopsychosocial approach of the intervention and indicated a clear preference for a medical approach to the management of fatigue:

I personally don't think people want anything but a pill (M\_69\_Fatigue Improved)

and

I'm hoping I get a transplant soon and everything will change! (F\_59\_Fatigue Improved).

These accounts highlight how some of the participants were not incorporating psychological and social factors into their personal model of fatigue. This lack of coherence is likely to be a barrier for engaging with, and potentially benefitting from, the intervention. It may also have been a factor contributing to the low uptake of the intervention in the first place, with patients preferring to seek biomedical solutions to their fatigue.

*Making sense of the intervention*

Beyond participants' understanding of the causes for their fatigue, coherence in relation to the treatment model underlying the intervention also appeared important to establish the overarching

sense of coherence. Some participants found it easy to understand and accept the biopsychosocial underpinning of the treatment model:

this programme, it was for my thinking, my activity also, everything was tackled in this programme...it was more helpful (M\_32\_Fatigue Improved).

Some participants, however, found it difficult to make sense of or relate to the intervention:

I found some of the experiences of other people who appeared to have contributed to it[the manual] ... unusual (M\_69\_Fatigue Improved).

This illustrates how some of the participants did not understand the reasons why certain information was selected to be part of the intervention manual and could not relate to the treatment model.

However, many participants changed their understanding and became more accepting of the treatment model through exposure over time:

I was expecting it would give me some... remedy towards the fatigue problems... ..that wasn't really the intention of the whole thing...[t]he whole thing was to give you the techniques in which you can use to, analyse and... the problems that you get (M\_69\_Fatigue Improved).

This illustrates how some participants were able to increase their acceptance of the treatment model, likely underpinned by a change in their personal understanding of fatigue, enabling them to engage and benefit from the intervention.

## Barriers to intervention engagement

There were two main barriers participants faced when undertaking the intervention, including the cognitive demands of the intervention and challenges they faced related to their illness and treatment.

### *Cognitive burden*

Many participants spoke about the cognitive demands of the intervention and the impact of this on their engagement. Difficulties concentrating were widespread and frequently raised as a challenge during the intervention:

I just find it so difficult to concentrate (F\_59\_Fatigue Improved).

These cognitive demands were particularly evident for the intervention manual, illustrating how written material was perceived as more burdensome:

the amount of information in the manual...was just a bit to digest (M\_50\_Fatigue Improved).

Participants also discussed how tiredness reduced their ability to concentrate, accentuating how challenging treating fatigue can be:

It could help me if I have the energy. But sometimes I feel so tired (M\_75\_Fatigue Improved).

Therefore, it is important that interventions developed for fatigue take into consideration the cognitive difficulties that are often present in this population, in addition to mental fatigue, and are adapted to increase engagement. The cognitive burden of the intervention is likely to have reduced the possibility of participants increasing their coherence of their fatigue and the treatment model.

Some participants overcame these cognitive burdens by prioritising parts of the intervention they felt were most relevant or developed habits for using the intervention:

I've just used bits of it that I took on board more (M\_69\_Fatigue Improved).

and

going back to...the book, I really didn't think about it (F\_71\_Fatigue Improved).

These strategies reduced the cognitive demands of the intervention by minimising the amount of information processed and the cognitive demand of deciding to use the intervention.

Participants also suggested modifications to the intervention to address the cognitive demands, such as delivering the content in the intervention manual in a video format:

You can more concentrate ...because when you reading, after a while you start to feel, fatigued, you know but if...you have a DVD playing, you can lie down and look, and see (M\_75\_Fatigue Improved).

Therefore, the delivery format of the intervention manual could be adapted to respond to the cognitive burden of written material.

### *Illness and treatment burden*

Another barrier to engaging with the intervention was the illness and treatment burdens participants experienced. The burden of dialysis, caused by the amount of time in hospital and the recovery time, made it difficult for participants to find time for the intervention:

it [dialysis] does encroach on your time a bit (F\_80\_Fatigue Improved)

and

When I've come off, I can't tell you how I feel when I've come off of dialysis. It's awful (F\_59\_Fatigue Improved).

This illustrates that many participants felt they only had limited time and energy to complete the intervention. The demands of dialysis also interfered with participants' ability to engage in helpful self-management behaviours suggested in the intervention manual:

Exercising. But I never do it! I tell you the truth. I didn't do it because, the time you have to do it, is, is not there (M\_75\_Fatigue Improved).

