



## ORIGINAL ARTICLE

# Qualitative interviews results from heart failure survey respondents on the interaction between symptoms and burden of self-care work

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## Abstract

**Aims and objectives:** Following a cross-sectional survey, a sub-sample of participants was interviewed to explore the interaction between symptoms and burden of treatment.

**Background:** Burden of treatment considers both the work associated with illness and treatment, including self-care work, as well as the individuals' capabilities and resources to engage in that work. The recent survey revealed the existence of a complex interaction.

**Design:** Qualitative abductive analysis of semi-structured interviews.

**Methods:** Adults with heart failure who participated in the survey were purposely sampled and invited to participate in semi-structured interviews. Location and mode of interview varied by participant choice. Excerpts from the verbatim transcripts were assessed for interactions between symptoms and burden of treatment, and when identified these were characterised and explained. We followed COREQ checklist for reporting. The patient research ambassador group was involved from research design to dissemination.

**Results:** Participants ( $n = 32$ ) consistently discussed how symptoms altered their capability to engage in self-care work. As symptom intensity increased the difficulty of their self-care work increased. A number of intervening factors appeared to influence the relationship between symptoms and burden of treatment. Intervening factors included illness pathology, illness identity, the value of the tasks attempted and available support structures. These factors may change how symptoms and burden of treatment are perceived; a model was constructed to explain and summarise these interactions.

**Institution(s) where work was performed:** Portsmouth Hospitals University NHS Trust, University Hospital Southampton NHS Foundation Trust, and Solent NHS Trust, University of Southampton.

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**Conclusions:** The interaction between symptoms and burden of treatment is complex. Intervening factors—illness identity and pathology, task value and performance, and available support structures—appear to exert a strong influence on the interaction between symptoms and burden of treatment.

**Relevance to clinical practice:** These intervening factors present clinicians and researchers with opportunities to develop interventions that might reduce burden of treatment and improve symptoms and quality of life.

**Clinical trial registration:** SYMPACT was registered with ISRCTN registry: ISRCTN11011943.

**KEYWORDS**

burden of treatment, chronic heart failure, mixed methods, qualitative research, self-care, symptoms

## 1 | INTRODUCTION

Chronic heart failure (CHF) is accompanied by distressing, uncomfortable and disabling symptoms including dyspnoea, oedema and fatigue. These symptoms often persist despite optimal treatments (Alpert et al., 2017) which can lead to adverse symptoms (Albert et al., 2010). While patients may be supported by healthcare professionals, the onus for care often lies with the patient who is expected to participate in complex self-care regimens. Jaarsma et al. (2021) identify more than 30 components of these regimens, divided into three main areas of activity: maintenance (behaviours to sustain physical and emotional status), monitoring (tracking symptoms) and management (responding to signs and symptoms). These activities can constitute a significant personal workload for the patient who are likely suffering from disabling symptoms.

Intuitively disciplined adherence to self-care regimens is essential to symptom control and avoiding exacerbation, with the goal improved quality of life. Negative interactions between complex symptom burden and self-care work are an important but under-recognised problem and may explain some non-adherence to self-care regimens. The literature acknowledges that patients with CHF frequently appear to *fail* with self-care (Liljeroos et al., 2020; Toukhsati et al., 2015) with responsibility for adherence placed primarily on patient poor knowledge (McMurray et al., 2012).

## 2 | BACKGROUND

Burden of Treatment (BoT) theory (May et al., 2014) proposes effective participation in self-care is dependent on the balance between two main concepts: the burden of self-care work (workload) combined with the available personal and external resources to do that work (capacity) (Eton et al., 2012; May et al., 2014). Research in CHF and treatment burden has demonstrated that patients struggle with self-care work (e.g. multiple medications and barriers to accessing healthcare services) (Gallacher et al., 2011; Jani et al., 2013). Which

### What does this paper contribute to the wider global community?

- The analysis of interviews provided greater clarity on the relationship between symptoms and BoT after the survey results revealed a complex relationship with unexpected results, demonstrating the value of mixed methods research.
- Presents evidence that chronic heart failure symptoms create widespread burden in a patient's life that alters their ability to engage in the work required by illness and treatment that goes beyond altering health education and personal motivation.
- Intervening factors, identified in this research, may present clinicians possible options to alter patients' symptoms and burden of treatment with possible impact on patient quality of life.

is compounded by failures (e.g. siloed and complex healthcare systems) in healthcare service delivery, adding to BoT (Jani et al., 2013; Nordfonn et al., 2020). Emotional burden associated with accepting CHF illness and managing self-care regimens was observed (Nordfonn et al., 2019), and patients CHF self-care ability was influenced by personal capacity (Nordfonn et al., 2020). Systematic reviews (Austin et al., 2021; Boehmer et al., 2016; Demain et al., 2015; Lippiett et al., 2019; May et al., 2016; Roberti et al., 2018) demonstrated these problems appear common in range of long-term conditions.

In our previous work (Austin et al., 2022), validated tools measuring treatment burden were used in a sample of people with CHF where interactions with symptoms were explored. Symptoms were measured with heart failure symptom survey (HFSS) (Pozehl et al., 2006) and Minnesota living with heart failure questionnaire (MLHFS) (Bilbao et al., 2016; Rector, 1987). Treatment burden

was measured with the patient experience of treatment and self-management (PETS) (Eton et al., 2020). The brief PETS has two indices, workload and impact, which were used to summarise BoT. The impact index captures how engaging in self-care work affects participants' feelings and interferes with their role and social activity. The workload index captures the ease or difficulty reported with specific self-care work (Eton et al., 2020).

We reported strong associations between MLHFQ emotional sub-score and PETS impact index. Weak associations were reported between symptoms (HFSS score and MLHFQ physical sub-score) and PETS workload index (Austin et al., 2022). Sub-groups of participants were observed, whose scores on disease severity, symptom measures and workload were mismatched. For example, some respondents reported low symptom scores with high workload and vice versa. The results suggested the interaction between symptoms and BoT for patients with CHF is more complex—and more paradoxical—than is currently captured by these questionnaires.

