

# BMJ Open Do chronic heart failure symptoms interact with burden of treatment? Qualitative literature systematic review

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## ABSTRACT

**Objective** Explore the interaction between patient experienced symptoms and burden of treatment (BoT) theory in chronic heart failure (CHF). BoT explains how dynamic patient workload (self-care) and their capacity (elements influencing capability), impacts on patients' experience of illness.

**Design** Review of qualitative research studies.

**Data sources** CINAHL, EMBASE, MEDLINE, PsycINFO, Scopus and Web of Science were searched between January 2007 and 2020.

**Eligibility Criteria** Journal articles in English, reporting qualitative studies on lived experience of CHF.

**Results** 35 articles identified related to the lived experience of 720 patients with CHF. Symptoms with physical and emotional characteristics were identified with breathlessness, weakness, despair and anxiety most prevalent. Identifying symptoms' interaction with BoT framework identified three themes: (1) Symptoms appear to infrequently drive patients to engage in self-care (9.2% of codes), (2) symptoms appear to impede (70.5% of codes) and (3) symptoms form barriers to self-care engagement (20.3% of codes). Symptoms increase illness workload, making completing tasks more difficult; simultaneously, symptoms alter a patient's capacity, through a reduction in their individual capabilities and willingness to access external resources (ie, hospitals) often with devastating impact on patients' lives.

**Conclusions** Symptoms appear to be integral in the patient experience of CHF and BoT, predominately acting to impede patients' efforts to engage in self-care. Symptoms alter illness workload, increasing complexity and hardship. Patients' capacity is reduced by symptoms, in what they can do and their willingness to ask for help. Symptoms can lower their perceived self-value and roles within society. Symptoms appear to erode a patient's agency, decreasing self-value and generalised physical deconditioning leading to affective paralysis towards self-care regimens. Together describing a state of overwhelming BoT which is thought to be a contributor to poor engagement in self-care and may provide new insights into the perceived poor adherence to self-care in the CHF population.

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## INTRODUCTION

Chronic heart failure (CHF) is increasing in prevalence, it is now estimated there are just

## Strengths and limitations of this study

- This is the first systematic literature review to explore the role of symptoms in burden of treatment in chronic heart failure (CHF).
- This is a review of previously published qualitative studies; observations are restricted by the choice of published quotes from the included articles, and our conclusions were formed by using data to develop explanatory ideas different from those of the original researchers.
- Difference in articles, like various healthcare settings, and broad patient characteristics strengthens the confidence that our observations are common in the CHF patient population.
- The innovative methods to visually illustrate the qualitative data, allows the reader to observe the depth and breadth of the themes outlined in the results.
- Examining existing qualitative literature with a different theoretical framework may form the foundation for an adaptation to burden of treatment theory with practical application to CHF service delivery.

under 1 million patients living with CHF in the UK.<sup>1</sup> Despite major advances in its treatment, many people with CHF experience substantial symptom burden and life-limiting prognosis.<sup>2-4</sup> The focus of CHF management is increasingly centred on self-care.<sup>5</sup> This includes behavioural changes (limiting fluid intake, diet restrictions, physical activity); self-monitoring of physiological processes (weight gain, fluid retention, breathlessness, fatigue); management of multiple medications; and appropriate help-seeking in response to symptoms. These self-care activities form the core of patient workload or treatment burden. It has been suggested that poor adherence to self-care regimens contributes to delays in seeking help, hospital admissions, increasing treatments and costs, and poor patient outcomes.<sup>6</sup> It should be noted, however, that experiences of illness and adherence to self-care regimens may be

influenced by CHF symptoms or comorbidities, such as cognitive impairment,<sup>7</sup> anaemia<sup>8</sup> and fatigue.<sup>9</sup>

Understanding interactions between symptoms and treatment burden in CHF is an important question, which has yet to be explored. It has been proposed that as symptom burden increases, there is a reduction in the affective, cognitive, relational, informational, material and physical capacity of people with long-term conditions. This reduction in capacity is reflected in increases in experienced burden of treatment (BoT), the dynamic modifiable workload delegated to patients.<sup>10–12</sup> BoT theory<sup>12</sup> explains how patient workload (assigned illness tasks) and their capacity (elements influencing capability), impacts on the experience of illness; where overwhelming BoT leads to patient disengagement with self-care.<sup>10 12–16</sup> BoT theory was chosen as it provides a patient focused framework to explore CHF patient experience, focusing on patients' individual capacity, illness workload and their effects. We have previously argued<sup>17</sup> that interactions between symptoms and treatment burden are important in CHF and in this qualitative literature review we identify, characterise and explain these interactions as they are reported in the literature, and explore their implications for understanding patient experience and self-care outcomes.

### Aim of review

To undertake a systematic review of qualitative literature on the lived experiences of CHF to identify, characterise and explain interactions between symptoms and BoT using mixed-method content analysis using BoT theory as a framework for analysis.

### Research question

Do symptoms in CHF interact with BoT?

## METHODS

### Identification of studies

Using a refined search strategy (adapted from May *et al.*,<sup>15</sup> we searched CINAHL, EMBASE, MEDLINE, PsycINFO, Scopus and Web of Science. Search strategies are provided (online supplemental material S1). Bibliographies of included articles and relevant review articles were hand searched. Worldwide English language primary qualitative research articles were examined for descriptions of living with, and managing, CHF from the patient perspective. Mixed-method studies were considered for inclusion but required a substantial focus on qualitative methods to be included. Patient experience of heart transplant, end-of-life care, and CHF treatment effects were excluded. Searches were limited to articles published between January 2007 and 20 January 2020 (table 1).

### Study selection

RA screened titles and abstracts, using Covidence,<sup>18</sup> against eligibility criteria. MC, who was blinded to RA's decisions, reviewed a random selection of 357 articles.

**Table 1** Eligibility criteria for included articles

Inclusion criteria	Exclusion criteria
Participants: aged >18 years old with a diagnosis of CHF	Experience of patients with heart transplant or palliative care related to CHF
Articles: Qualitative studies of participants lived experience of living with and managing CHF, published in peer-reviewed journals or as part of successful PhD thesis. Mixed-methods studies will be considered but must have a substantial focus on qualitative methods	Qualitative studies not reporting on general or holistic lived experience (eg, paper with a singular focus). Reports of intervention effectiveness, for example, where the focus is on the treatment effect or service delivery rather than the patients experience (randomised control trials, healthcare organisation or delivery) Literature review papers (including qualitative synthesis, meta-synthesis, etc)
Settings: Worldwide	
Date of publication: between 1 January 2007 and 20 January 2020	
Language: English	

CHF, chronic heart failure.

