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# BMJ Open

## Do chronic heart failure symptoms interact with burden of treatment? Qualitative literature review.

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3 **Title:** Do chronic heart failure symptoms interact with burden of treatment? Qualitative literature  
4 review.  
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**Abstract (current 299):**

*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, PsychINFO, Scopus, and Web of Science were searched.

*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 appear integral to their experience. Symptoms appear to alter BoT by; increasing treatment workload and decreasing individual capacity, which negatively impacts on the patients' view of their identity. Symptoms appear to infrequently drive patients to engage in self-care. Instead they appear to impede and even form barriers to self-care. Symptoms increase illness workload, making completing tasks more difficult and by creating additional work (e.g. asking for assistance). Simultaneously, symptoms alter a patient's capacity, through a reduction in their individual capabilities and willingness to access external resources (i.e. hospitals). These alterations had a devastating impact on patients' lives. Symptoms appear to erode a patient's agency, decreasing self-value and generalised physical deconditioning leading to affective paralysis towards self-care regimens.

*Conclusions:* Symptoms appear to be essential 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 their family. Together this describes 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 this population.

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**ARTICLE SUMMARY: STRENGTHS AND LIMITATIONS**

- This is the first qualitative literature review to explore the role of symptoms in burden of treatment in chronic heart failure.
- 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 chronic heart failure patient population.
- The innovative methods to visually illustrate the qualitative data, allows the reader to observe the depth and breadth of the themes outline 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.

## INTRODUCTION

Chronic heart failure (CHF) is increasing in prevalence, it is now estimated there are just 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 behaviour 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 co-morbidities, 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, the dynamic modifiable workload delegated to patients<sup>10-12</sup>. Burden of treatment (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 therefore provides a framework to explore CHF patient experience, by focusing on individual capacity, illness workload and its 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,

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2  
3 characterise and explain these interactions as they are reported in the literature, and explore  
4  
5 their implications for understanding patient experience and self-care outcomes.  
6

### 7 **Aim of Review**

8  
9 To undertake a systematic review of qualitative literature on the lived experiences of CHF to identify,  
10  
11 characterise, and explain interactions between symptoms and BoT using mixed-method content  
12  
13 analysis using BoT theory as a framework for analysis.  
14  
15

### 16 **Research Question**

17  
18 Do symptoms in CHF interact with BoT?  
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23

## 24 **METHODS**

### 25 **Identification of studies**

26  
27 Using a refined search strategy (adapted from May, et al. <sup>15</sup>), we searched CINAHL, EMBASE,  
28  
29 MEDLINE, PsychINFO, Scopus, and Web of Science. Search strategies are provided (*LINK: Search*  
30  
31 *strategies*). Bibliographies of included articles and relevant review articles were hand searched.  
32  
33 Worldwide English language articles were examined for descriptions of living with, and managing,  
34  
35 CHF from the patient perspective. Mixed method studies were considered for inclusion but required  
36  
37 a substantial focus on qualitative methods to be included. Patient experience of heart transplant,  
38  
39 end-of-life care, and CHF treatment effects were excluded. Searches were limited to articles  
40  
41 published between January 2007 and January 20, 2020.  
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### 49 **Study Selection**

50  
51 RA screened titles and abstracts, using Covidence<sup>18</sup>, with reference to eligibility criteria. MC, who  
52  
53 was blinded to RA's decisions, reviewed a random selection of 357 articles. Disagreements were  
54  
55 resolved by CRM and LS. Full text articles were then retrieved, and a final decision regarding  
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3 eligibility made. The comprehensiveness of the search was confirmed through hand searching  
4  
5 articles bibliography.  
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### 8 9 **Article quality assessment**

10 RA, CRM and LS assessed articles using Critical Appraisal Skills Program (CASP)<sup>19</sup>. Papers were scored  
11  
12 on the presence of additional participant and CHF characteristics. Articles were grouped into high or  
13  
14 medium quality categories. Nvivo<sup>20</sup> analysis demonstrated no theme was preferentially represented  
15  
16 in either high or medium quality articles; therefore, all articles were considered equally.  
17  
18

### 19 20 21 **Data extraction and analysis**

22  
23 Data from the findings/results sections, including published supplemental data, were extracted from  
24  
25 each paper. Using the extracted data a mixed-method content analysis was performed which  
26  
27 combines quantitative and qualitative content analysis methods<sup>21</sup>.  
28  
29

### 30 31 **Quantitative content analysis**

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35 Descriptive characteristics of the articles and participants were extracted and where possible  
36  
37 summarized using descriptive statistics. Nvivo assigns the term node to a grouping of codes defined  
38  
39 by the researcher. A code is a segment of text from result section of included articles. Nvivo creates  
40  
41 automatic counts of how often a node was coded (frequency) and how many articles that node  
42  
43 appeared in across all articles (consistency). Custom Nvivo queries were built to count when  
44  
45 symptom nodes occurred within the a priori BoT framework which was developed by RA, CRM and  
46  
47 LS (*Link Supplemental material 2: BoT Framework BMJ*). Counts of symptom nodes were used to rank  
48  
49 the symptoms according to the frequency and consistency of coding in included articles. Sankey  
50  
51 diagrams were built using an open-source coding program, SankeyMATIC<sup>22</sup>.  
52  
53  
54

### 55 56 **Qualitative analysis**



Location	Total
North America	11
Asia	9
Europe	14
Africa	1

A refinement of Thomas and Harden <sup>23</sup>

methodology for thematic synthesis was used.

*Stage one, 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, reorganizing and refining the nodes, whilst simultaneously checking for errors and bias. This process was repeated by a Heart Failure Specialist Nurse (MG). *Stage two, characterization:* 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 three, explain:* Descriptive themes were systematically examined, compared to 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 Nov 4, 2017 and repeated on Jan 1, 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 (Supplemental material: S3\_IncludedArticles). Table 1 presents a summative description of included articles.

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
Co-morbidities	12
Duration of illness	18
Employment	17
Education	10
Marital status	21
Ethnicity	18

Table 1 (a & b): Characteristics of included articles

	Total	
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*
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*

A) Summarised articles characteristics. (n) represents number of papers with that characteristic.

These articles present the CHF patient experience from healthcare systems in 14 countries, represent the experience of 720 participants (57.6% male) and emotional characteristics (Figure 2). In this article we

B) Summarized participant descriptives for included articles. (n) represented the number of participants. NYHA: New York Heart Association, CHF: Chronic Heart Failure. \*Numbers presented are the sums of published data, characteristics were not consistently published across all articles. We will refer to these groupings as physical and

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3 emotional symptoms. Breathlessness, weakness, and disturbed sleep were the three most prevalent  
4 physical symptoms; while despair, anxiety, and fear the most prevalent emotional symptoms.  
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9 Figure 3 illustrates how coded symptoms interacted with coded elements of BoT framework. The  
10 width of the connectors represents how frequently these nodes interacted, acting as a visual  
11 representation of the prevalence of each type of interaction observed in the data. CHF symptoms  
12 appeared to drive (9.2% of codes, n=238), impede (70.5% of codes, n=1823) or form a barrier to  
13 patients' engagement with elements of BoT (20.3% of codes, n=525). Suggesting that symptoms are  
14 rarely encouraging patients to engage with self-care. Predominantly, symptoms make self-care more  
15 difficult and can stop patients from engaging with self-care.  
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### 25 **Results: qualitative content analysis**

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

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

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Table 2: Symptoms drive patients to engage with self-care. 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.