Exploring complexities and paradoxes in quantitative data are best accomplished by qualitative investigations (Feilzer, 2010; Timmermans & Tavory, 2012). This gives opportunity to discover how patients account relevant aspects of their lived experiences of interactions between symptom burden and treatment burden. The following paper will explore (a) if an interaction between symptoms and BoT is experienced, (b) characterise the nature of observed interactions between symptoms and BoT, and (c) describe the impact of symptoms on engagement with the work of illness and treatment management. The aim of the paper is to develop a model that explains the observed interaction between symptoms of CHF and BoT.

## 3 | METHODS

### 3.1 | Design

This work is a part of a larger mixed methods research project, SYMPACT (Austin et al., 2020). Previously participants with CHF (for at least 6 months,  $n = 333$ ) had completed three questionnaires. Interim survey results were used to inform the interview schedule, (Appendix S1: final interview schedule). Semi-structured interviews explored participants' experience of living with and managing CHF, aligned with the BoT framework (Appendix S2: a priori BoT framework) with a focus on exploring interactions between symptoms and self-care work.

The Consolidated Criteria for Reporting Qualitative Research (COREQ checklist) provided a framework for reporting (Tong et al., 2007) (Appendix S3).

### 3.2 | Eligibility for semi-structured interviews

Adults (English speaking over the age of 18) with CHF, previous participants of SYMPACT, were invited to participate. Participants were in receipt of inpatient and/or outpatient care or attended a

community support group in Hampshire, UK. Exclusion criteria were as follows: participants in receipt of palliative care or with a decline in cognitive function (in the investigators' clinical opinion) or had moved out of the region.

### 3.3 | Ethics

Ethical approval was granted by University of Southampton Ethics Committee (ERGO: 41287) and the Nottingham HRA1 Research Ethic Committee, Health Research Authority (MREC: 18/EM/0339, IRAS: 247773). SYMPACT conforms with the Declaration of Helsinki principles (Rickham, 1964). SYMPACT was registered with ISRCTN registry: ISRCTN11011943.

### 3.4 | Purposive sampling

Participants were purposively sampled to ensure maximum variation. The purposive sampling grid was developed using key criteria from survey results. The following variables: personal characteristics (gender and age), illness characteristics (left ventricular ejection fraction [LVEF]) and questionnaire scores (HFSS, MLHFQ, PETS) were used to inform sampling. Purposive maximum variation sampling ensured a wide variety of participant characteristics and survey responses were captured in this sub-sample, ensuring representation of the survey sample and reflected both expected and unexpected results from the survey. Identified participants were approached by the local research team by telephone and provided with a patient information leaflet in the post. The method of consent and interviews were altered to facilitate remote interviews during COVID-19 pandemic.

### 3.5 | Data collection

After receiving written or verbal consent, interviews were organised between January 2020 and September 2020: face-to-face, telephone, or online video call according to patient preference and timing in regard to the COVID-19 pandemic (interviews paused between March and July 2020). Interview recordings were transcribed and uploaded into NVivo (QSR International, 1999), used to organise the data.

### 3.6 | Data analysis

Using the verbatim transcriptions of semi-structured interviews, any observed interactions between symptoms and the a priori BoT framework (Appendix S2) were identified, characterised and explained. Any excerpts from the interviews which related to the over-arching question do symptoms interact with BoT, were identified, coded and organised by themes. Those themes which characterised and described

the interaction were then examined for an explanation as to how they might explain the previously observed interactions in the survey. Using abductive analysis (Timmermans & Tavory, 2012), these themes were integrated to inform a model of how CHF symptoms interact with BoT. Abductive analysis encourages the researcher to carry forward their own experience together with previous research findings to inform the analysis and refine conclusions and observations. The a priori framework (Appendix S2) was used in previous work informed the coding structure (Austin et al., 2021). Themes were formed around the participant interactions between symptoms and BoT.

The same interviewer (RCA) conducted all the interviews; she is a nurse who completed this research as a part of her clinical doctoral research fellowship. Although RCA was a novice to qualitative research, she was supported by co-authors and had completed training in various interview techniques. Field notes formed a part of the interviewer reflective practice. Interviews continued until all researchers felt that maximum variation sampling was achieved, and multiple consecutive interviews revealed the lack of novel information in researcher reflections following the interview. This was confirmed in discussions with co-authors throughout the data analysis. Data were coded by RCA; codes and themes were checked and discussed with CRM and LS.

### 3.7 | Patient and public involvement

The patient research ambassadors (PRA), at Portsmouth Hospitals University NHS Trust (PHU), provided the patient and public involvement for this research. They made contributions from the design of SYMPACT where they edited patient-facing documents and reviewed the protocol. They also helped with recruitment acting as gate keepers to community support groups inviting the researcher to speak at those groups. They helped to refine the interview schedule and sense checked the interpretation of the analysis. They verified that the findings included in the research made sense to their own illness experience. Finally, they helped with the editing and creation of findings communication to participants of the study, in the form of a thank you letter.

## 4 | RESULTS

### 4.1 | Study population

Following screening (Figure 1), 54 participants were approached and 32 consented to interview. The maximum sample grid demonstrates the variability in the characteristics of those who participated (Appendix S4: purposive sampling grid). All participants chose for the interviews (in person, telephone or video call) to be conducted at their home, except one. Participants could choose to have a loved one present during the interview, in these cases verbatim data were not captured those individuals, but a summary of their contributions was captured. This was explained to them before the interview started. Interviews lasted between 32 and 113 minutes. Participants