Disagreements were resolved by CRM and LS. Full-text articles were retrieved, and a final decision regarding eligibility made. The comprehensiveness of the search was confirmed through hand searching articles bibliography.

### Article quality assessment

RA, CRM and LS assessed articles using Critical Appraisal Skills Programme.<sup>19</sup> Papers were scored on the presence of additional participant and CHF characteristics. Articles were grouped into high or medium quality categories. NVivo<sup>20</sup> analysis demonstrated no theme was preferentially represented in either high or medium quality articles; therefore, all articles were considered equally.

### Data extraction and analysis

Data from the findings/results sections, including published supplemental data, were extracted from each paper. Using the extracted data a mixed-method content analysis was performed which combines quantitative and qualitative content analysis methods.<sup>21</sup>

### Quantitative content analysis

Descriptive characteristics of the articles and participants were extracted and where possible summarised using descriptive statistics. NVivo assigns the term node to a grouping of codes defined by the researcher. A code is a segment of text from included articles. NVivo creates automatic counts of how often a node was

coded (frequency) and how many articles the node was present in (consistency). Custom NVivo queries were built to count when symptom nodes occurred within the a priori BoT framework which was developed by RA, CRM and LS (online supplemental material S2). Counts of symptom nodes were used to rank the symptoms according to the frequency and consistency of coding in included articles. Sankey diagrams were built using an open-source coding programme, SankeyMATIC.<sup>22</sup> A Sankey diagram is a flow diagram, where the width of the arrows represents the depth of that interaction or flow rate.

### Qualitative analysis

A refinement of Thomas and Harden<sup>23</sup> methodology for thematic synthesis was used. Stage 1, identification: Extracted data were examined by RA for text referring to symptoms of CHF, forming symptom nodes. A patient and public involvement (PPI) group reviewed the symptom nodes, reorganising and refining the nodes, while simultaneously checking for errors and bias. This process was repeated by a Heart Failure Specialist Nurse (MG). Stage 2, characterisation: Codes in each symptom node were read in context and a descriptive theme created capturing the context associated with that symptom. The constant comparison method<sup>24</sup> facilitated an in-depth exploration of the nature of any observed interactions. Stage 3, explain: Descriptive themes were systematically examined, compared with the BoT a priori framework coding. Simultaneously, how each symptom acted on the framework was also coded.

### Role of public and patient involvement

PPI included the refinement of the research question, symptom nodes, and confirmed coding structure. PPI members reported that results presented in this paper related to their experiences.

## RESULTS

### Results: quantitative content analysis

Searches were first run on 4 November 2017 and repeated on 1 January 2020. This returned 7349 results, duplicates were removed leaving 4497 articles to be examined for eligibility, resulting in 35 articles to be included (figure 1). A full list of included articles is provided (online supplemental material S3). Table 2 presents a summative description of included articles.

These articles present the CHF patient experience from healthcare systems in 14 countries, primarily through interview techniques and represent the experience of 720 participants (57.6% male). Symptoms were grouped by physical and emotional characteristics (figure 2). In this article we will refer to these groupings as physical and emotional symptoms. Breathlessness, weakness, and disturbed sleep were the three most prevalent physical symptoms; while

despair, anxiety, and fear the most prevalent emotional symptoms.

Figure 3 illustrates how coded symptoms interacted with coded elements of BoT framework. The width of the connectors represents how frequently these codes interacted, acting as a visual representation of the prevalence of each type of interaction observed in the data. CHF symptoms appeared to drive (9.2% of codes, n=238), impede (70.5% of codes, n=1823) or form a barrier to patients' engagement with elements of BoT (20.3% of codes, n=525). Suggesting that symptoms rarely encourage patients to engage with self-care. Predominantly, symptoms make self-care more difficult and can stop patients from engaging with self-care.

### Results: qualitative content analysis

Here interaction is defined as how a CHF symptom impacted on the patient, influencing their self-care engagement and concurrently altering BoT. Constant comparative analysis<sup>25</sup> revealed positive (drive) and negative (impede and barrier) interactions between symptoms and BoT. Each of these interactions are considered in turn in the following section. Drive was defined as an interaction where the presence of a symptom meant the patient then positively engaged with an element of their BoT (eg, attend hospital, take medications, etc...). Where Impede was defined as the symptoms making this engagement more difficult and Barrier was defined as symptoms stopping patient engagement in this work.

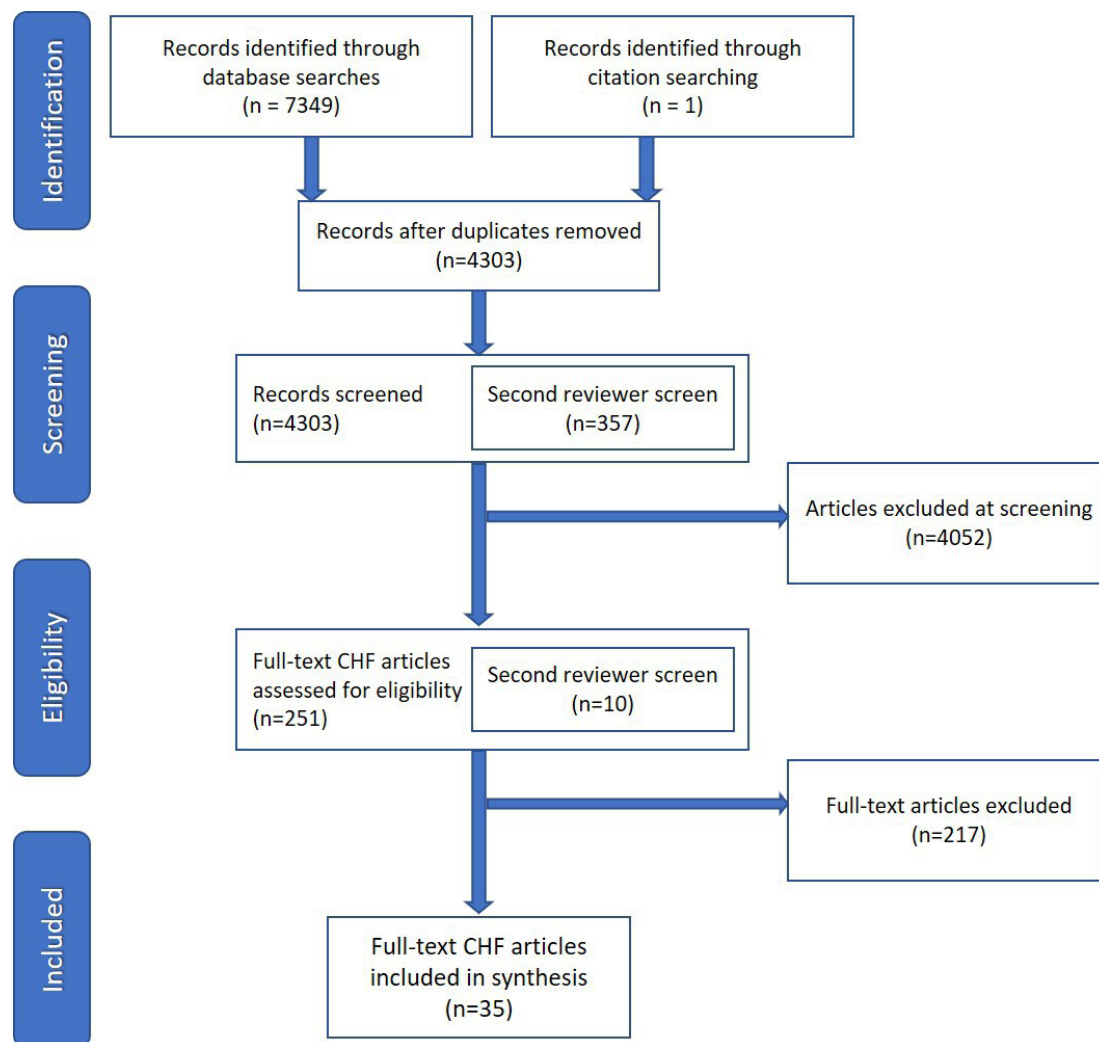
### Symptoms drive patients to engage with self-care