Construct	Themes with exemplar quotes
Workload	<p>In asking for help from social support networks (n=15)  <i>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."</i><sup>26</sup> pg. E13</p> <p>In asking for help from healthcare professionals (n=13)  <i>"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...."</i> (patient 36).<sup>27</sup> pg. 2  <i>online supplementary data</i></p> <p>Performing tasks of CHF self-care; activities of daily living, illness management, lifestyle changes (n=12)  <i>"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."</i><sup>28</sup> pg. 588</p> <p>Gaining knowledge around CHF; baseline understanding, and evaluating outcomes (n=7)  <i>"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."</i><sup>29</sup> pg. 2042</p>
Capacity	<p>To utilize individual capacity; physical, mental, emotional, spiritual (n=8)  <i>"... acute onset breathlessness caused significant anxiety and triggered a decision to seek emergency care."</i><sup>30</sup> pg. 3</p> <p>To utilize external resources; healthcare system, support networks, financial resources, physical environment (n=15)  <i>"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."</i><sup>31</sup> pg. 197</p>

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3 Symptoms can encourage patients to engage in the tasks of CHF self-care; from seeking urgent help  
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5 from healthcare services to adapting activities of daily living to control and limit symptom  
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7 exacerbation<sup>26-50</sup>. Symptoms urged patients to access healthcare systems for treatment adjustments  
8  
9 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</sup>  
10  
11 <sup>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</sup>  
12  
13 <sup>29 31 49</sup>. Symptoms compelled patients to recruit help from their social networks. Family and friends  
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15 assumed tasks without being asked, that were beyond patient capacity. They also provided  
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17 emotional support to patients. Without help from friends and family patients felt managing their  
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19 illness was more difficult.  
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#### 23 24 Symptoms Impede patient engagement with self-care

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27 Symptoms of CHF are acknowledged as burdensome, this type of interaction was coded *impede*,  
28  
29 meaning symptoms made self-care more difficult. Symptoms appear to impede patients' ability to  
30  
31 engage with their self-care. Symptoms appeared to hinder patients in the following areas: (1)  
32  
33 workload in performing the tasks of CHF self-care, (2) workload in gaining knowledge of CHF, (3)  
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35 capacity to utilize physical, emotional, mental, and spiritual abilities, (4) capacity to access external  
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37 resources, and (5) impact of changes to patient self and role. Table 3 provides exemplar quotes and  
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39 figure 3 illustrates the interactions.  
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Table 3: Symptoms as impede patients in engaging with self-care. 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

Construct	Themes with exemplar quotes
Workload	<p>Preforming tasks of CHF self-care (N=31):</p> <p>Activities of daily living (n=20): <i>"I can be just sitting, watching TV. And all of a sudden I get to breathing hard, you know."</i><sup>36</sup> pg. 1632</p> <p>Specific illness management tasks (n=23): <i>"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)"</i><sup>53</sup> pg. 275</p> <p>Lifestyle changes (n=7): <i>"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."</i><sup>46</sup> pg. 4</p> <p>Gaining knowledge around CHF; baseline understanding, and evaluating outcomes (n=21)</p> <p><i>"I thought the signs were related to my prostate or lung problem, I never thought it was my heart."</i><sup>38</sup> pg. 3602</p> <p>In asking for help from social support networks or healthcare professional (n=15)</p> <p><i>"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."</i><sup>52</sup> pg. 7</p>
Capacity	<p>To utilize individual abilities (n=29):</p> <p>Physical (n=27): <i>"I liked my garden and I used to come out and potter. I can't do that now..."</i> (P7)<sup>34</sup> pg. 266</p> <p>Emotional (n=25): <i>"some very dark days over the years" and that much of the depression was caused by physical limitations."</i><sup>32</sup> pg. 99</p> <p>Mental (n=13): <i>"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)."</i><sup>40</sup> pg. 826</p> <p>Spiritual (n=7): <i>"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)"</i><sup>45</sup> pg. 227</p> <p>To utilize external resources (n=24)</p> <p>Support networks (n=20): <i>"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)"</i><sup>50</sup> pg. 1787</p> <p>Healthcare system (n=9): <i>"To see a doctor, you have to wait for an hour. This is very tiring."</i><sup>28</sup> pg. 588</p> <p>Financial resources (n=9): <i>"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.'"</i><sup>42</sup> pg. 266</p> <p>Physical environment (n=9): <i>"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."</i><sup>41</sup> pg. 10</p>

Construct	Themes with exemplar quotes
Impact	<p>Disruption to self-ability: change of what a patient could do (n=25)  <i>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.”</i><sup>32</sup> pg. 98</p> <p>Disruption to role: change of a patient identity (n=24)  <i>“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.’”</i><sup>54</sup> pg. 159</p> <p>Disruption to adherence: changes in self due to treatments or self-care regimens making adherence more difficult (n=14)  <i>“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).”</i><sup>37</sup> pg. 142</p>



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3 Symptoms make monitoring and management of CHF harder<sup>28-31 35-38 40 41 44 46 48 50 51 53 55</sup>. Similarly,  
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5 completing specific tasks such as taking medications, attending appointments, and other self-care  
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7 activities become more difficult in the presence of symptoms<sup>27 28 30 34-40 44 46 48-51 53</sup>. Further multiple  
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9 co-morbidities (common in CHF) can create confusion around which illness was responsible for what  
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11 symptom and which treatment takes priority<sup>28 33 35 37 40 41 46 47 53</sup>.

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14  
15 Symptoms make daily activities like housework, leisure activities, sexual intimacy, and personal  
16  
17 hygiene more difficult restricting patients' holistic participation in life<sup>26 28 29 31 32 34-43 46 49-51 53 56 57</sup>.

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19 Within this context of impaired capability, engagement with lifestyle changes is also limited<sup>31 36 39 40 43</sup>  
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21 <sup>46 51 53</sup>. When CHF patients were unsuccessful in completing work assigned by health care  
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23 practitioners: then stress, guilt, and anxiety were exacerbated<sup>28 37 40 44 48 50</sup>. Some reported purposely  
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25 choosing not to make lifestyle behaviour changes as the effort of these changes outweighed  
26  
27 perceived benefits<sup>46 50</sup>.

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31 Symptoms can restrict patients' ability to acquire knowledge around CHF. The sometimes  
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33 progressive and vague nature of CHF symptoms together with the presence of co-morbidities  
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35 creates confusion hindering the development of baseline understanding of CHF<sup>26 29 30 35-37 46-50 55</sup>.

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38 Treatments for CHF can have iatrogenic effects leading to confusion between disease progression or  
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40 treatment side effects hindering the evaluation of treatment outcomes<sup>28 30 35-38 40 50</sup>. Increased self-  
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42 monitoring of symptoms sometimes intensified fear and awareness of their life-limiting diagnosis.  
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44 Being taught about CHF was reported by patients as creating fear and sadness<sup>28 30 50</sup>.

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48 Symptoms have a pervasive interaction on patients' physical, mental, emotional and spiritual  
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50 capabilities, reducing capacity. The interaction between CHF symptoms and patients' physical  
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52 capability makes activities from talking to exercising more difficult<sup>26-32 34-38 40 41 45-47 50-53 55-59</sup>. Decreases  
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54 in physical capability often requires patients to recruit others to help with physical tasks, shifting the  
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56 burden from physical onto emotional through reduced independence<sup>26-32 34 36-38 40 42 43 45 47 50-57 60</sup>. The  
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58 co-ordination and recruitment of this assistance also increases the demand on mental capabilities,  
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3 with a negative affect. We observed reported difficulties in comprehending information, decision  
4 making, forgetfulness and psychological distress<sup>28 30 31 36-38 40 41 45 47 50-52</sup>. Emotional capability appears  
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6 affected by symptoms in four main ways: 1) physical symptoms directly causing emotional distress<sup>28-</sup>  
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13 work<sup>26 29 34 38 41 42 45 56</sup>, 2) additional emotional distress due to being reliant on others to do their  
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15 life-limiting diagnosis<sup>27 28 30-32 34 36 37 40 51 52 54 56</sup>. Symptoms mean patients lose what was and  
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17 begrudgingly accept a new normal.