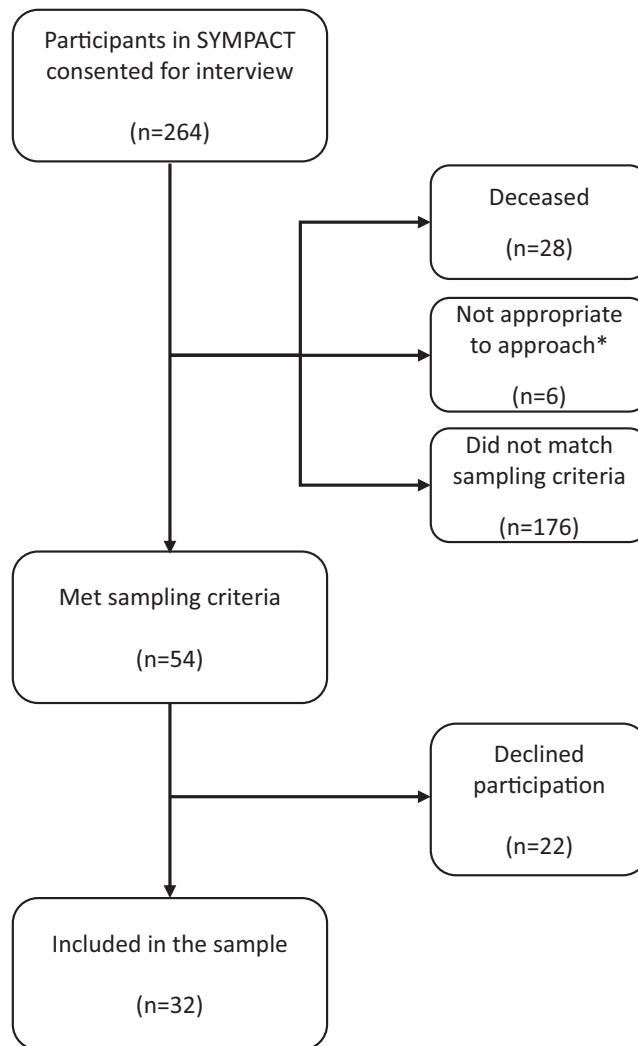


FIGURE 1 Flowchart showing participant eligibility process

were not known to the interviewer, nor had they been under the direct clinical care of RCA.

Participants (50% female) had a mean age 68 ( $\pm$  14 years). LVEF ranged between 8% and 65%. Table 1 shows detailed participant characteristics.

### 4.2 | Interview findings

Participants generally described an interaction between symptoms and participating in the work of self-care. In exploring what they said about this interaction, we were able to describe the nature of that interaction and how symptoms impacted on the ability to perform the self-care.

#### 4.2.1 | Symptoms of CHF interact with self-care work

The majority ( $n = 26$ ) of participants agreed that symptoms interacted with self-care work, based on their experience of living with

TABLE 1 Sample characteristics

Gender	<i>n</i>
Male	16
Female	16
Ethnicity	
White British	27
Asian	1
Unknown	4
Living situation	
Living alone	14
Living with others	16
Unknown	2
Heart failure type	
HFpEF	10
HFrEF	19
Unknown	3
NYHA classification	
I	5
II	7
III	5
IV	1
Unknown	14
Heart failure treatments	
Pharmaceutical CHF triple therapy <sup>a</sup>	22
Implantable cardiac device	11

Abbreviations: CHF, chronic heart failure; HFpEF, heart failure with preserved ejection fraction; HFrEF, heart failure with reserved ejection fraction; NYHA, New Your Heart Association.

<sup>a</sup>Triple therapy was defined as a participant who was on at least three medications from the following classifications: Angiotensin-converting enzyme inhibitors, Angiotensin receptor blocker, beta blocker, mineralocorticoid receptor antagonists, and/or Sacubitril/valsartan.

and managing CHF. Participants described how symptoms influenced task difficulty in both self-care work and activities of daily living. They explained how the relationship between symptoms and self-care work was dependent on symptom severity or activity attempted, proving multiple examples of how the relationship was situational (Table 2).

You don't know on a day-to-day basis if it is going to be a good day or bad day. So that can be quite frustrating. One day you'll get really breathless cleaning your teeth and another day you'll, manage it perfectly well.

(T141 F53yo)

Four participants were unsure that the association was true for them but stated that it was hard to evaluate for multiple reasons including: (a) it might be true for others, (b) the influence

of co-morbidities made it difficult view the relationship for CHF symptoms alone and (c) self-care work was seen as so valuable that even when symptoms made the work more bothersome, they described the work as easy despite high demand on time or energy (Table 2). These four individuals still shared experiences within their interviews reflecting on times where symptoms did alter the difficulty of self-care work.

One participant stated that symptoms would not interact with treatment burden, citing her positive mindset towards engaging in work around managing CHF. The high value attributed to performing self-care work meant, regardless of how poorly she felt, self-care work was still performed, while symptoms made the work annoying it did not make it difficult.

#### 4.2.2 | Intensity of CHF symptom intensity is linked with BoT

The interaction between symptoms and BoT appears to alter with symptom intensity, the activity attempted and passage of time. Around half the participants described how they would rate themselves in different places on the spectrum (low symptoms easy work to high symptoms hard work) dependent on the activity attempted or how they felt at a given time (Table 3). Symptom intensity seemed to have a direct influence on the perceived level of difficulty in relation to the work attempted (Table 3). Just over a quarter of participants' experience reflected the following association: easy symptoms meant easy work. The majority of the participants described situations where their experience reflected: manageable symptoms, manageable work or extreme symptoms, overwhelming work. If symptoms and/or work was overwhelming, all work was either delayed or not performed due to decreased personal capacity. Alternatively, patients may rely on support networks to assume the responsibility of self-care work, shifting the burden away from themselves. This could also shift the perceived level of difficulty to that task.

Um my daughter and granddaughter take me anyway to the [local district hospital] so I've got no problem, so I've always got someone with me.

(T108 F72yo)

#### 4.2.3 | Symptoms of CHF alter engagement with self-care work

Participants described how breathlessness, fatigue and forgetfulness together with side effects from their medications (e.g. dizziness) increased task difficulty. Thereby influencing the work associated with both self-care work and activities of daily living. This effect ranged between minimal and maximal effect (Table 4). Participants described how when symptoms increased the difficulty of work also increased resulting in four main outcomes: (1) recruit others to do

**TABLE 2** Exemplar quotes illustrating participants' thoughts and experiences about the statistical association between symptoms and BoT