Symptoms are generally accepted to be the impetus which causes an individual to seek healthcare advice, take medications, and make lifestyle changes. Symptoms appeared to drive patients to positively engage with: (1) workload in asking for help, and (2) workload in performing tasks of CHF self-care. Symptoms also encouraged patients to use their capacity to access external resources. Table 3 provides exemplar quotes and figure 3 illustrates the interactions.

Symptoms can encourage patients to engage in the tasks of CHF self-care; from seeking urgent help from healthcare services to adapting activities of daily living to limiting symptom exacerbation.<sup>26–50</sup> Symptoms urged patients to access healthcare systems for treatment adjustments or hospital admissions,<sup>27 28 30 33 35 36 38 43 46–49 51</sup> receive support from social networks,<sup>26 27 29–32 34 35 37 39–43 45 47 49 52</sup> engage with self-care tasks<sup>26–29 32 36 40 45–47 49 50</sup> and make physical environments alterations.<sup>26 29 31 49</sup> Symptoms compelled patients to recruit help from their social networks. Family and friends assumed tasks without being asked, that were beyond patient capacity. They also provided emotional support to patients. Without help from friends and family patients felt managing their illness was more difficult.

### Symptoms impede patient engagement with self-care

Symptoms of CHF are acknowledged as burdensome, this type of interaction was coded impede, meaning symptoms



**Figure 1** PRISMA flow chart for CHF articles on patient experience. CHF, chronic heart failure; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

made self-care more difficult. Symptoms appear to impede patients' ability to engage with their self-care. Symptoms appeared to hinder patients in the following areas: (1) workload in performing the tasks of CHF self-care, (2) workload in gaining knowledge of CHF, (3) capacity to utilise physical, emotional, mental and spiritual abilities, (4) capacity to access external resources and (5) impact of changes to patient self and role. [Table 4](#) provides exemplar quotes and [figure 3](#) illustrates the interactions.

Symptoms made monitoring and management of CHF harder.<sup>28–31 35–38 40 41 44 46 48 50 51 53 54</sup> Completing specific tasks such as taking medications, attending appointments and other self-care activities become more difficult in the presence of symptoms.<sup>27 28 30 34–40 44 46 48–51 53</sup> Further multiple comorbidities (common in CHF) can create confusion around which illness was responsible for what symptom and which treatment takes priority.<sup>28 33 35 37 40 41 46 47 53</sup>

Symptoms made daily activities like housework, leisure activities, sexual intimacy and personal hygiene more difficult restricting patients' holistic participation in life.<sup>26 28 29 31 32 34–43 46 49–51 53 55 56</sup> Within this context of impaired capability, engagement with lifestyle changes

was limited.<sup>31 36 39 40 43 46 51 53</sup> When CHF patients were unsuccessful in completing work assigned by health-care practitioners: stress, guilt, and anxiety were exacerbated.<sup>28 37 40 44 48 50</sup> Some reported purposely choosing not to make lifestyle behaviour changes as the effort of these changes outweighed perceived benefits.<sup>46 50</sup>

Symptoms can restrict patients' ability to acquire knowledge around CHF. The sometimes progressive and vague nature of CHF symptoms together with the presence of comorbidities created confusion hindering baseline understanding of CHF.<sup>26 29 30 35–37 46–50 54</sup> Treatments for CHF can have iatrogenic effects leading to confusion between disease progression or treatment side effects deterring the evaluation of treatment outcomes.<sup>28 30 35–38 40 50</sup> Increased self-monitoring of symptoms intensified fear and awareness of life-limiting diagnosis. Being taught about CHF was reported by patients as creating fear and sadness.<sup>28 30 50</sup>

Symptoms have a pervasive interaction on patients' physical, mental, emotional and spiritual capabilities, reducing capacity. The interaction between CHF symptoms and patients' physical capability makes activities from



**Table 2** (A, B): characteristics of included articles

		Total
A. Summarised article characteristics. (n) represents no of papers with that characteristic		
Location	North America	11
	Asia	9
	Europe	14
	Africa	1
Methodological approach	Qualitative approach	16
	Phenomenology	6
	Secondary analysis	3
	Hermeneutic	2
	Mixed methods	1
	Constructivist	2
	Anthropologic	1
	Grounded theory	2
	Patient narrative	2
Methods	Interview	30
	Focus group	3
	Patient narrative	2
Published participant characteristics	NYHA Class	21
	Ejection Fraction	9
	Aetiology of CHF	8
	Comorbidities	12
	Duration of illness	18
	Employment status	17
	Education level	10
	Marital status	21
Ethnicity	18	
(B) Summarised participant descriptives for included articles. (n) represented the no of participants.		
Sample size	Total participants	720
	Male: n (%)	415 (57.6)
	Female: n (%)	270 (37.5)
Age range (years)		22–90
CHF characteristics	NYHA I (n of participants)	25*
	NYHA II (n of participants)	111*
	NHYA III (n of participants)	163*
	NHYA IV (n of participants)	62*
	Ejection fraction range	15%–64%
Marital status	Married	186*
	Divorced	38*
	Widow	32*
	Single	61*
Employment	Retired	171*
	Unemployed	35*
	Employed	50*
	Disabled	27*