Not being able to engage in these self-management behaviours could hinder progress towards reduced fatigue.

Some participants also described how comorbidities were important contributors to fatigue:

So, my fatigue is probably partly down to Parkinson's, and partly down to the kidney problem (M\_69\_Fatigue Improved).

In light of the burden of comorbidities and complex needs of this patient population, participants described the importance of tailored interventions:

I think, to be honest, you need something different for different people's problems (M\_69\_Fatigue Improved).

They also described the importance of multidisciplinary input:

Because the physio I'm doing now...It helped me to do more walking (F\_71\_Fatigue Improved).

This highlights the complex needs of the population and intricate links of fatigue and other symptoms and comorbidities.

## Collaboration with therapist as a facilitator of engagement

The main facilitator of engagement discussed by participants was collaboration with the therapist during the therapy sessions. The therapist provided encouragement and guidance, and many of the participants described how they would not have engaged in the intervention without therapist input:

I think if she [therapist] hadn't been there, I probably wouldn't have done it at all (F, 59, Fatigue Improved).

The therapist was also perceived as a source of credible information, which facilitated engagement:

She could give me some advice, what to do, and what not to do, and what I am doing is that (M\_32\_Fatigue Improved).

The therapist also helped to promote coherence of the treatment model:

I was happy to see her. Because I learnt a lot from what she was saying (F, 71, Fatigue Improved).

Particularly at the start when scepticism in relation to the intervention may be present and the intervention may be perceived as burdensome, therapist input may promote engagement through improved coherence and encouragement.

## Processes and perception of change

Participants described three main processes of change, related to activity, thoughts, emotions, and social identity, through which a reduction in fatigue was achieved. These processes linked to the areas targeted in the intervention manual.

### *Establishing consistency in activity patterns*

Participants described changes in their activities. This encompassed introducing more consistency in activity, by avoiding cycles of high levels of activity followed by excessive rest to recuperate:

I tend to pace myself out now rather than...sort of burn myself out (M\_50\_Fatigue Improved).

As well as increasing and incorporating physical activity into their daily lives:

I will do cycling in the morning (M\_32\_Fatigue Improved).

Changes in activity patterns appeared important for the reduction in fatigue. Participants' narratives portrayed a change in the perception of activity, linking to the subtheme below, as well as increased capability to engage in physical activity.

Consistency in activity also includes sleeping patterns, and whilst some participants had improved, others were still struggling:

I still take sleeping tablets (M\_41\_Fatigue Deteriorated).

### *Managing thoughts and emotions*

Another important process of change was managing thoughts and emotions. Participants described how they utilised techniques introduced in the intervention, for instance, breathing exercises when on dialysis:



I found doing daily breathing, deep breathing calming...it helped...me...not be quite so, hurry, hurry, get this session [dialysis session] over (F\_80\_Fatigue Improved)

As well as formulating alternative thoughts:

... when I was sinking into my usual negativity then the chapter on alternative thoughts I used to think of that and I'd think, all right, let's not think about that, think of something different (F\_80\_Fatigue Improved).

However, a few participants were still working on trying to change their thoughts and manage emotions:

[thoughts and feelings] still up and down to be fair (M\_41\_Fatigue Deteriorated).

This aspect of the intervention, although relevant, was also perceived as challenging by many:

yeah that last one [how to manage your emotions] was good. But I don't think I gain anything with that with my ability (M\_75\_Fatigue Improved).

This is in contrast to changes in activity patterns that were more readily experienced by participants, suggesting that more time and effort may be necessary to make changes to thinking patterns and management of emotions.

#### *Changing social identity*

A few participants described how they had experienced a positive change in their social identity. This encompassed improved relationships with their friends and family:

I'd say that my relationships are better ... I appreciate my friends and family more (F\_80\_Fatigue Improved).

As well as gaining independence, which characterised a large shift in personal social identity:

I could not go alone, I used to go with my family. But now I can go anywhere because of this programme... (M\_32\_Fatigue Improved).

Through improved relationships and gaining independence, participants are likely to also utilise their social support more effectively and this could also increase positive emotions, illustrating the importance of this process of change.

However, other participants described how they still saw themselves as a burden to those around them and were not at ease to ask for support:

but I don't like to be asking him [partner] to do too much for me. I think 'I'll leave it and I'll do it myself (F\_59\_Fatigue Improved).

and

I don't really moan about it only with the kids (M\_50\_Fatigue Improved).