Symptoms of CHF interact with self-care work	
True	<p>'Yes, that is true! One hundred percent'. (T070 F37yo)</p> <p>'But... you know I often find when I've got a cold or whatever you know everything just seems like an effort (laughs) and I think it's because your body's busy fighting whatever and you know you feel drained because of it'. (T132 M38yo)</p> <p>'Well not to take my tablets but to go to the doctors it is hard. It is hard'. (S104 F87yo)</p> <p>'Yes, and it's also true... in the fact of not only around your health, but around doing things socially, whether it be preparing your foods, um or hygiene? Uhm, I have to think do I have the energy to get myself out of a bath? No? So, I have to shower because it takes less energy. So it does have a major impact. The more I think, the more... issues you have regarding your condition, the more impact it has on your life... style'. (B004 F65)</p> <p>'I consider that I am lucky umm because I can still do virtually everything easily, but I got a friend who I made through going to the heart group and she is a lot worse than I am. So even getting out of bed for her in the morning is an effort. You wouldn't think that we had the same condition because she is so much worse than I am and she finds it- she does find it hard work to do everything, and to keep things going. So yes, I think your analogy is right, the more you've got the harder it is'. (T328 F74)</p> <p>'Yes, it does yeah, it can vary in degrees, so like if I'm having a good couple of days then, I'm in, in sort of my mind is clearer. I can focus more, um...I can perhaps try and do a bit more research. But on poorly days um.... physically and mentally I'm weak as a kitten'. (T141 F53yo)</p> <p>'My life seems to be run by my heart things; I don't find the work hard. I would imagine if I was in a worse state than I am in my physical state, I couldn't walk, I couldn't breathe properly. I can imagine that doing the work would be a lot harder, because you are so involved how you are feeling about this condition. Attempting to do anything would be really difficult. But personally, I feel very lucky, that my symptoms on the physical side of things aren't horrendous so the work isn't very hard'. (L015 F62yo)</p> <p>'It impacts you in lots of different ways and I think, I think when I first came out of hospital though I was a lot better I wasn't well um and I probably struggled a bit at that point to do the simple things in life, you know. Um but also as always it was something that hits you emotionally and you feel that as well. So... um if you're not feeling good um emotionally it affects your physical ability to do things and that that sounds odd but it is true you know!' (L016 M79)</p> <p>'...then I suddenly started getting breathless and it made life harder because then I couldn't start walking and then obviously, I started on the medication and life became a little bit easier. So life was easier to do things. Then as the times gone on... um... them medications although it obviously must help, I have well the symptoms have got worse. So things are ... harder to do'. (L033 F59yo)</p>
Unsure	<p>'I think a lot of it, I mean obviously the symptoms can be severe. I think a lot of it depends on the person himself. I mean um... (pause) I had some people myself when I've been work [as a nurse] It-- it depends on the person, how well they take to um - heart problems'. (T017 F83yo)</p> <p>'Well, (pause) I mean the thing is though you are asking me specifically about heart failure, isn't it? Mine is kind of loaded and that, 'cause I've got diabetes, but these are other factors that I have got to kind of gotta put into that as well. So, it's not just about cardiomyopathy it's about diabetes and Lupis. So and they are all kind of—you know... at the moment I'm kind of okay, I'm not 100%'. (S052 M51yo)</p> <p>'(Pause) Yeah (pause) I think that is true of life in general! Yeah, I don't find any of it difficult. You know as I said you know, if it wasn't me who showed an interest in my own health care - You know, how do you not... I don't understand. You know, I know I've got to go to hospital, so I don't think - OH CHRIST! I've got to go to hospital, oh woe is me, it's the end of the world. I'm oh that's all right then. I hop on the bus, you know, I go out there- I take the positive from it I have a little look round town... I - I - I like to go in and talk to them. They keep - they kept me alive!' (S030 M53yo)</p>
No	<p>'...um no, I think again it's your attitude of mind, um I talk to myself; I have got you know; my heart condition isn't ah... it's like I said I try and see the positive. Doing my pills whether I'm more breathless or less breathless, I don't know whether it would make any difference because you sit down to do it because it's not physically exerting to put pills into a small box. Um and in going to places umm if I didn't have any transport again, if I was more breathless then yes, I would see it annoying and an issue. But if I had it less and I had to go to the doctors, I think, it's swings and roundabouts'. (T122 F55yo)</p>

the work, (2) adapt the task, (3) delay the task or (4) the task is not performed.

Symptoms and treatment side effects also appear to create an emotional affect within participants. The nature of the interaction appears to vary between a minimally reported affect to an extreme affect (Table 4). Those who reported minimal emotional affect also

reported low symptom burden. Participants cited multiple reasons for the ease of the work such as, perceived good medical treatment, previous life experiences, acceptance of their prognosis or the support of informal caregivers, but this was not always the case. Some participants with a mild symptom burden reported experiencing a more intense emotional affect. Participants with more intense

TABLE 3 Intensity of CHF symptoms are linked to BoT

	Exemplar quotes
The interaction is dynamic due to	<p>Activity attempted:</p> <p>'Um no I don't think I find it a problem I mean um just organising a medication making sure you take it etc um... there's been a couple of times where I've forgotten to take it but literally um it's not been a problem.</p> <p><i>Interviewer: And what about something like coming to terms with heart failure and what it means for your life and future, is that different?</i></p> <p>Yeah, it can be um I try not to think too long and hard about it. I- it's one of those situations where if you spend a lot of time thinking about it. You get worse. It gets- you get depressed and so on um as I've said to you when you're drifting off to sleep um that's the time when you start thinking about some of these things and um that's not good. um yeah- yeah'. (L016 M79yo)</p> <p>'Well... sitting still, I can cope with it reasonably well. I mean sitting her talking to you I feel totally fit! You know? But if I got up like to answer the door for my son when he comes round. I'd have to hang off his shoulders until I came round. Um... having started from the I feel perfectly fit condition and so if the activity is of that nature, then I'm edging towards the upper end of the scale'. (T137 M78yo)</p> <p>In relation to time:</p> <p>'I can quite easily see if I was still struggling like I was a year ago and having to take all these pills and probably even more, but I definitely find-- that I feel that it is you know impacted my life a lot more'. (T132 M38yo)</p>
Level of symptom intensity relates to difficulty level of self-care work	<p>Easy:</p> <p>'Well I, I, ahh... It [meaning heart failure] don't appear to affect me that much to be honest'. (S107 M87yo)</p> <p>'umm I don't- I don't know because I haven't got that many symptoms now like I did beforehand obviously'. (T037 M68yo)</p> <p>Manageable:</p> <p>'...because of the heart problems I've got I tend to be lethargic which makes me very lazy around the house. So, I don't do as much housework as I should, and I can't do it all in one go. I sort of have to take a couple of days to do it'. (T145 M59yo)</p> <p>'There is always a price to pay. Even if you don't think at the time there is. Even if you think your feeling quite ok and at this particular time you can achieve this task that you wanted to do, then you will pay the price for it'. (T141 F53yo)</p> <p>Overwhelming:</p> <p>'I can't remember anything! If that's a day of not remembering. Sometimes I remember fine other days I just forget I mean... it's no good saying I shouldn't forgot or put it on the fridge or whatever. I've done putting it on the fridge that works to a point, but then you've forgot it's on the fridge. No so it... nothing really helps because it's the memory and the brain'. (L032 M80yo)</p> <p>'I've noticed as the symptoms has worsened the breathlessness has come on more quickly umm you know the palpitations, the ectopics, leg weakness, and general feeling weak um... and so um...it affects your ability to do things on a day-to-day basis. In your head you...ah...you think you can do things, but then you realize your body's not going to allow you to do that'. (T141 F53yo)</p> <p>'Yes! There are days where I just can't be bothered whatsoever. I just can't be bothered the depression gets hold of me because of it [heart failure] and I think what is the point of me actually being here? If I wasn't here, then I'd be free of the pain and the problems and whatever problems I may be causing other people I'd be free'. (T145 M59yo)</p>