Continued

**Table 2** Continued

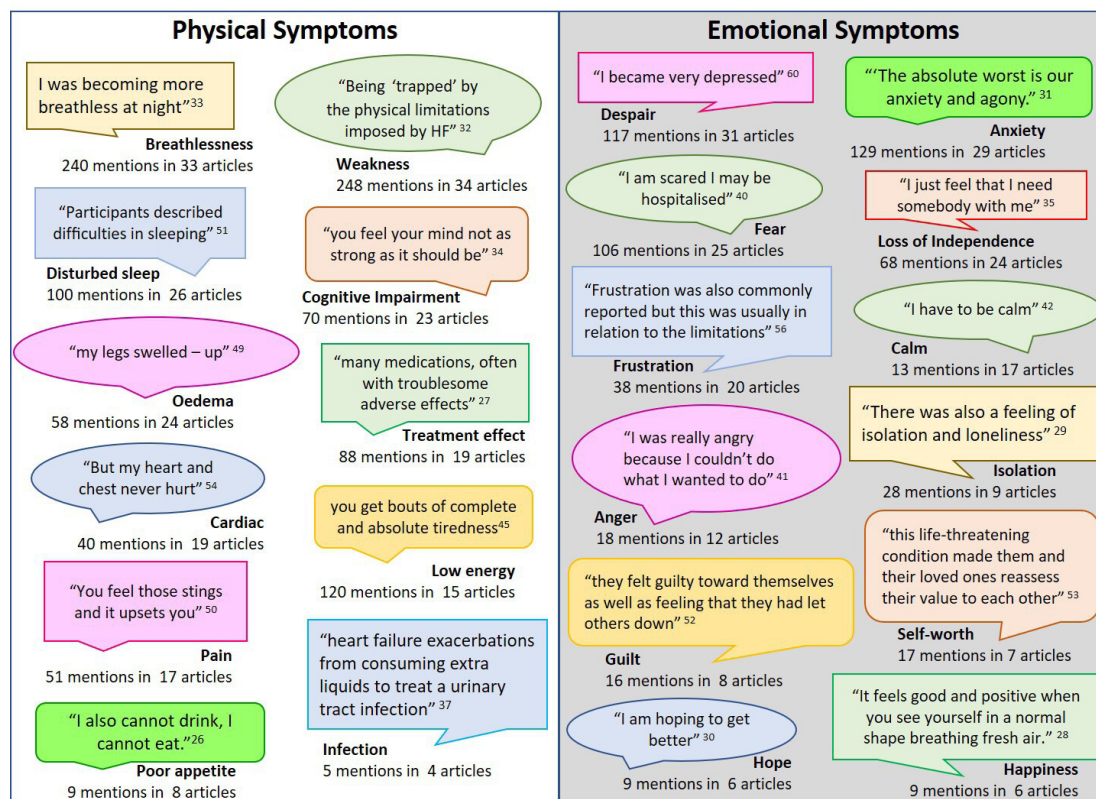
		Total
Education	Less than 12 years	92*
	High school or equivalent	106*
	University or higher	76*
Ethnicity	White	183*
	Black	143*
	Thai	50*
	Chinese	40*
	Malaysian	13*
	Indian	15*
	Hispanic	4*
	Other	4*

\*Numbers presented are the sums of published data, characteristics were not consistently published across all articles.

CHF, chronic heart failure; NYHA, New York Heart Association.

talking to exercising more difficult.<sup>26–32 34–38 40 41 45–47 50–58</sup> Decreases in physical capability often requires patients to recruit others to help with physical tasks, shifting the burden from physical onto emotional through reduced independence.<sup>26–32 34 36–38 40 42 43 45 47 50–56 59 60</sup> The co-ordination and recruitment of this assistance also increases demand on mental capabilities, with negative affects. We observed reported difficulties in comprehending information, decision making, forgetfulness and psychological distress.<sup>28 30 31 36–38 40 41 45 47 50–52</sup> Emotional capability appears affected by symptoms in four main ways: (1) physical symptoms directly causing emotional distress,<sup>28–30 32 34 38 40 45 47 50–53 55 56 60</sup> (2) emotional distress due to being reliant on others to do their work,<sup>26 29 34 38 41 42 45 55</sup> (3) a grief process around loss of abilities,<sup>28–31 34 36 37 40 42 45 50–55 59</sup> and (4) accepting a life-limiting diagnosis.<sup>27 28 30–32 34 36 37 40 51 52 55 59</sup> Symptoms mean patients lose what was and begrudgingly accept a new normal.

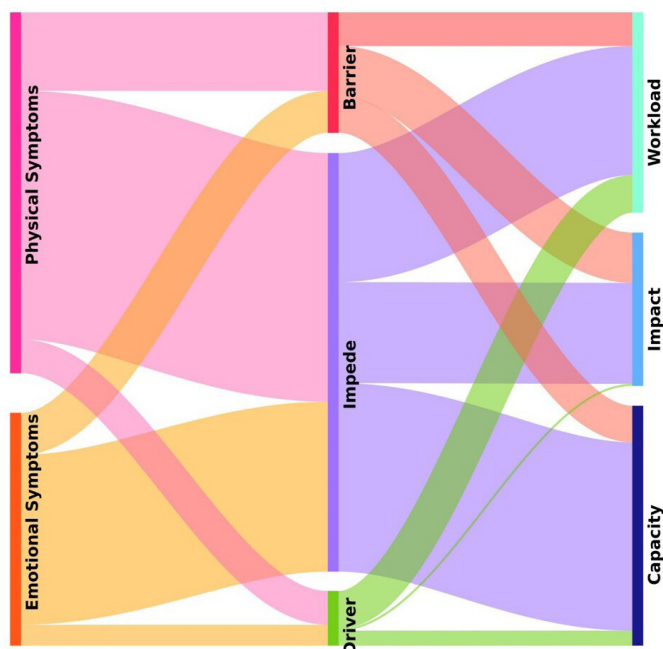
Symptoms appear to impede a patient's willingness to access capacity building external resources, such as, social support networks and healthcare systems. Patients' ability to access their social networks is hindered by creating emotional distress and a lack of belonging<sup>26 31 40 45 46 50–52 59</sup>; yet, symptoms require reliance on family or friends due to decreased physical capability.<sup>29 32 34 35 41 45 49 50 53 55 60</sup> There was also a sense that physical limitations meant adapting or giving up recreational and social activities leading to isolation and loneliness.<sup>28 30 40 50 51 53 59</sup> Interactions with healthcare systems, around symptoms, were reported to cause fatigue, fear, confusion and depression.<sup>28 30 36 50 53</sup> The ambiguous nature of CHF symptoms saw healthcare professionals sometimes mis-diagnose patients'; providing patients with wrong information, adding further confusion and harming relationship's