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20 Symptoms appear to impede a patient's willingness to access capacity building external resources;  
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22 such as, social support networks, healthcare systems. Patients' ability to access their social networks  
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24 is hindered by creating emotional distress and a lack of belonging<sup>26 31 40 45 46 50-52 54</sup>; yet, symptoms  
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26 require reliance on family or friends due to decreased physical capability<sup>29 32 34 35 41 45 49 50 53 56 60</sup>. There  
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28 was also a sense that physical limitations meant adapting or giving up recreational and social  
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30 activities leading to isolation and loneliness<sup>28 30 40 50 51 53 54</sup>. Interactions with healthcare systems,  
31  
32 around symptoms, were reported to cause fatigue, fear, confusion, and depression<sup>28 30 36 50 53</sup>. The  
33  
34 ambiguous nature of CHF symptoms saw healthcare professionals sometimes mis-diagnose patients'  
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36 symptoms; thereby providing patients with wrong information, confusing their knowledge of CHF  
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38 and harming their relationship with healthcare professionals<sup>33 36 47</sup>. Healthcare systems were  
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40 described as costly in terms of energy<sup>28 30 50</sup> as well as finances.

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45 Symptoms also negatively impact financial resources draining family finances due to associated  
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47 healthcare costs, a finding observed in articles from Japan, Iran, Kenya, USA, Pakistan, Italy, United  
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49 Kingdom, Sweden and Thailand<sup>26 28 30 36 40 42 46 52 53</sup>. Symptoms also alter a patient's employability  
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51 decreasing family incomes and change their role within the family<sup>26 28 30 36 40 42 46 52 53</sup>. Lack of  
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53 affordability of healthcare and treatments meant that symptoms were often ignored by patients  
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55 until the patients felt they could no longer cope or that their lives were threatened<sup>26 28 30 40</sup>.

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3 Symptoms impact on an individual's capabilities, altering their role within social networks, through a  
4 reduction in performing desired activities. The lack of ability to engage in tasks like housework or  
5 baking may seem trivial, but patients experience grief, frustration, anxiety at these changes<sup>26 28 29 31-36</sup>  
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10 <sup>38-42 45 46 49-57</sup>. If those alterations are central to their identity, then the impact of symptoms may  
11 extend to their perceived role in their social networks. Symptoms can strip the ability to provide for  
12 family, care for children, and/or accepting the possibility of an early death<sup>26 28-31 35-38 40 42-47 49-53 56 57 60</sup>.  
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16 CHF treatments and self-care regimens designed to help patients were often recorded as disruptions  
17 thwarting patients' engagement in their self-care or causing further negative impact on capacity<sup>26 28-</sup>  
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20 <sup>31 35-37 40 41 44 50 53 59</sup>. Disruptive side-effects of medication meant medications were not taken and/or  
21 social activities were restricted<sup>28 35-37 40 50</sup>.  
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26 Symptoms create a barrier to patient engagement with self-care  
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30 Finally, the presence of CHF symptoms appears to form a barrier to patients doing the work of  
31 illness. Symptoms appeared to hinder patients in the following areas: (1) workload in performing  
32 tasks of CHF management, (2) workload in gaining knowledge of CHF syndrome, (3) capacity to  
33 utilize physical, emotional, mental, and spiritual abilities, (3) individual capacity to access external  
34 resources, , and (4) impact of changes to self and role. Table 4 provides exemplar quotes highlighting  
35 coding density for this interaction and figure 3 illustrates the interactions.  
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Table 4: Symptoms as a barrier to patients in engaging with self-care. 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.

Construct	Themes with exemplar quotes
Workload	<p>Performing tasks of CHF self-care (n=20):</p> <p>Activities of daily living (n=12): <i>"Tired, tired, tired, when I sit and watch TV my eyes just fall down..."</i><sup>55</sup> pg. 634</p> <p>Specific illness management tasks (n=11): <i>"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)"</i><sup>50</sup> pg. 1787</p> <p>Gaining knowledge around CHF; understand illness and evaluating outcomes (n=9)</p> <p><i>"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."79/M/Mix"</i><sup>37</sup>pg. 138</p> <p>In asking for help from social support networks or healthcare professional (n=7)</p> <p><i>"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)"</i><sup>51</sup> pg. 77</p>
Capacity	<p>To utilize individual abilities (n=18):</p> <p>Physical (n=16): <i>"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."</i><sup>56</sup> pg.195</p> <p>Emotional (n=6): <i>"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)"</i><sup>60</sup> pg.94</p> <p>Mental (n=3): <i>"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."</i><sup>40</sup> pg.827</p> <p>Spiritual (n=2): <i>"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."</i><sup>53</sup> pg. 277</p> <p>To utilize external resources (n=14)</p> <p>Support networks (n=11)</p> <p><i>"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.'"</i><sup>42</sup> pg. 267</p> <p>Healthcare system (n=5)</p> <p><i>"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"</i><sup>35</sup> pg.5</p>

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Construct	Themes with exemplar quotes
Impact	<p>Disruption to self-ability: change of what a patient could do (n=19)  <i>"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."</i><sup>54</sup> pg. 159</p> <p>Disruption to role: change of a patient identity (n=19)  <i>"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."</i> pg. 98<sup>32</sup></p>

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3 Symptoms can stop patients from engaging in the work of illness; from daily tasks to specific illness  
4 management tasks. Persistent and severe symptoms turn simple tasks into impossible ones<sup>26-30 33-38 40-  
5 42 44-46 48 50-55 57 60</sup>. The assigned complex CHF self-care regimens likely become insurmountable in the  
6 face of such symptoms<sup>27 38 42 50 51 54</sup>. The subjective nature of CHF symptoms can form a barrier to  
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8 both patients and healthcare providers acting in a timely matter to those symptoms<sup>30 33 35 37 38 41 48 54</sup>  
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55. This can result 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 52-56 58 60</sup>. The limitation in abilities creates a substantial deficit in their  
individual capacity, appearing to erode agency immobilizing patients, who then suffer with CHF  
rather than living with it<sup>29 32 37 40-42 45 50 56 60</sup>.

Symptoms also create a barrier to patients' accessing external resources. When symptoms were not  
correctly considered or interpreted by the healthcare professionals it led to negative feelings and  
lack of trust from patients<sup>30 35 38 45 47</sup>. Symptoms stop patients accessing their social support  
networks; they retreat from their social support networks out of fear of embarrassment and  
becoming burdensome<sup>26 28 30 40 42 45 50 52 53 56 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 54-56 59 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 49-54 56 57</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

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3 Across all the key domains of BoT (capacity, workload and impact) a primarily negative interaction  
4 with symptoms was found. This interaction is complex; rarely driving patients to engage in self-care.  
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6 We observed that CHF symptoms are intrinsic patients' description of CHF experience, altering BoT.  
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10 *Symptoms as a driver to engagement with self-care* were seen in the minority (<10%) of coded  
11 interactions with our BoT framework. This was unexpected as it is generally assumed that symptoms  
12 are the impetus for patients to engage with self-care. This finding, is in keeping with the body of  
13 work relating to CHF patients' delaying in seeking healthcare support due to multiple influencing  
14 factors (e.g. previous negative experiences, perceived barriers to care, misattribution of symptoms,  
15 etc.)<sup>61</sup> rather than symptoms alone<sup>62</sup>.