symptom burden, emotional affect appeared related to tasks with high personal value, physical limitations, not completing self-care work or in wrestling with life-limiting diagnosis (Table 4).

Participants with an extreme symptom burden tended to report a more extreme emotional affect. The latter described as living a life that was stolen and being fearful of the life-limiting prognosis, of having no hope or release from symptoms, alongside an additive effect from co-morbidities (Table 4).

We observed that some participants reported lower emotional affect despite higher symptom burden. These individuals cited factors like their social support or informal caregivers, attributes of positivity or resilience, and an acceptance of their life-limiting diagnosis, all of which may contribute to their perceived lower emotional affect.

No...You know, we are sort of working as a team. If I forget something, she [L002's wife] usually remembers it, that sort of thing.

(L002 M72yo)

#### 4.2.4 | Explaining the interaction between symptoms and BoT observed across the themes

In the recursive adductive analysis process through examining the above themes, factors were identified across the themes which appeared to influence the interaction between symptoms and BoT. These factors were observed as sub-themes present across the main themes; we chose to classify them as intervening factors as they

TABLE 4 Symptoms of CHF alter engagement with self-care work

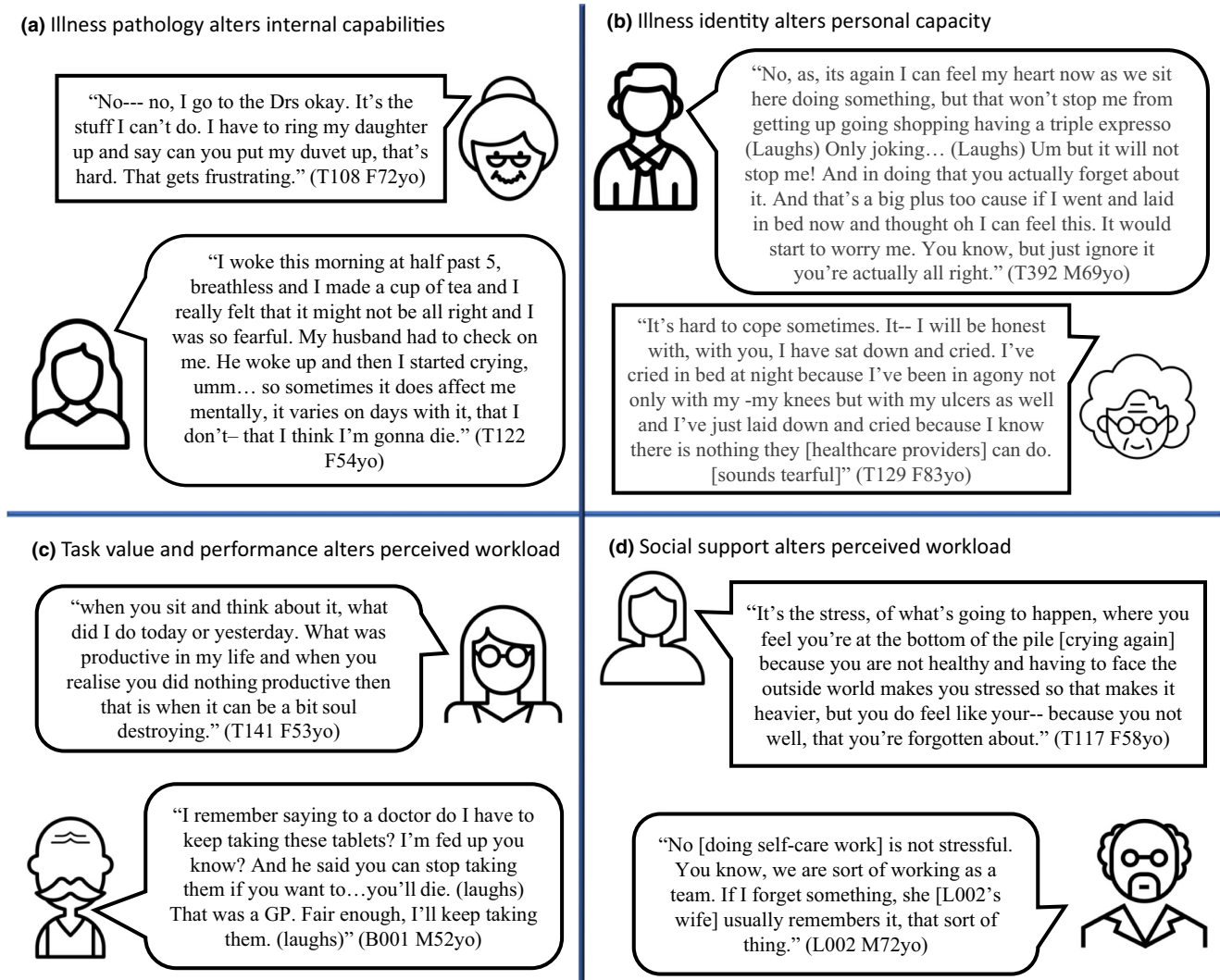
	Exemplar quotes
Physical symptoms	<p>Minimal effect:</p> <p>'But to be honest it [heart failure] doesn't affect me'. (S107 M87yo)</p> <p>Manageable effect:</p> <p>'It's affecting me I- I avoid certain things (...) but I have noticed that when I'm carrying heavy things I quite often start struggling with my breathing as well I'm assuming that's probably because I'm exerting more energy and then probably struggle a bit more, but I don't know why?' (T132 M38yo)</p> <p>'Definitely the physical implications of it. I have to think about, well I can park or how far it is to walk. Prior to the heart failure that wouldn't be a problem. But I have, you know, to think is the blue badge space available is... and that sort of thing and that... that's irritating'. (S110 M57yo)</p> <p>Maximal effect:</p> <p>'Well not to take my tablets but to go to the doctors it is hard. It is hard.</p> <p><i>Additional Information: daughter adds that her mum wouldn't even be able to get in and out of a taxi on her own'. (S104 F87yo)</i></p> <p>'It's like waking up and thinking, 'I'm going to get up tomorrow and I'm going to this and I'm going to do that'. Then you wake up and think I don't want to get up, or you get up and have a shower and by the time you come back the bed looks inviting because you are so fatigued. You think I could lay down and go back to sleep. You don't want to be like that because the sun is shining you want to be out there doing things'. (PHT117 F58yo)</p>
Emotional affect derived from limitations due to symptoms or treatments	<p>Minimal effect:</p> <p><i>Interviewer: so all of that sort of work that's caused by their heart failure they find that emotionally difficult or stressful do you ever find that?</i></p> <p>'No. More than anything else, I've been through in my life and-- no one-- that's just part of life'. (L032 M80)</p> <p>'You have to lead a normal life, or you won't, but 'Blimely don't get any library books out'... you know... that's what [Jim] said... 'don't get any long play records' (chuckles). It's TRUE. (claps) You know, you, you know, I go, we go down to cardiology in [local district hospital] there and you sit there and I... I think God! Blimely, I hope I don't look like this...you know. They are... they're scared I suppose. They're scared of their own mortality. You know... I'm well aware that one day...Yeah, and I, I, I say to myself right if there is nothing on the other side then that's it and if there is then I'll see my daughter [who died at a young age] again (claps)'. (T392 M69yo)</p> <p>Manageable effort:</p> <p>'YES, not being able to do those things could be a bit depressing. I'm not a depressive person, but whatever you want to call it, but it does have that effect... those limitations'. (T137 M78)</p> <p>'If I forget to take my pills then that really puts me in a quandary, and if I drink too much wine. It puts me into a massive panic. I forget. Yeah, my mind, my mind actually closes over. I forget things very easily, so it frightens me, I put alarms on my phone to take my pills. I have to make it public to remind myself'. (T122 F54yo)</p> <p>Maximal effect</p> <p>'It's a bit of a (sigh) a round- circle if you like because there is just no end to it all. 'Cause I get depressed about the heart condition which causes the anxiety which makes me even more depressed. And then I get anxious about being depressed about condition which I wish that I didn't have, But I do have. And it doesn't seem to be um... an end to it'. (T145 M59yo)</p> <p>'It impacts without a doubt with every day and with your future and how much that is fear of aggravating the current and existing symptoms and how much of it is just me being careful. I couldn't differentiate. (...) I don't wanna end up in [hospital] again, and if I don't end up in [hospital] I'm gonna end up in a box. (...) I've got to be sensible. So, the fact that that is there at the back of my mind IMPACTS on ANYTHING I want to do'. (T144 F86yo)</p> <p>'It's the stress, of what's going to happen, where you feel you're at the bottom of the pile [voice emotional] because you are not healthy and having to face the outside world makes you stressed so that makes it heavier, but you do feel like your-- because you not well, that you're forgotten about'. (T117 F58yo)</p>