**Figure 2** Symptom terms found in included articles: name of symptom node in bold font with example quote in speech bubble. Counts of frequency consistency of coding are provided. HF, heart failure.

with healthcare professionals.<sup>33 36 47</sup> Healthcare systems were described as costly in terms of energy.<sup>28 30 50</sup>

Symptoms negatively impacted financial resources draining family finances due to associated healthcare



**Figure 3** Sankey diagram of symptoms and the type of interaction they have with burden of treatment. Thickness of the flow bars represents the frequency of that interaction being coded in the analysis.

costs, a finding observed in articles from Japan, Iran, Kenya, USA, Pakistan, Italy, UK, Sweden and Thailand.<sup>26 28 30 36 40 42 46 52 53</sup> Symptoms also alter a patient's employability decreasing family incomes and changing family roles.<sup>26 28 30 36 40 42 46 52 53</sup> Unaffordable healthcare and treatments meant that symptoms were ignored by patients until the symptoms were unbearable or that their lives were threatened.<sup>26 28 30 40</sup>

Symptoms impact on an individual's capabilities, altering their role within social networks, through a reduction in performing desired activities. The lack of ability to engage in tasks like housework or baking may seem trivial, but patients experience grief, frustration, anxiety at these changes.<sup>26 28 29 31-36 38-42 45 46 49-56 59</sup> If those alterations are central to their identity, then the impact of symptoms may extend to their perceived role in their social networks. Symptoms can strip the ability to provide for family, care for children and/or accepting the possibility of an early death.<sup>26 28-31 35-38 40 42-47 49-53 55 56 60</sup> CHF treatments and self-care regimens designed to help patients were often recorded as disruptions thwarting patients' engagement in their self-care or causing further negative impact on capacity.<sup>26 28-31 35-37 40 41 44 50 53 58</sup> Disruptive side effects of medication meant medications were not taken and/or social activities were restricted.<sup>28 35-37 40 50</sup>

#### Symptoms create a barrier to patient engagement with self-care

Finally, the presence of CHF symptoms appears to form a barrier to patients doing the work of illness. Symptoms

**Table 3** Symptoms drive patients to engage with self-care

Construct	Themes with exemplar quotes
Workload	<p><b>In asking for help from social support networks (n=15)</b>            One man said, ‘Because my body is not strong anymore, I ask my 2 sons, who are working for me, to do things needing to be done. Luckily both of them work pretty well so far.’<sup>26</sup> pg. E13</p> <p><b>In asking for help from healthcare professionals (n=13)</b>            ‘Well if I got them now, the symptoms I get now if I’d have got them years ago I would be going to see my doctor, but as it is now over the years, I more or less know how far it can go. I’ll know when it’s gone too far and then I’ll ring a doctor or an ambulance....’ (patient 36).<sup>27</sup> pg. 2 online supplemental data</p> <p><b>Preforming tasks of CHF self-care; activities of daily living, illness management, lifestyle changes (n=12)</b>            ‘Now, if I get even little bit short of breath, I limit my fluid intake and call doctor immediately because I do not want to go through that pain of breathlessness and hospitalization again.’<sup>28</sup> pg. 588</p> <p><b>Gaining knowledge around CHF; baseline understanding, and evaluating outcomes (n=7)</b>            ‘it was evident people living with CHF were able to recognise the differences in how they felt and what they could do, and developed strategies, often their own, to overcome the level of breathlessness they were feeling.’<sup>29</sup> pg. 2042</p>
Capacity	<p><b>To utilize individual capacity; physical, mental, emotional, spiritual (n=8)</b>            ‘... acute onset breathlessness caused significant anxiety and triggered a decision to seek emergency care.’<sup>30</sup> pg. 3</p> <p><b>To utilize external resources; healthcare system, support networks, financial resources, physical environment (n=15)</b>            ‘The patients provided different portrayals on aspects that facilitated living in their home despite physical changes. For instance, to have the bedroom close by to the toilet was of importance since the symptoms of the disease might result in rapid access to toilets.’<sup>31</sup> pg. 197</p>

Exemplar quotes illustrating how symptoms drive patients to engage with various elements of self-care connected to bot framework. ‘N’ is number of articles coded to this theme in the BoT framework and had an interaction with a symptom of CHF. CHF, chronic heart failure.

appeared to hinder patients in the following areas: (1) workload in performing tasks of CHF management, (2) workload in gaining knowledge of CHF syndrome, (3) capacity to use physical, emotional, mental and spiritual abilities, (3) individual capacity to access external resources, and (4) impact of changes to self and role. [Table 5](#) provides exemplar quotes and [figure 3](#) illustrates the interactions.

Symptoms can stop patients from engaging in the work of illness, from daily tasks to specific illness management tasks. Persistent and severe symptoms turn simple tasks into impossible ones.<sup>26–30 33–38 40–42 44–46 48 50–54 56 59 60</sup> Assigned complex CHF self-care regimens likely become insurmountable in the face of such symptoms.<sup>27 38 42 50 51 59</sup> The subjective nature of CHF symptoms can form a barrier to both patients and healthcare providers acting in a timely matter to those symptoms.<sup>30 33 35 37 38 41 48 54 59</sup> Resulting in delayed treatment seeking and poor illness management.<sup>30 33 35 38 45 48 51</sup>

Symptoms of CHF appear to form a barrier to patients’ physical, mental, emotional and spiritual abilities.<sup>27 29 31 32 36 37 40–42 45 50 52–55 57 59 60</sup> The limitation in abilities creates a substantial deficit in their individual capacity, appearing to erode agency immobilising patients, who then suffer with CHF rather than living with it.<sup>29 32 37 40–42 45 50 55 60</sup>