Interestingly, this subtheme highlights the role of social support in both providing necessary aid, while also fostering independence.

#### *Perceived change in fatigue*

The processes of change, described above, fed into participants' perceived changes in fatigue (Figure 1). Some of the participants discussed changes in their fatigue by describing the activities they were able to do because of the intervention, for example, engaging in daily activities:

I was able to get up and...tidy and do stuff around the house. I even started painting the other day (F\_30\_Fatigue Improved).

As well as being able to pursue bigger goals:

I am taking my...driving test (M, 32, Fatigue Improved).

One marker of particular importance to participants was how they felt after dialysis sessions. Some participants saw an improvement:

now I feel more normal after dialysis than before (M\_69\_Fatigue Improved).

Other participants did not notice any improvement in their fatigue, and their expectations were not met:

Yeah, I don't feel any different (laughs) (M\_75\_Fatigue Improved).

and

I don't know what I expected but... [the intervention] would maybe make me feel a bit better than I do (F\_59\_Fatigue Improved).

This shows the mixed perceptions of change in fatigue from the perspective of participants which at times did not align with the observed changes in fatigue following the intervention, which emphasises the complexity of fatigue and the personal nature of what constitutes meaningful change in fatigue.

## Intervention delivery

Participants discussed key characteristics related to the intervention delivery which could act as facilitators to engagement, including the timing of when and how it is offered, as well as the structure and duration of the intervention (Figure 1).

### *Right time and approach*

Participants discussed the best time and approach for uptake of psychological interventions. Most participants thought patients should be approached early on in their illness journey, such as at the time of diagnosis:

it should be part of the overall diagnosis and dialysis treatment (M\_69\_Fatigue Improved).

However, a few participants felt that acceptance of diagnosis would be needed before the intervention was offered to them:

When they've accepted it and perhaps, they're looking around for something helpful, but not at the beginning of their illness (F\_80\_Fatigue Improved).

As diagnosis and acceptance often do not occur simultaneously, gauging readiness is likely to be an important consideration for when intervention is offered.

Most participants agreed the best way to approach participants was during dialysis:

good time to do it [during dialysis], yeah. And because we also get bored! (M\_32\_Fatigue Improved).

This illustrates how during dialysis patients may have the time and attention to consider uptake of such an intervention. This again resonates with the importance of minimising time dedicated to the illness as dialysis already represents a significant time commitment. Participants also focused on the importance of establishing the relevance and potential benefits of the intervention when approaching potential participants:

so they would understand the book...they can see it says the things I am feeling also (M\_32\_Fatigue Improved)

and

show them the results of people that have... done well from it (M\_41\_Fatigue Deteriorated).

Another important consideration is the format of delivery, which was discussed across the interviews. Most participants said they would not have benefited from having an online version of the intervention:

I don't go online (F\_71\_Fatigue Improved).

### *Structure and length*

The structure of the intervention was well-received by participants, the intervention manual, sessions with a therapist, and working on goals/activities each week was described as motivating and manageable:

There were good ideas...to give yourself some motivation to look forward to do (F\_80\_Fatigue Improved).

Gradually covering the content of the intervention and working on goals/activities is also likely to increase their coherence of the intervention.

Additionally, most participants felt that the intervention was the appropriate length:

It was the right amount...everything was covered (M\_32\_Fatigue Improved).

However, some of the participants stated they would have preferred the intervention to be longer or include additional sessions with a therapist:

you get in...and then suddenly the weeks are finished (F\_71\_Fatigue Improved).

However, participants acknowledged the practical and financial limitations to having a longer treatment duration:

I do appreciate that it's a time to get round... people (M\_41\_Fatigue Deteriorated).

This subtheme highlights that there may be differences in preferences for how the intervention is delivered, lower and higher intensity options may be necessary to meet different needs.

## DISCUSSION

### Overview of findings

This is the first study to explore the acceptability of, and engagement with, a CBT intervention for fatigue in patients receiving haemodialysis. The theme of coherence of fatigue and the treatment model provided an overarching framework for the other themes in the analysis, with the perceived acceptability of and engagement with the intervention grounded in the perceived coherence of a biopsychosocial approach to fatigue and the CBT treatment model. The two main barriers discussed were the cognitive burden of the intervention and participants' illness and treatment burdens. Most participants described the role of the therapist as central to their engagement with the intervention. Three main processes of change were identified from the participants' narratives: establishing consistency in activity patterns, managing thoughts and emotions, and changing social identity. Participants' perceptions of the change in their fatigue

varied, with some perceiving a positive difference, while others not perceiving an improvement. Participants also discussed ways of improving uptake of and engagement with the intervention.