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25 *Symptoms impede engagement with self-care* was coded in 70.5% interactions within our BoT  
26 framework. The work of managing CHF was made more difficult not only in increasing task difficulty  
27 due to decreased capacity, but also through how symptoms are considered by healthcare  
28 professional. The work of Lippiett, et al. <sup>11</sup> described how different patient clinical pathways  
29 influenced BoT in COPD and lung cancer, where lung cancer patients are expected to follow a  
30 structure treatment pathway meant less BoT and COPD patients are expected to be engaged with  
31 self-care meant greater BoT. This has similarities to how symptoms in CHF maybe considered by  
32 differing healthcare professionals or systems. The high prevalence of this type of interaction within  
33 the framework suggests an intrinsic relationship with symptoms, and the importance of considering  
34 symptoms when assigning work to patients. Adding to the work of Goncalves, et al. <sup>63</sup>, which  
35 identified a negative influence between BoT and the pathophysiology of illness across multiple  
36 health conditions.

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53 *Symptoms as a barrier to engagement with self-care* was coded in 20.3% of the interactions within  
54 our BoT framework. If CHF symptoms removed patients' capacity, an unsurmountable illness  
55 workload can be created. The high workload of CHF patients is similar to the exhausting and invasive  
56 BoT that Roberti, et al. <sup>64</sup> noted in chronic kidney disease. From a patient perspective, symptoms  
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3 strip their capacity and increase their workload creating overwhelming BoT. For them the effort of  
4 attempting to do the work assigned by healthcare professionals is not worth the physical effort or  
5 emotional stress as perceived benefits are so low. This affectively inhibits patients from engaging in  
6 self-care.  
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13 From the findings, a preliminary model describing how symptoms interact with BoT has been  
14 developed (see figure 5). Symptoms in CHF can erode patient agency through a complex interaction  
15 of symptoms decreasing capacity and increasing workload. This in turn leads to a loss of self-value  
16 and physical deconditioning, which together can inhibit a patients' ability to engage with self-care  
17 regimens due to perceived overwhelming BoT.  
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25 Current research on self-care in CHF focuses on the assumption of patient self-efficacy, which  
26 assumes given the right approach, intervention, and education a patient will have the capacity to  
27 engage in self-care regimens which will positively impact clinical outcomes. Recent revisions to the  
28 theory of self-care in CHF includes the consideration of symptom monitoring and management as a  
29 part of patients' self-care work<sup>65</sup>. However, the theory of self-care in CHF has yet to examine how  
30 symptoms might impact on the patients' agency to perform self-care. To the best of our knowledge,  
31 no empirical work has yet explored the observed interaction between symptoms, self-care  
32 engagement in CHF, and how that influences BoT.  
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#### 44 **Strengths and weakness of the study**

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46 Our review is the first to explore qualitative literature on patients' experiences of CHF with respect  
47 to the interactions of symptoms with BoT. It builds on the foundation of BoT theory<sup>15</sup> with specific  
48 consideration for CHF patients. It characterises the types of symptom interaction with patient  
49 engagement in the context of BoT; which our PPI group recognized and verified as true to their  
50 experiences.  
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3 Using BoT as a framework was a strength, leading to the original observation of CHF symptoms  
4 forming a barrier to patient engagement with BoT and self-care. Hinting at the possibility of an  
5 alternative explanation for why health care professionals may perceive high levels of non-adherence  
6 in CHF patients.  
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13 A strength of the synthesis of qualitative research, through content analysis, is that conclusions  
14 drawn were viewed through multiple theoretical, epistemological and ontological stance of the  
15 included studies' authors as well as the authors of this review. Thus, commonalities observed are  
16 stronger due to heterogeneity of their context, but it may also be a limitation as the multiple  
17 interpretations may have altered the 'true' view of the original data. The review was restricted by  
18 the choice of published quotes from the included articles, our conclusions formed by using data from  
19 published primary studies to develop explanatory ideas the original researcher did not intend. Only  
20 English language articles were included.  
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32 Strengthening our analysis with the use of matrix queries, in Nvivo, to facilitate comparative pattern  
33 analysis as well as textual comparison<sup>66</sup>, confirmed the patterns observed in the constant  
34 comparison process and provided the data to create visual illustrations of these complex  
35 interactions. Our coding analysis strategy, has precedent, as it was a refinement of Thomas and  
36 Harden<sup>23</sup> methodology for thematic synthesis, which used a three stage coding process. We  
37 adapted their third stage to follow Gallacher, et al.<sup>14</sup> work which takes second stage codes  
38 (describe) and compares them against an a priori framework helping to explain the observations.  
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#### 49 **Future work**

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52 The role of symptoms in CHF and their interaction with patient engagement in self-care are not well  
53 understood and need more research. The authors are currently conducting empirical research to  
54 better understand this concept<sup>67</sup>.  
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## CONCLUSIONS AND CLINICAL IMPLICATIONS

Our synthesis suggests that relying on symptoms as the impetus for 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 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. Patients' capacity and current workloads should be carefully considered when altering patient self-care regimens: reducing workload may improve patient outcomes. 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.

*Figure 1: RISMA Flowchart for CHF articles on patient experience. CHF, chronic heart failure; PRISMA, Preferred Reporting Items for Systematic Reviews and MetaAnalyses.*

*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.*

*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.*

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

*Figure 5: Initial model of CHF symptoms interaction with BoT theory primary constructs. BoT, Burden of Treatment*

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2  
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16 framework that informed this work. RCA designed the review with support and guidance from CRM,  
17 LS, and PRK. RCA assisted by CRM and LS performed the work of the literature searches. MC assisted  
18 in the screening of the articles and CRM and LS acted as the arbiter for any disputes. RCA performed  
19 the first-line analysis and was guided by CRM, LS, and AR throughout constant comparison analysis.  
20 PRA's and MG checked line by line symptom coding, refined the symptom coding structure, and  
21 confirmed the results to be representative of their personal patient experiences. CRM, LS, AR, and  
22 PRK critically reviewed the manuscript for intellectual and clinical content. All authors approved the  
23 final version of the paper. RCA is the guarantor.  
24

25  
26 **Patient consent:** Not required  
27

28 **Any checklist and flow diagram for the appropriate reporting statement:**  
29 PRIMSA2009Checklist\_Austin.doc  
30

31 **A data sharing statement:** Data presented in this work was taken from previously published articles.  
32

33 **Supplemental data:** 1) Search strategies, 2) A priori BoT framework, and 3) list of included articles  
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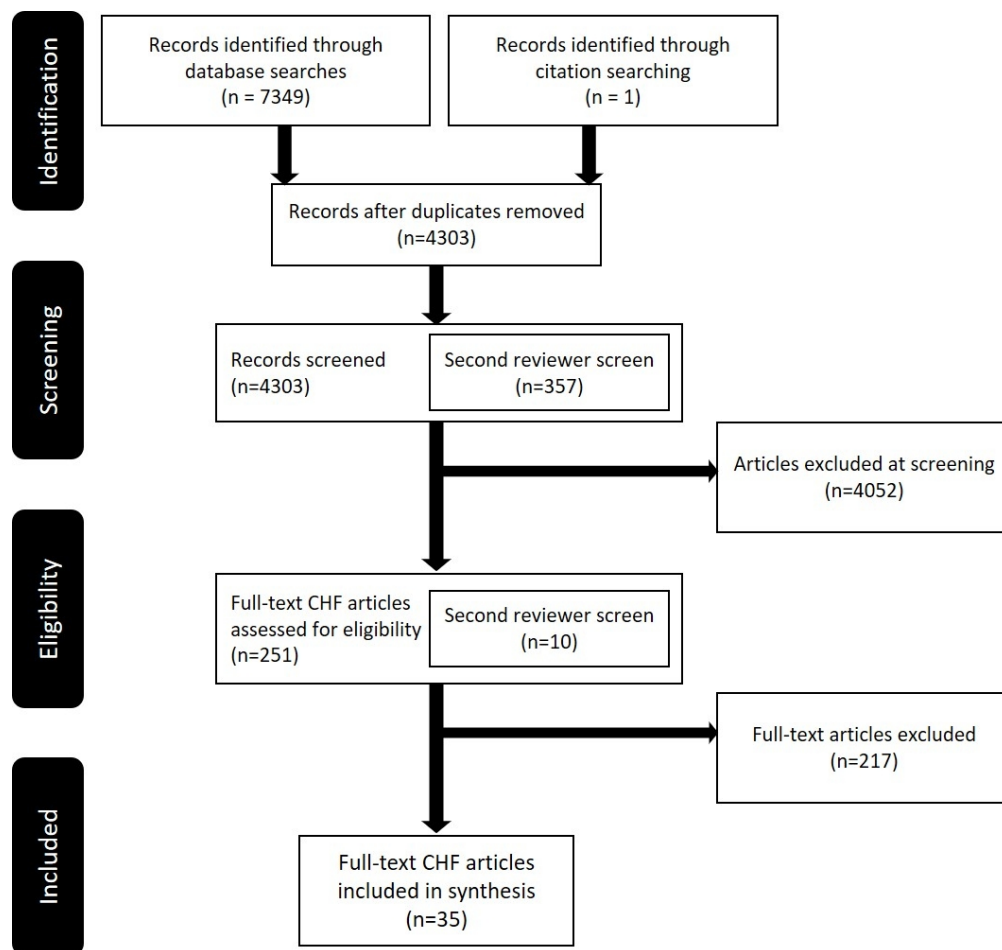