Symptoms also create a barrier to patients’ accessing external resources. When symptoms were not correctly considered or interpreted by the healthcare professionals leading to negative feelings and mistrust from patients.<sup>30 35 38 45 47</sup> Symptoms stop patients accessing their social support networks; they retreat from their social

support networks fearing embarrassment and becoming burdensome.<sup>26 28 30 40 42 45 50 52 53 55 60</sup>

Symptoms inhibit patients from performing desired activities, creating a sense of personal worthlessness.<sup>26 29 30 32 36 37 40–42 45 46 50–52 54 55 58–60</sup> The lack of individual capability alters their role in social support networks, forming a barrier to patients’ relationships and future lives.<sup>26 28–30 32 33 36 37 40 42 45 46 49–53 55 56 59</sup> The loss of perceived roles in social support networks has high cost. The power of the metaphors (see [figure 4](#)) used in patients’ description of this interaction demonstrates the high degree of impact of symptoms on patient identity.

## DISCUSSION

### Statement of findings

Across the key domains of BoT (capacity, workload and impact) a complex interaction with symptoms was found; rarely driving patients to engage with self-care. We observed that CHF symptoms are intrinsic patients’ description of CHF experience, altering BoT; adding to the understanding of factors which influence BoT in chronic illness.<sup>15</sup> The work of treatment burden by Jani *et al*<sup>61</sup> outlined the areas in CHF, in which symptoms likely play a role (eg, evaluation of treatments based on symptom monitoring). Previous work aligns with our finding that physical symptoms and their emotional affect may have a substantial influence on those with CHF limiting their physical and social capabilities and impacting on their psychological well-being align.<sup>62–65</sup>

Symptoms as a driver to engagement with self-care were seen in the minority (<10%) of coded interactions with



**Table 4** Symptoms as impede patients in engaging with self-care

Construct	Themes with exemplar quotes
Workload	<p><b>Performing tasks of CHF self-care (N=31):</b>            Activities of daily living (n=20): 'I can be just sitting, watching TV. And all of a sudden I get to breathing hard, you know.'<sup>36</sup> pg. 1632            Specific illness management tasks (n=23): 'I tried to walk up the health centre Monday before last...it must have taken an hour and 15 minutes to get back home...it's only a 10 minute walk. It's uphill and every couple of minutes I was sitting like a poor wino, with my feet in the road, sitting on the footpath to get my breath back and rested. (patient 18, male, aged 69)<sup>53</sup> pg. 275            Lifestyle changes (n=7): 'Although the patients were aware of the need to modify their life-style, they believed that stress was worse and that it would be better to reduce stress by eating what they liked.'<sup>46</sup> pg. 4  <b>Gaining knowledge around CHF; baseline understanding, and evaluating outcomes (n=21)</b>            'I thought the signs were related to my prostate or lung problem, I never thought it was my heart.'<sup>38</sup> pg. 3602  <b>In asking for help from social support networks or healthcare professional (n=15)</b>            'The informants sometimes felt that other people did not understand or believe them when they said they were seriously ill. As signs of disease often are invisible in conditions of CHF.'<sup>52</sup> pg. 7</p>
Capacity	<p><b>To utilize individual abilities (n=29):</b>            Physical (n=27): 'I liked my garden and I used to come out and potter. I can't do that now...' (P7)<sup>34</sup> pg. 266            Emotional (n=25): 'some very dark days over the years' and that much of the depression was caused by physical limitations.'<sup>32</sup> pg. 99            Mental (n=13): 'About a quarter of the participants were experiencing cognitive impairments such as memory loss and concentration impairment. A 41year-old woman said: 'I need to read something several times to comprehend the material' (p13, higher education).'<sup>40</sup> pg. 826            Spiritual (n=7): 'I went down to Mass then in the car and I—my wife said to me 'You shouldn't go down because you're not able to walk all that far' and I really couldn't walk from the car park—I attempted and failed...and I'd only gone a few yards and I said 'Look I can't—you're right I can't go any further—I'll have to stop'—so I had to come back and get into the car and go home' (PI, p4) (Field Notes: Eyes filled with tears and voice became shaky)<sup>45</sup> pg. 227  <b>To utilize external resources (n=24)</b>            Support networks (n=20): 'Due to my illness, there are so many things I can't be a part of anymore. I can't do so many things at a time, and I need plenty of time to do everything. (P14, NYHA III)<sup>50</sup> pg. 1787            Healthcare system (n=9): 'To see a doctor, you have to wait for an hour. This is very tiring.'<sup>28</sup> pg. 588            Financial resources (n=9): 'a 68-year-old male patient in NYHA class II reported 'I had to stop my job and I feel this has impacted negatively on me and my family life because I feel useless and now we have to live with only one salary.'<sup>42</sup> pg. 266            Physical environment (n=9): 'As she spoke, she pointed to her environment—a three – levelled townhouse. She describe how she sometimes needed to sit on the stairs on the way up to her bedroom, she couldn't get downstairs to do her laundry and she couldn't go for walks because of snow on the sidewalks as she feared falling and not being able to get up. She talked about her shortness of breath, and how she 'slept' fearfully on the stairway.'<sup>41</sup> pg. 10</p>
Impact	<p><b>Disruption to self-ability: change of what a patient could do (n=25)</b>            Participants described the need to "plan activities around how [they] feel," though they yearn "to be able to do things that [they] used to be able to do."<sup>32</sup> pg. 98  <b>Disruption to role: change of a patient identity (n=24)</b>            'Limitations in physical activity were sometimes associated with changes to home and family life. Another participant reflected that '...as far as being physically able to exercise ...run, jump, play, play with my grandkids or roughing it up a little bit ... overall, you just don't have the ability anymore. You are limited.'<sup>59</sup> pg. 159  <b>Disruption to adherence: changes in self due to treatments or self-care regimens making adherence more difficult (n=14)</b>            'Consequences on life and daily routine (70%) were primarily related to medications. Many (57%) described how diuretics, which caused frequent urination, controlled their lives and made it difficult to leave the house or get enough sleep ('I'm up all night. I mean, right now it's killing me. I'm getting up four or five times a night,'74/M/Wh).'<sup>37</sup> pg. 142</p>

Exemplar quotes illustrate how symptoms hindered patients' engagement with various elements of self-care connected to the bot framework. 'N' is number of articles coded to this theme in the bot framework and had an interaction with a symptom of CHF. CHF, chronic heart failure.

our BoT framework. This was unexpected as it is generally assumed that symptoms are the impetus for patients to engage with self-care. This finding, has parallels to the body of work relating to CHF patients' delaying in seeking healthcare support due to multiple influencing factors (eg, previous negative experiences, perceived barriers to care, misattribution of symptoms, etc)<sup>66</sup> rather than symptoms alone.<sup>67</sup> Failures in self-care were previously blamed

on a patients' denial of illness or poor health literacy<sup>63 68</sup> rather than as this work suggests symptoms having a more complex interaction with patient engagement with healthcare services.