appeared to influence the observed relationship between symptoms and BoT. These intervening factors were grouped into four categories: (1) illness pathology, (2) illness identity, (3) task value and performance, and (4) available social support structures. These observations were throughout the data set, but exemplar quotes and examples are provided (Figure 2).

#### *Illness pathology*

Observations from participant interviews described how the factors around CHF illness pathology was noted to alter physical and mental functions (internal capabilities) (Figure 2a). Included in the factor of illness pathology is both the effect of illness and treatments on patients' capabilities as well as the resultant healthcare service





**FIGURE 2** Exemplar quotes illustrating the interaction of symptoms with intervening factors. Icons from various artists (Vectorstall, alimasykurm, mooms, Teewara soontom, Nikita Kozin, Becris, nook Fulloption) on <https://thenounproject.com> (Vectorstall et al., 2022). [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

pathway they entered due to illness characteristics. While this might be attributed directly to CHF or treatment side effects, decreases in capabilities were also described in relation to co-morbidities and the cumulative effect of illness(es), hence why we described this factor more broadly as illness pathology. The resultant limitations from symptoms influenced the perceived difficulty of a given task. Additionally, these processes also appeared to affect task performance, which could lead to further emotional affect and/or create additional work in recruiting help.

You, you get to the point where the symptoms start to um... outnumber the need to do something. So, like more difficult it becomes the less likely you are... to either carry on doing that certain thing or even attempt to start to do that thing.

(T145 M59yo)

#### Illness identity

Participants varied in how they viewed themselves and their illness. While symptoms often informed this viewpoint, other factors like previous life experiences and personality also seemed to shape illness identity (Figure 2b). Illness identity appeared to alter the perception of symptoms, the difficulty of the self-care work and individual capacity influencing overall BoT. As an intervening factor illness identity offers some explanation for anomalies in the data. For example: T392 (male, 69 years old, HFREF) who experienced benefits from treatments, he rated symptoms and BoT as very easy. His personality and previous life experiences had built high personal resilience. He viewed CHF as a challenge and refused to let illness affect his life. Despite having symptoms, he refused to acknowledge them. He viewed self-care work at home as habit and visits to the doctor as valuable, creating minimal BoT. In comparison, T137 (male, 78 years old, HFREF) was on optimal

medications, but desired more treatment options for unresolved symptoms. He rated his symptoms as severe, but his burden as low. He believed his age and illness characteristics excluded him from desired treatments. He was discharged from specialist heart failure care and rarely sees any medical professionals. He has adapted his life to incorporate self-care work as habit. When his symptoms change, he does not seek help as he has been told there is nothing more that can be done.

I feel as though I've been shunted. Like in a railway shunter. Like I've switched at the points and I'm sitting waiting. I don't have any prospects or things that can be done for my condition that will improve it.