Figure 1: PRISMA Flowchart for CHF articles on patient experience. CHF, chronic heart failure; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta Analyses.

179x169mm (150 x 150 DPI)



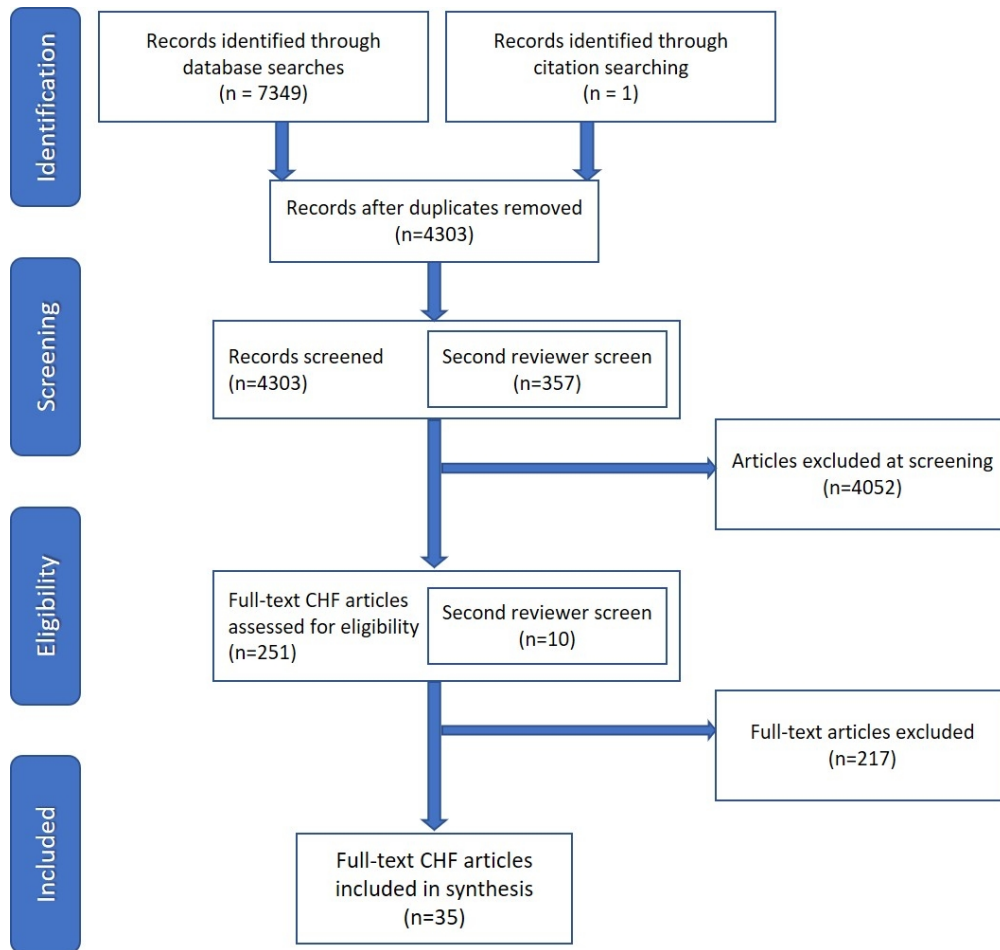


Figure 1: PRISMA Flowchart for CHF articles on patient experience. CHF, chronic heart failure; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta Analyses.

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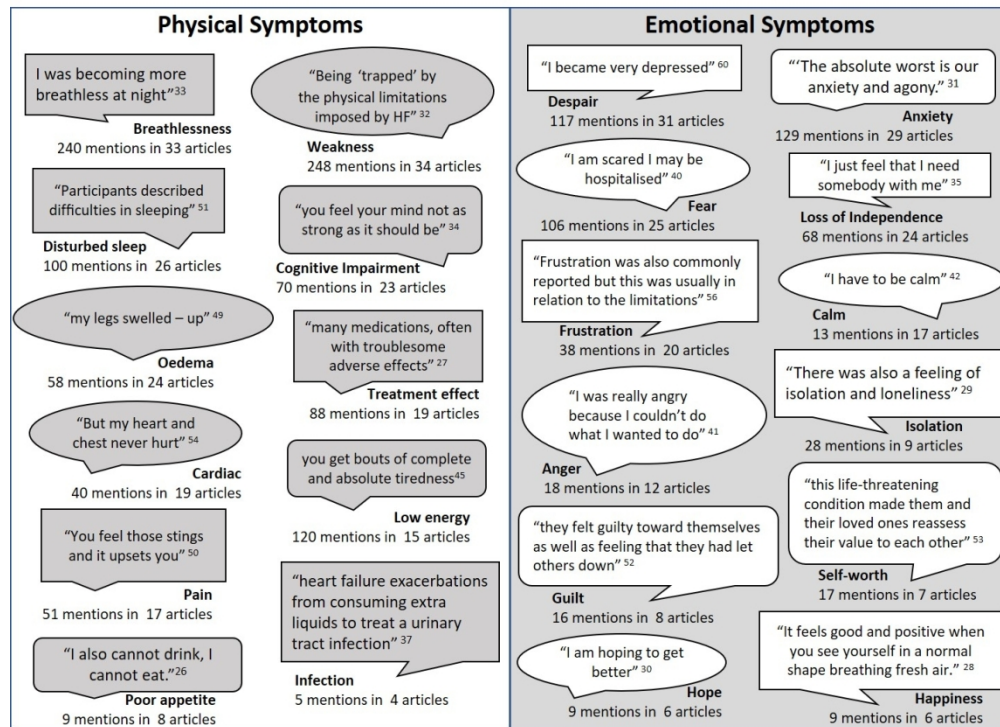


Figure 2: Symptom terms found in included articles: Name of Symptom node in bold font with example quote in speech bubble. Counts of frequency consistency of coding are provided.