Symptoms impede engagement with self-care was coded in 70.5% interactions within our BoT framework. The work of managing CHF was made more difficult not only in increasing task difficulty due to decreased capacity, but



**Table 5** Symptoms as a barrier to patients in engaging with self-care

Construct	Themes with exemplar quotes
Workload	<p><b>Performing tasks of CHF self-care (n=20):</b>            Activities of daily living (n=12): ‘Tired, tired, tired, when I sit and watch TV my eyes just fall down...’<sup>54</sup> pg. 634            Specific illness management tasks (n=11): ‘The treatment regimen is so complex I cannot figure it all out myself. I do not have the energy or the ability to manage it all. (P 6 NYHA II)’<sup>50</sup> pg. 1787</p> <p><b>Gaining knowledge around CHF; understand illness and evaluating outcomes (n=9)</b>            ‘For instance, one participant readily described having heart failure symptoms of fatigue and shortness-of-breath that he attributed to problems with his back, stating ‘my heart is just fine.’<sup>79/M/Mix</sup><sup>37</sup> pg. 138</p> <p><b>In asking for help from social support networks or healthcare professional (n=7)</b>            ‘I don’t try for it [help], I’m too tired. I mean if anything went wrong I used to ring and shout and do something until they did it. Now I just sit back and wait. All the fight’s gone out of me...I’m tired, I’m tired of fighting the world. (86-year-old female; NYHA III)’<sup>51</sup> pg. 77</p>
Capacity	<p><b>To utilize individual abilities (n=18):</b>            Physical (n=16): ‘My friends have invited me over to France a couple of times and I’ve said that I couldn’t manage it, getting in a car, driving over and driving back again. I’ve said I just can’t do it.’ P9.<sup>55</sup> pg.195            Emotional (n=6): ‘It affected me emotionally, I became very depressed, I had bouts of depression. At one time I sort of gave up on life... one of the common emotion is frustration. I used to be able to do this thing you know, I used to be able to go out, to handle such situations; now I cannot.’ (57 years, male, Chinese, married, FG3)<sup>60</sup> pg.94            Mental (n=3): ‘Decision-making problems lead to impairment in self-care, failure in the timely reporting of the symptoms of disease severity, disability, frequent hospitalisation, decreased QOL and increased mortality rate, which indicates the importance of evaluating cognitive impairment in patients with HF.’<sup>40</sup> pg.827            Spiritual (n=2): ‘The discipline and practice of Islam was mentioned in relation to knowledge and understanding about diet, exercise and general health... an inability to conduct ritual ablutions before daily prayers proved to be distressing for some patients, as did not being able to prostrate during prayer.’<sup>53</sup> pg. 277</p> <p><b>To utilize external resources (n=14)</b>            Support networks (n=11)            ‘A 62-year-old woman in NYHA class II reported ‘I have friends but I can’t go on holiday with them anymore. They recently went on holiday for 8–10 days and invited me, but I couldn’t go because I feel tired and walking is more and more difficult for me.’<sup>42</sup> pg. 267            Healthcare system (n=5)            ‘However, some respondents were less positive about primary care professionals. A number of respondents reported an apparent delay in diagnosis by their GP, which had negative effects on their relationship. ‘That was while the doctors were saying chest infections... so they weren’t spotting the fluid.’ KP5 ‘Oh it’s your asthma, here...he didn’t even examine me....it’s only when my legs started, my ankles started swelling and we insisted.’ KP4<sup>35</sup> pg.5</p>
Impact	<p><b>Disruption to self-ability: change of what a patient could do (n=19)</b>            ‘Since I’ve had my heart problems I just feel so tired all the time and it’s just made me so depressed. And I can’t do the things that I used to do, and I know I’ve gotten up in age, but ... I just feel like I should be able to do more than what I’m doing now at 65.’<sup>59</sup> pg. 159</p> <p><b>Disruption to role: change of a patient identity (n=19)</b>            ‘Because my status was very serious when I was first diagnosed, my husband and I ... were advised to no longer ... try to become pregnant. My heart was too weak to go through childbirth. I was sad, but I understood. It wasn’t fair to bring a child into the world with ... such a very sick mommy ... Being a childless mother is a fallout of my CHF.’ pg. 98<sup>32</sup></p>

Exemplar quotes illustrate how symptoms stopped patients’ engagement with various elements of self-care connected to the bot framework. ‘N’ is number of articles coded to this theme in the bot framework and had an interaction with a symptom of CHF. CHF, chronic heart failure.

also through how symptoms are considered by healthcare professionals. The work of Lippiett *et al*<sup>11</sup> described how different patient clinical pathways influenced BoT in chronic obstructive pulmonary disease (COPD) and lung cancer, where lung cancer patients are expected to follow a structure treatment pathway meant less BoT. Where patients with COPD are expected to be engaged with self-care meant greater BoT. Deficits in CHF healthcare service delivery has previously been observed to make the work of self-care more difficult.<sup>65 69</sup> The high prevalence

of this type of interaction within the framework suggests an intrinsic relationship with symptoms. Thus, emphasising importance of considering symptoms as more than an indicator for disease progression or treatment effectiveness, by healthcare professionals when assigning self-care work to patients. Adding to the work of Gonçalves *et al*,<sup>70</sup> which identified a negative influence between BoT and the pathophysiology of illness across multiple health conditions.



**Figure 4** Exemplar metaphors used in description of how symptoms form barriers to engagement in desired activities and their perceived role.