(T137, M78yo)

#### *Task value and performance*

The value assigned to self-care tasks by participants altered perceived difficulty. While sometimes this was straightforward (high value = easy task), the assignment of value can also be complex. If a task was difficult or has negative side effects, then the difficulty level is less straight forward (Figure 2c). High value on difficult tasks can result on reporting lower difficulty regardless of energy or effort expended. For example, T144 and T384 (female, 86 and 90 years old, HFpEF) both described how medication management took a lot of time and energy to perform, but they both described how they valued that task. It made them feel like they were contributing to improving their health, despite the energy and effort required.

I know that I'm still mentally alert, but I wonder about some of the other people, who may not be as old as me, who are not as mentally alert as me. How the devil do they sort them [medications] out!? (...) maybe they've got a way at the pharmacy or whatever, but that would take some sorting cause they are not all the same- some are morning only, some are evening only, some are three times a day. I do this job when I'm more alert and when I'm not weary or anything. It's an am [morning] job. Because without a doubt it's a job.

(T144, F86yo)

Ability to perform self-care work and everyday activities appears to inform illness identity by either stripping self-worth or building resilience (Figure 2a). The value of the task informed illness identity based on task performance. In the above example, doing the work built resilience, alternatively if unable to do valued tasks negative emotional affect was observed.

#### *Available support structures*

The support structures accessible to participants were wide ranging (e.g. family friends, healthcare professionals and community group). Support structures were seen as a positive influence by the participants, increasing their capacity to perform the work successfully by

improving availability of resources (Figure 2d). Participants also gave examples where well-intentioned support from family or friends added to burden as it lowered their sense of self or changed their role affecting their illness identity.

Well as I say, it worries me, because as I've got to ask people all the time to take me [to health appointments]. And [daughters name] never complains.

(S104 F87yo)

Alternatively, when support was required/desired by participants but not received from healthcare providers or other support structures this decreased participants' capacity by lowering the accessible resources. When CHF symptoms changed they did not feel there was accessible support available (Figure 2d). For example, T129 (Female, 83 years old, HFpEF) despite reporting living with a moderate amount of symptoms she reported low treatment burden. The self-care work she was in charge of (e.g. medication management) was habitual but as attending her local surgery was not physically possible, her self-care work associated with CHF was decreased resulting in a low reported BoT.

I don't go to the doctors anymore because I umm- I'm in a wheelchair and I've got one of those electric scooters. And- and it's not always possible to get into the doctors, not in one of those [scooters] and I could never walk into one.

(T129 F83yo)

## 5 | DISCUSSION

These findings provide evidence that symptoms interact with a person's ability to participate in the self-care work, providing explanations into why PETS workload index scores were lower than expected (Austin et al., 2022), through the identification of intervening factors. All participants described situations where symptoms of CHF had made the work of illness management more difficult, where the more intense symptoms became, the more difficult self-care work became.

### 5.1 | Factors which influence symptoms in CHF

Chronic heart failure symptoms are subjective and may be difficult to assess by patients and healthcare providers. Nordfonn et al. (2019) described this is more than physical process and includes emotional challenges around, accepting CHF diagnosis, self-care work and alterations to identity. The subjective nature of CHF symptoms and the emotional affect resultant from alterations in personal capabilities may mean that self-care work is viewed as a reminder of what was lost, and so greater burden is experienced without a similar intensity of symptoms.

A person's illness identity may alter how patients report their symptoms, due to individual levels of adaption to illness. Participants who described living limited lives enforced by symptoms of CHF, treatment side effects or comorbidity symptoms reported extreme ends of the symptom spectrum. Participants adapted and limited lives to cease any activity that exacerbates their symptoms, hence lowering symptom burden. Alternatively, participants who described how the illness had stolen their life and became engulfed by illness often reported more intense symptom burden, commonly observed in patients with unsatisfactory healthcare interactions. This is similar to observations seen by Van Bulck et al. (2018) in people with congenital heart disease. By considering a person's structural resilience, this may explain the variability of the symptom scores they reported, both participants who reported low symptoms but high BoT or vice versa. These observed paradoxes are further explained when looking at factors that influence BoT.

## 5.2 | Factors which influence BoT

In describing BoT, participants discussed how self-care tasks captured by the workload index (PETS), had been incorporated as habits or as normalised life experiences. When self-care work was spoken about in these terms, those participants also appeared to attribute a high value to performing that work. Alternatively, they also described how when symptoms became overwhelming, they turned to support structures to take on responsibility for those tasks. This may explain why patients with high reported symptoms may also report low BoT and self-care work.

While this reassignment of work to a loved one may appear to alleviate the burden, Gallacher et al. (2011) and Jani et al. (2013) described how informal caregivers added to patients' self-care work by requiring communication and organisational work. Together with the added feeling of guilt due to reliance on others (Kitko et al., 2020; Nordfonn et al., 2019), this may impact on resilience. This may help to explain, how in our survey why the correlation was weak between symptoms and workload index, but strong between symptoms and impact index, which captured how engagement with self-care work affect the participants' sense of self (Austin et al., 2022).

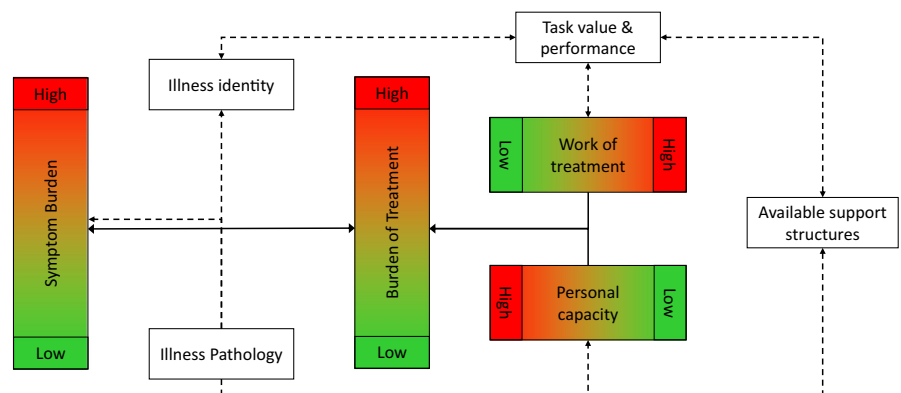
In the interviews' participants spoke of self-care work, not included in PETS workload index (e.g. healthcare co-ordination and exercise), as factors which were heavily influenced by symptoms. Interviewed participants reported that symptoms could decrease accessibility to healthcare services and previous negative interactions made them less likely to seek assistance from those healthcare professionals. Previous research findings also reported that healthcare interactions are key to patients perceived BoT (Gallacher et al., 2011; Jani et al., 2013). By excluding these key tasks in CHF self-care work from the PETS workload index, the observed lower workload scores and weaker correlations may reflect those exclusions.