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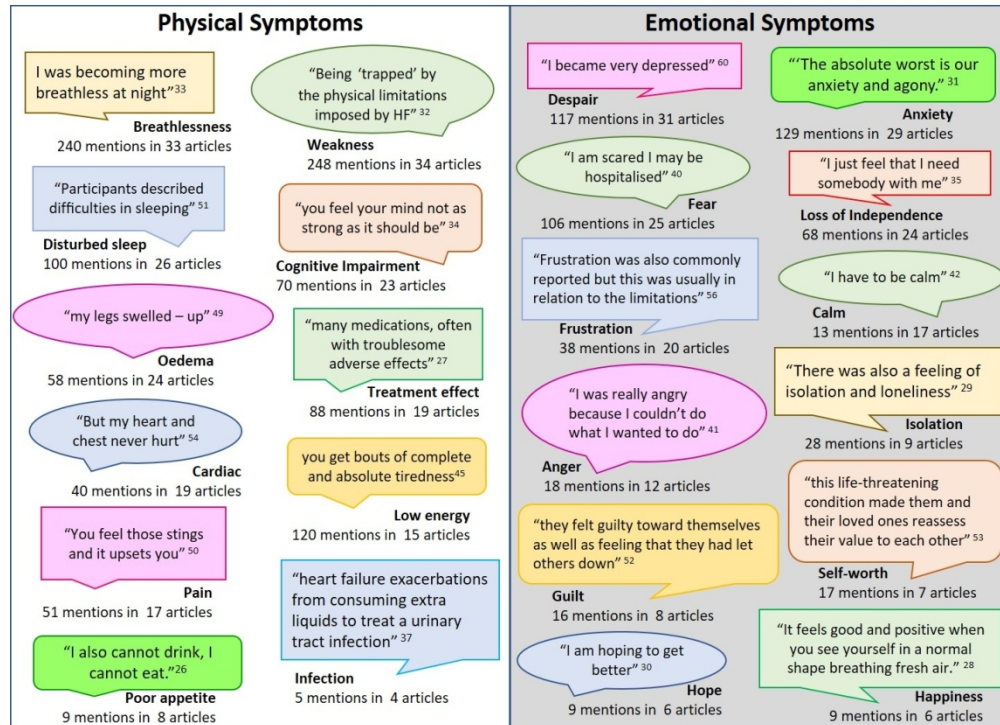


Figure 2: Symptom terms found in included articles: Name of Symptom node in bold font with example quote in speech bubble. Counts of frequency consistency of coding are provided.

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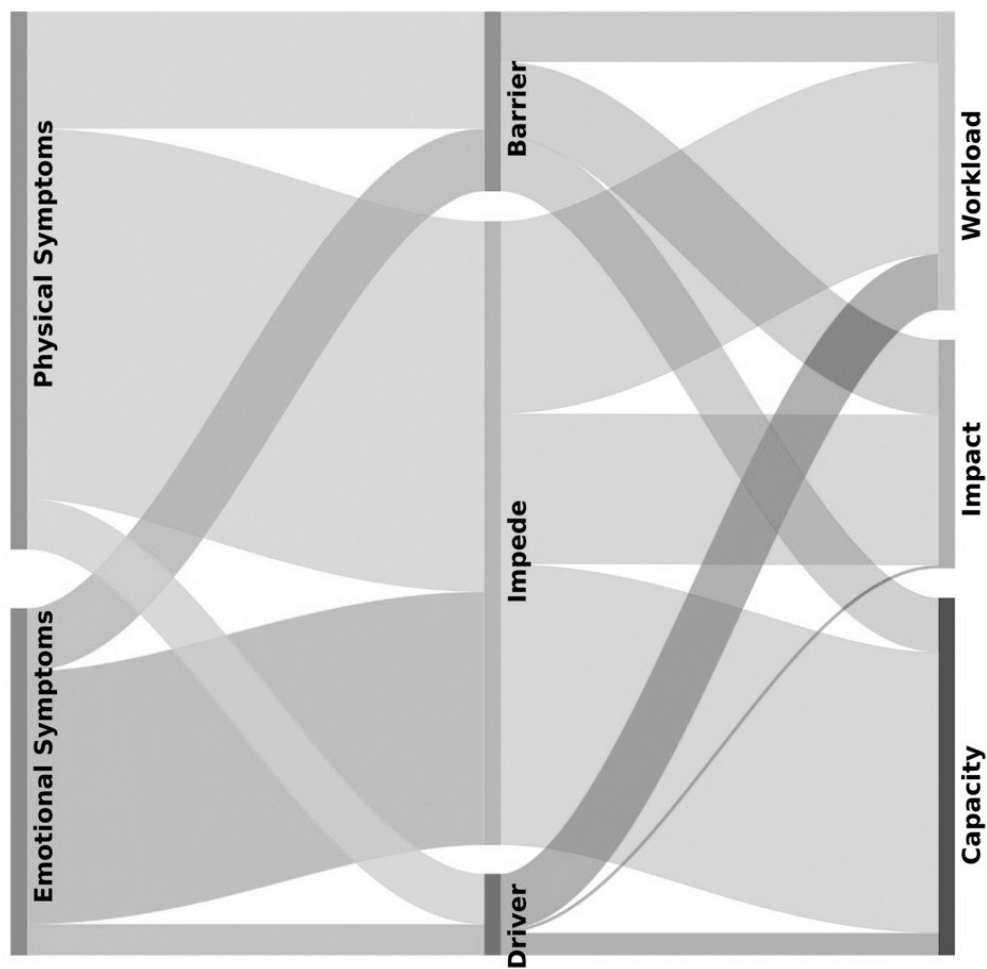


Figure 3: Sankey diagram of symptoms and the type of interaction they have with Burden of treatment. Thickness of the flow bars represents the frequency of that interaction being coded in the analysis.

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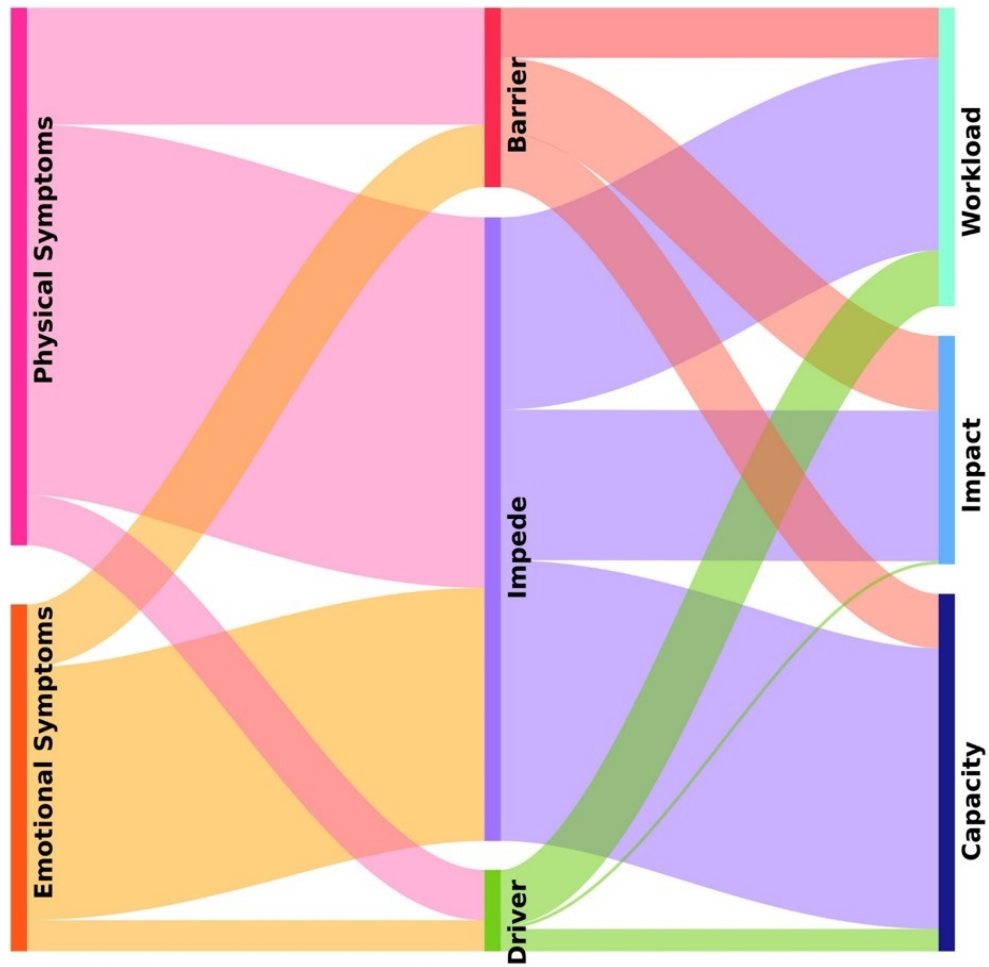


Figure 3: Sankey diagram of symptoms and the type of interaction they have with Burden of treatment. Thickness of the flow bars represents the frequency of that interaction being coded in the analysis.