Symptoms as a barrier to engagement with self-care was coded in 20.3% of the interactions within our BoT framework. If CHF symptoms removed patients' capacity, an unsurmountable illness workload can be created. Similarly, Yu *et al*,<sup>64</sup> reported in older adults with CHF the work around symptom monitoring contributed to patients' physical and mental exhaustion; meaning poor self-care or reliance on social support systems. The high workload of CHF patients is similar to the exhausting and invasive BoT that Roberti *et al*<sup>71</sup> noted in chronic kidney disease. From a patient perspective, symptoms strip their capacity and increase their workload creating overwhelming BoT. For them the effort of attempting to do the work assigned by healthcare professionals is not worth the physical effort or emotional stress

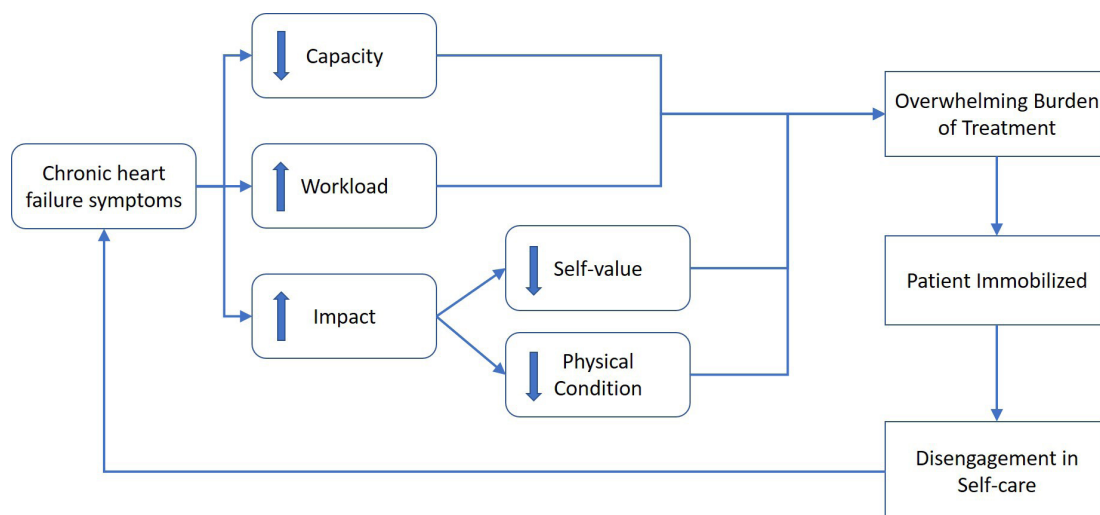
as perceived benefits are so low. This affectively inhibits patients from engaging in self-care. Previous reviews on living with heart failure appear to neglect highlighting the importance of symptoms on capacity to do this work instead focusing on patients' poor adaptation to their illness and its impact on their lives<sup>68</sup> and their health literacy<sup>72 73</sup>, as well as inadequate healthcare encounters.<sup>65 72 73</sup>

A preliminary model describing how symptoms interact with BoT has been developed (see figure 5). Symptoms in CHF can erode patient agency through a complex interaction of symptoms decreasing capacity and increasing workload. This in turn leads to a loss of self-value and physical deconditioning, which together can inhibit a patients' ability to engage with self-care regimens due to perceived overwhelming BoT.

Current research on self-care in CHF focuses on the assumption of patient self-efficacy, which assumes given the right approach, intervention, and education a patient will have the capacity to engage in self-care regimens which will positively impact clinical outcomes. Recent revisions to the theory of self-care in CHF includes the consideration of symptom monitoring and management as a part of patients' self-care work.<sup>74</sup> However, the theory of self-care in CHF has yet to examine how symptoms might impact on the patients' agency to perform self-care. To the best of our knowledge, no empirical work has yet explored the observed interaction between symptoms, self-care engagement in CHF, and how that influences BoT.

**Strengths and weakness of the study**

Our review is the first to explore qualitative literature on patients' experiences of CHF with respect to the interactions of symptoms with BoT. It builds on the foundation of BoT theory<sup>15</sup> with specific consideration for CHF patients. It characterises the types of symptom interaction with patient engagement in the context of BoT; which our PPI group recognised and verified as true to their experiences across multiple chronic illnesses.



**Figure 5** Initial model of CHF symptoms interaction with bot theory primary constructs. CHF, chronic heart failure.

Using BoT as a framework was a strength, leading to the original observation of CHF symptoms forming a barrier to patient engagement with BoT and self-care. Hinting at the possibility of an alternative explanation for why healthcare professionals may perceive high levels of non-adherence in CHF patients.

A strength of the synthesis of qualitative research is that conclusions drawn were viewed through multiple theoretical, epistemological, and ontological stance of the included studies' authors as well as the authors of this review. Thus, commonalities observed are stronger due to heterogeneity of their context but could also be a limitation as the multiple interpretations may have altered the 'true' view of the original data. The review was restricted by the choice of published quotes from the included articles, our conclusions formed by using data from published primary studies to develop explanatory ideas the original researcher did not intend. Only English language articles were included.

Strengthening our analysis by using matrix queries, in Nvivo, to facilitate comparative pattern analysis as well as textual comparison,<sup>75</sup> confirmed the patterns observed in the constant comparison process and provided the data to create visual illustrations of these complex interactions. Our coding analysis strategy, has precedent, as it was a refinement of Thomas and Harden<sup>23</sup> methodology for thematic synthesis, which used a three stage coding process. We adapted their third stage to follow Gallacher *et al.*<sup>14</sup> work which takes second stage codes (characterise) and compares them against an a priori framework helping to explain the observations.

### Future work

The role of symptoms in CHF and their interaction with patient engagement in self-care are not well understood and need more research. The authors are currently conducting empirical research to better understand this concept.<sup>76</sup>

## CONCLUSIONS AND CLINICAL IMPLICATIONS

Our synthesis suggests that relying on patients' symptom experience as the impetus for them to seek healthcare support may not be as successful as currently assumed. Examination of symptom interaction with BoT in CHF has demonstrated a complex relationship. CHF symptoms appear to negatively interact with patients' engagement with self-care regimens, including healthcare interactions, through the creation of overwhelming BoT. Symptoms increase patients' illness workload simultaneously decreasing their capacity, with a detrimental impact on their lives. This interaction of symptoms suggests that patients with CHF may not be as poor at self-care as reported in current literature. CHF symptoms have an integral role in patient BoT predominately acting to impede patients' efforts to engage in self-care. Healthcare professionals need to carefully consider patients' capacity and current workloads when altering patient self-care regimens, as reducing workload may improve patient

outcomes and improve engagement with self-care. The results of this review postulate that patients previously being blamed for poor self-care may be suffering from overwhelming BoT of which symptoms, which are modifiable are a major contributor. Our findings call for more research underpinned by BoT in CHF; exploring changes CHF service delivery and interventions to enhance patient self-care by focusing on their experiences.

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