### Understanding and accepting the biopsychosocial approach to fatigue

Coherence appeared to be central to the acceptability of and engagement with the intervention here. Illness coherence refers to whether an illness (and its treatment) makes sense to the individual (Moss-Morris et al., 2002), and forms part of the CSM-SR (Leventhal et al., 1980, 1984, 2016). The concept of intervention coherence has also been proposed as a key construct of acceptability (Sekhon et al., 2017). Here, holding a predominately biomedical understanding of fatigue was a barrier to participant engagement and acceptance of BReF, since there was incoherence between an individual's understanding of their illness (and symptoms) and the treatment being offered. The value of coherence has been particularly evident in CBT for chronic fatigue syndrome (CFS) (Picariello et al., 2017a; Timmer et al., 2006). Similarly to CFS (Clements et al., 1997), physical attributions for fatigue and scepticism towards psychological interventions for fatigue have been previously observed among kidney disease patients (Picariello et al., 2018a). Stigma associated with psychological therapies is likely to be an important barrier (Clement et al., 2015). Therefore, establishing coherence related to the biopsychosocial approach to fatigue and treatment model is key.

### Processes of change

In line with evidence arising from mediational analyses of CBT for fatigue in other LTCs, the importance of addressing unhelpful patterns of activity and rest (i.e., cycles of boom and bust) has been previously observed (Van Den Akker et al., 2018; Hyland et al., 2021; Chalder et al., 2015) as articulated by participants here. This sets CBT for fatigue aside from standard CBT for mood disorders. Similarly, improvements in thoughts related to fatigue and emotions have been previously observed in quantitative (Hyland et al., 2021; Knoop et al., 2012; Van Den Akker et al., 2018) and qualitative studies (Dures et al., 2012; Picariello et al., 2017a). However, according to quantitative evidence, changes in mood alone are likely to be insufficient to lead to improved fatigue, again highlighting the importance of a fatigue-targeted approach (Knoop et al., 2012). This aligns with the CSM-SR, where cognitions are of particular importance in guiding coping behaviours. The role of social factors in fatigue is often overlooked in quantitative studies, but appears to be key according to qualitative evidence (Picariello et al., 2018a). Similarly, to the findings here, another qualitative study of CBT for fatigue in rheumatoid arthritis found changes to social interactions following treatment (Dures et al., 2012). The processes of change described by participants provide support to the proposed biopsychosocial approach to fatigue (Donovan et al., 2007; Picariello et al., 2017c).

### Burdens experienced by patients receiving haemodialysis

Two key barriers to engagement with the intervention related to the cognitive and illness and treatment burdens patients receiving haemodialysis face. Cognitive impairment is common, affecting 51%–76% of patients receiving haemodialysis (Dasgupta et al., 2018; San et al., 2017). The scoping review of fatigue interventions across LTCs found that the evidence in support of CBT and exercise was less consistent in neurological conditions, specifically poststroke, traumatic brain injury and Parkinson's disease, suggesting that cognitive difficulties may hinder the benefits of treatment (Hulme et al., 2018). The high treatment burden of dialysis and the presence of multi-morbidities have also been previously raised as important challenges of this patient population (Reid et al., 2016), particularly depression (Chilcot & Hudson, 2019). Symptom burden is also high in kidney failure (Almutary et al., 2013). Symptom management cannot be considered in isolation from the demands of the illness, as postulated by the CSM-SR. Therefore, interventions need to acknowledge the complex needs of patients through multidisciplinary input and/or a multi-symptom approach.

### Importance of therapist

The centrality of therapist support for engagement with the intervention was discussed by participants in this study, as previously observed in other qualitative studies of CBT for fatigue in other LTCs (Dures et al., 2012; Picariello et al., 2017a). The role of the therapist in treatment outcomes of psychotherapy, including CBT, has been previously reported (Fluckiger et al., 2018; Heins et al., 2013) and further substantiated by meta-analytic reviews comparing supported and unsupported digitally-delivered CBT (Andersson et al., 2014; Karyotaki et al., 2021). Remote delivery may be more cost-efficient to services and appealing to patients given the high treatment burden and disabilities in this population; however, retaining some element of guided support is likely to be necessary.