159x156mm (150 x 150 DPI)



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

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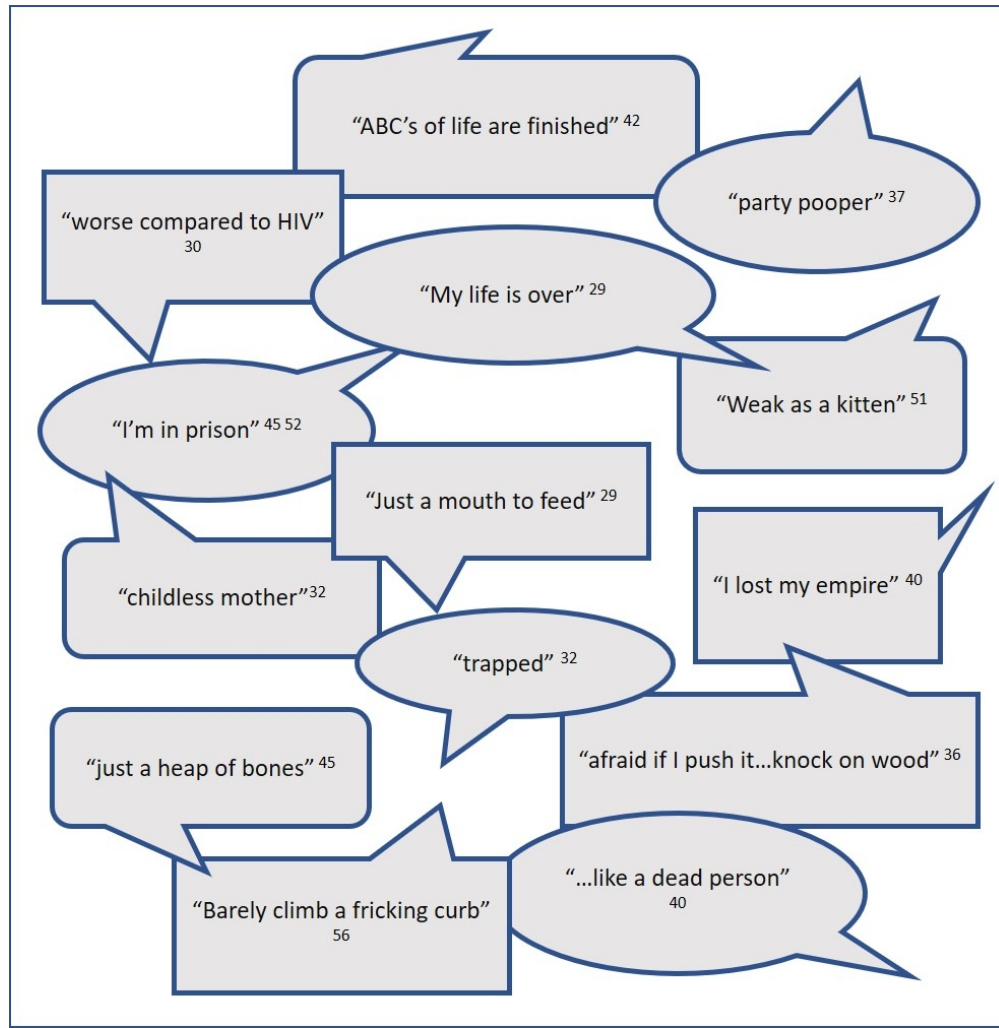


Figure 4: Exemplar metaphors used in description of how symptoms form barriers to engagement in desired activities and their perceived role.

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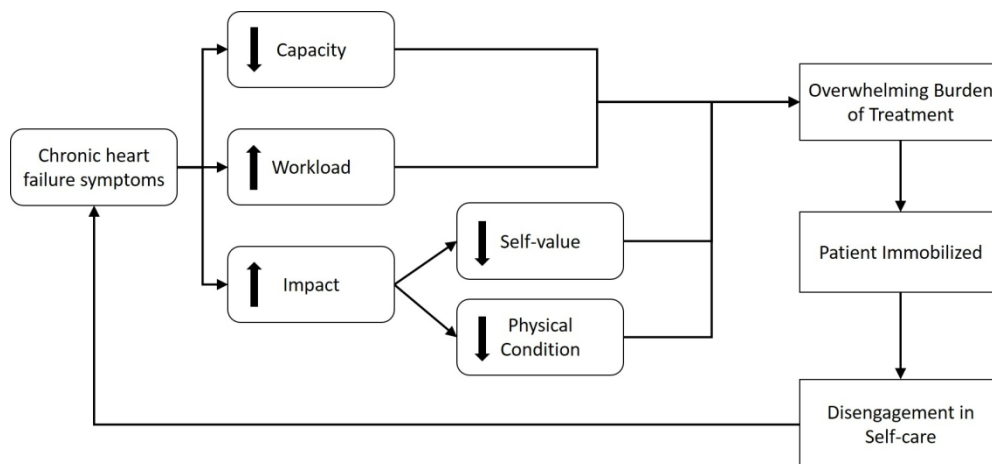


Figure 5: Initial model of CHF symptoms interaction with BoT theory primary constructs. BoT, Burden of Treatment

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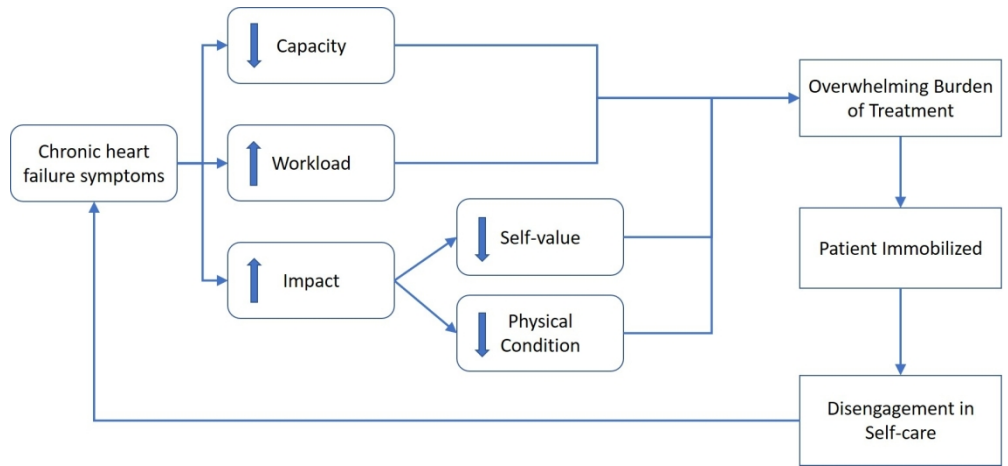


Figure 5: Initial model of CHF symptoms interaction with BoT theory primary constructs. BoT, Burden of Treatment

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## Literature Synthesis Search strategies

**MEDLINE (Ovid interface) Ovid MEDLINE (R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE (R) Daily and Ovid MEDLINE (R) 1946 to Present. Search run on 4/Nov/2017, re-run Jan 20, 2020**