## 5.3 | Model to explain how symptoms and BoT interact

The interaction between symptoms and BoT was not as straightforward as we had expected—Figure 3 sets out a model of that complex interaction. In describing the interaction of symptoms with the work of participating in their care, patients with CHF acknowledged that symptoms could affect their ability to do this work, but factors present in their lives might alter how they reported on the difficulty of those tasks. First, in considering symptom burden, illness pathology factors including CHF-specific processes, co-morbidities and treatment side effects must be considered. The limitations imposed by symptoms resulting from illness pathology inform illness identity and influence patient's capacity. Illness identity may affect how self-care work is valued and performed. The role of available support structures also alters treatment burden by altering illness identify and pathology, through multiple processes (e.g. physically unable to attend medical appointments or social isolation caused by not wanting to be a burden).

Second in considering BoT, the balance self-care work and personal capacity needs to be examined. In the interviews, participants explained how self-care work was influenced by their illness identity which informed the value assigned to a task and the results of performing tasks. The difficulty of the work was also informed by the accessibility of available support structures that ranged from loved ones to healthcare services. Personal capacity was influenced by illness pathology altering internal capabilities (i.e. physical, mental,

**FIGURE 3** Model of how symptoms interact with BoT. Solid lines represent a relationship that was observed in the survey and interview data set. Dashed lines represent a relationship that was observed in the interview data set. [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]



spiritual and emotional). When the self-care work outstripped personal capacity, the person would turn to available support structures to increase their capacity by recruiting others to perform the work of treatment. If assistance was not accessible, the work was not performed. The interaction of symptoms with BoT is complex, with identified intervening factors appearing to influence both symptom burden and dimensions of BoT, which then alters how they relate to each other. The model offers an explanation of the broad distribution of data observed and statistical associations from our survey results.

## 5.4 | Limitations

While there were limited ethnic minorities represented in this subsample, it did represent the overall SYMPACT population. The sample includes a broad range of CHF characteristics in a single country in England, so differences in CHF care pathways may further alter the conclusions and model presented.

An acknowledged limitation of the sequential explanatory mixed method study design used is the lengthy timeframe to complete data collection (Ivankova et al., 2016). A pragmatic approach was taken using interim analysis to inform our interview schedule. The final survey results were used to inform the analysis of the interview data.

While some participants ( $n = 6$ ) recounted a story with most salience for them, over their experiences of CHF. The experiences varied between emergency cardiology treatments, as well as multiple chronic illnesses. These observations were included, as participants commented on the inability to untangle a specific illness experience due to the commonality of symptoms. We view this as a strength as it adds to the transferability of these results to other chronic illnesses.

This model was built with data pertaining to how participants described the relationship between symptoms and BoT. We acknowledge that health literacy and healthcare service complexity may also contribute to this phenomenon, as they are more commonly blamed for patients' poor self-care engagement. In this research, while these concepts were discussed in broad terms, the focus was on the interaction between symptoms and BoT in general.

## 6 | CONCLUSIONS

Burden of Treatment is the balance between workload and individual capacity, where the workload associated with chronic illness management (self-care work) is thought to outstrip patient's capacity. To date perceived failures to engage in self-care are commonly attributed to patient's health literacy and healthcare system complexity. Symptoms, by their very nature, can decrease a person's capacity and increase workload difficulty. If that person has available social support, then this decrease in capability may not be noticed by healthcare professionals. If they lack that support then the

work is likely to be put off, or not performed, which may result in hospital admissions, where commonly CHF patients are labelled as non-compliant. The novel observation in our research highlights that contrary to current thoughts, these readmissions may not be due to poor health literacy or a lack of motivation. Instead, the nature of CHF illness and persistent symptoms may keep patients from engaging in this work.

## 7 | RELEVANCE TO CLINICAL PRACTICE

Symptoms of CHF can stop a patient from engaging with their self-care work. This can be a direct interaction (e.g. legs too swollen to mobilise to healthcare appointments) or indirect (e.g. a life stripped of value due to symptoms, becomes depressing to live). Our results are helpful to clinicians for patients on maximal medical therapies with ongoing persistent symptoms, as it offers the opportunity to explore both additional symptoms and factors not typically assessed in clinical heart failure evaluations. By incorporating BoT into clinical evaluation, health professionals can address ways to enhance care co-ordination with patients' and their social support networks. It may be that improved CHF symptom management and more accessible clinical support alongside the consideration of patient's illness identity and value assigned to self-care work may decrease BoT, but more research is needed to explore whether this relationship can be modified by interventions.

### AUTHOR CONTRIBUTIONS

RCA drafted this paper. RCA designed the research with guidance and support from CRM, LS and PRK. RCA analysed the data with support and guidance from CRM and LS. Interpretations of the data analysis were discussed between all authors and then described by RCA. CRM, LS, AR and PRK critically reviewed the manuscript for intellectual and clinical content. All authors approved the final version of the paper. RCA is the guarantor.

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Chris Stapes and Darren Jenkinson) provided introductions to community support groups, editing patient-facing documents, creating short name of study, informing study logo choice, sense checking conclusions drawn from data and editing the findings communication to participants. Linda Morris and Kirsten Hobday (medical secretaries at PHU) transcribed 60% of the interviews.

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## CONFLICT OF INTEREST

Professor Alison Richardson is a National Institute for Health Research (NIHR) Senior Investigator. Professors Carl May and Alison Richardson collaborated to develop burden of treatment theory. Dr Rosalynn Austin receives support from the NIHR ARC Wessex and was funded by an ARC Wessex Internship.

## DATA AVAILABILITY STATEMENT

Data will be provided at reasonable request.

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## SUPPORTING INFORMATION

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

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