### Implications for clinical practice

The findings of this study provide important evidence on the acceptability of a CBT-based intervention for fatigue in haemodialysis and barriers and facilitators of engagement, highlighting the importance of coherence, in line with the CSM-SR and Sekhon's acceptability framework. Given the low uptake of the intervention, building an understanding of how to increase appeal of a behavioural intervention for fatigue in the context of a physical health condition is essential. Of particular importance to increasing appeal of adjunctive therapies was the burden of dialysis. Findings related to the processes of change provide support for the biopsychosocial model of fatigue and suggest that a transdiagnostic approach to fatigue, with some tailoring for the challenges of the specific condition, is

appropriate (Menting et al., 2018). The findings of the study accentuate that treating fatigue is essential, but needs to be integrated as part of wider illness self-management, meaning that practicality, flexibility, and tailoring lie at the core of a successful and effective intervention. As raised earlier, a multi-symptom approach is likely to be an appropriate way forward in this population given the complex needs, burden of dialysis, and limited healthcare resources. Beyond considerations specific to intervention development, when and how a psychological intervention for fatigue or a cluster of symptoms is offered is likely to be significant to uptake and engagement at the start given the role of coherence and existing attributions for fatigue.

## Limitations and future directions

There were several limitations to this study. Participants interviewed were likely to be more engaged and in better health: one participant dropped out before the interview took place and two participants were unreachable or unwell during the data collection window. Non-response and attrition biases are more general weaknesses pertaining to the feasibility trial. Only participants in the BReF arm were interviewed and the interview schedule focused exclusively on the intervention yet given the feasibility nature of the trial it would have been equally important to also capture experiences with the trial methodology to inform a future efficacy trial. Interviewing participants at multiple time points would have enabled a more dynamic understanding of the views of the intervention and perceptions of change, from expectations before treatment start to progress through the intervention and reflection following treatment completion. The analysis here was inductive in nature; however, based on the recently proposed acceptability framework, it would be valuable to further explore more systematically all constructs of acceptability as proposed in the framework, particularly ethical consequences and opportunity costs (Sekhon et al., 2017). In light of the overarching role of coherence here, it would be valuable to explore the acceptability of a biopsychosocial model of fatigue and a psychological intervention from the perspective of healthcare professionals as ultimately they represent a key link in the chain from referral to treatment. Finally, the complex needs of the population mean that a one-off phase of intervention development is unlikely to be sufficient, instead continuous and iterative testing and optimisation are necessary before pursuing evaluation (Levati et al., 2016; O'Cathain et al., 2019b).

## CONCLUSION

In conclusion, this nested qualitative study has provided valuable insights regarding the experiences of patients receiving haemodialysis with CBT for fatigue. Most importantly, patients' understanding of fatigue and acceptance of the treatment model play an important role for acceptability and engagement. In the context of dialysis,

consideration is necessary of the cognitive and illness and treatment burdens that may hinder engagement. Guided support alongside a self-management intervention promotes engagement. In addition to highlighting the complex needs of the patient population and how these may impact upon engagement, the findings also showed the complex nature of fatigue and the different processes of change through which fatigue improves. Overall, there was indication that a CBT-based intervention for fatigue is acceptable to patients receiving haemodialysis and the mechanisms of change align with the proposed biopsychosocial model of fatigue. However, further work is needed to ensure that it can be delivered in a way that is appealing and practical to patients, taking into consideration cognitive difficulties, comorbidities, the burden of kidney disease and dialysis.

## AUTHOR CONTRIBUTIONS

All authors made substantial contributions in the conception and design of the study and the interpretation of the findings. Frances Waite and Federica Picariello led the analysis. Federica Picariello led the acquisition of the data. All authors contributed to the write-up and approved the manuscript.

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## CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

## ORCID

Joseph Chilcot  <http://orcid.org/0000-0001-6427-4690>

Rona Moss-Morris  <http://orcid.org/0000-0002-2927-3446>

Federica Picariello  <http://orcid.org/0000-0002-2532-3290>

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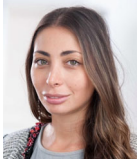
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#### AUTHOR BIOGRAPHY



**Federica Picariello** is a post-doctoral research associate and a health psychologist at King's College London. Federica's primary research interest lies in improving the understanding and treatment of fatigue across long-term physical conditions.

#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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