1. Heart failure.af.
2. (Heart failure, diastolic or heart failure, systolic).af
3. ((heart\$ or cardiac or cardial or myocardial) adj3 decompensat\$).af.
4. ((heart\$ or cardiac or cardial or myocardial) adj3 failure\$).af.
5. ((heart\$ or cardiac or cardial or myocardial) adj3 incompetenc\$).af.
6. ((heart\$ or cardiac or cardial or myocardial) adj3 insufficienc\$).af.
7. ((heart\$ or cardiac or cardial or myocardial) adj3 (standstill or stand-still)).af.
8. (CHF or CHF's or HF).af.
9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
10. exp Qualitative Research/
11. qualitativ\$.ti,ab,kf.
12. Interviews as Topic/
13. interview\$.ti,ab,kf.
14. Focus Groups/
15. Grounded Theory/
16. (grounded theor\$ or grounded stud\$ or grounded research or grounded analys\$).ti,ab,kf.
17. focus group\$1.ti,ab,kf.
18. phenomenol\$.ti,ab,kf.
19. (ethnograph\$ or ethnours\$ or ethno-graph\$ or ethno-nurs\$).ti,ab,kf.
20. (story or stories or storytelling or narrative\$1).ti,ab,kf.
21. (open-ended or open question\$ or text\$).ti,ab,kf.
22. Narration/
23. Personal Narratives/
24. Personal Narratives as Topic/
25. (discourse\$ analys\$ or discours\$ analys\$).ti,ab,kf.
26. Content\$ analys\$.ti,ab,kf.
27. ethnological.ti,ab,kf.
28. purposive sampl\$.ti,ab,kf.
29. (constant comparative or constant comparison\$1).ti,ab,kf.
30. theoretical sampl\$.ti,ab,kf.
31. (theme\$ or thematic\$).ti,ab,kf.
32. (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).ti,ab,kf.
33. data saturat\$.ti,ab,kf.
34. participant observ\$.ti,ab,kf.
35. exp Humanism/
36. (humanistic\$ or existential\$ or experiential\$ or paradigm\$).ti,ab,kf.
37. Postmodernism/
38. (social construct\$ or postmodern\$ or post-modern\$ or poststructural\$ or post-structural\$ or feminis\$ or constructivis\$).ti,ab,kf.
39. (action resesarch or cooperative inquir\$ or co-operative inquir\$ or coproduct& or co-producti\$).ti,ab,kf.
40. biographical method\$.ti,ab,kf.
41. human science.ti,ab,kf.
42. life world.ti,ab,kf.
43. theoretical saturat\$.ti,ab,kf.

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44. mixed method\$.ti,ab,kf.
  45. (observational method\$ or observational approach\$).ti,ab,kf.
  46. key informant\$1.ti,ab,kf.
  47. (field study or field studies or field research\$ or field work\$ or fieldwork\$).ti,ab,kf.
  48. (semi-structured or semistructured or unstructured or un-structured or informal or in-depth or indepth).ti,ab,kf.
  49. "face-to-face".ti,ab,kf.
  50. ((guide or structure) adj5 (discussion\$1 or questionnaire\$1)).ti,ab,kf.
  51. (heidegger\$ or colaizzi\$ or speigelberg\$ or van manen\$ or van kaam\$ or merleau ponty\$ or husserl\$ or giorgi\$ or foucault\$ or corbin\$ or glasser\$).ti,ab,kf
  52. 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51
  53. Consumer Behavior/
  54. Attitude/
  55. exp Attitude to Health/
  56. Attitude to Death/
  57. Personal Satisfaction/
  58. exp Emotions/
  59. Stress, Psychological/
  60. exp Patients/px [Psychology]
  61. Caregivers/px [Psychology]
  62. Professional-Patient Relations/
  63. Nurse-Patient Relations/
  64. Physician-Patient Relations/
  65. Professional-Family Relations/
  66. Empathy/
  67. Feedback/
  68. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) and (experienc\$ or perspective\$1 or perception\$1 or opinion\$1 or account or accounts or attitude\$1 or view or views or viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or disatisf\$ or belief\$1 or believ\$)).ti.
  69. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) adj3 (experienc\$ or perspective\$1 or perception\$1 or opinion\$1 or account or accounts or attitude\$1 or view or views or viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or disatisf\$ or belief\$1 or believ\$)).ab,kf.
  70. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) and (emotion\$ or feeling\$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet\$ or anxious\$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat\$ or stress\$ or distress\$ or embarrass\$ or empath\$ or accept\$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother\$ or unbother\$ or pleased or displeased\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$ or confus\$ or hope or hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or confiden\$ or unconfiden\$)).ti.
  71. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) adj3 (emotion\$ or feeling\$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet\$ or anxious\$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat\$ or stress\$ or distress\$ or embarrass\$ or empath\$ or accept\$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother\$ or unbother\$ or pleased or displeased\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$ or confus\$ or hope or hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or confiden\$ or unconfiden\$)).ab,kf.
  72. (life experience\$1 or lived experience\$1 or actual experience\$1 or real experience\$1).ti,ab,kf.
  73. 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72
  74. 9 and 52 and 73
  75. qualitativ\$.ti.

76. Qualitative Research/
77. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) and experiences).ti.
78. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) adj2 experienc\$).ti.
79. 75 or 76 or 77 or 78
80. 9 and 79
81. 74 or 80
82. exp animals/ not humans/
83. (news or comment or editorial or letter or case reports or randomized controlled trial).pt.
84. case-report.ti.
85. 81 not (82 or 83 or 84)
86. limit 81 to (english language and yr="2007 -Current")

**EMBASE (Ovid interface) EMBASE Classic + EMBASE 1947 to Week 45. Search run on 4/Nov/2017, re-run on Jan 20, 2020**

1. exp heart failure/
2. heart failure with preserved ejection fraction/
3. exp heart failure with reduced ejection fraction/
4. congestive heart failure/
5. (heart failure diastolic or heart failure systolic).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]
6. ((heart\$ or cardiac or cardial or myocardial) adj3 decompensat\$).mp.
7. ((heart\$ or cardiac or cardial or myocardial) adj3 failure\$).mp.
8. ((heart\$ or cardiac or cardial or myocardial) adj3 incompetenc\$).mp.
9. ((heart\$ or cardiac or cardial or myocardial) adj3 insufficienc\$).mp.
10. ((heart\$ or cardiac or cardial or myocardial) adj3 dysfunction\$).mp.
11. (((heart\$ or cardiac or cardial or myocardial) adj3 standstill) or stand-still).mp.
12. (CHF or CHF\$ or HF or HFpEF or HFrEF).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]
13. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14. exp qualitative research/
15. qualitativ\$.ti,ab,kw.
16. exp interview/
17. interview\$.ti,ab,kw.
18. focus group\$1.ti,ab,kw.
19. grounded theory/
20. (grounded theor\$ or grounded study or grounded studies or grounded research or grounded analys\$).ti,ab,kw.
21. phenomenology/
22. phenomenol\$.ti,ab,kw.
23. ethnography/
24. ethn nursing research/
25. (ethnograph\$ or ethn nurs\$ or ethno-graph\$ or ethno-nurs\$).ti,ab,kw.
26. verbal communication/
27. narrative/
28. storytelling/
29. (story or stories or storytelling or narrative\$1 or narration\$1).ti,ab,kw.
30. open ended questionnaire/

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31. (open-ended or open question\$ or text\$).ti,ab,kw.
32. discourse analysis/
33. (discourse\$ analys\$ or discours\$ analys\$).ti,ab,kw.
34. content analysis/
35. content\$ analys\$.ti,ab,kw.
36. ethnological.ti,ab,kw.
37. purposive sample/
38. purposive sampl\$.ti,ab,kw.
39. (constant comparative or constant comparison\$1).ti,ab,kw.
40. theoretical sample/
41. theoretical sampl\$.ti,ab,kw.
42. thematic analysis/
43. (theme\$ or thematic\$).ti,ab,kw.
44. (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).ti,ab,kw.
45. data saturat\$.ti,ab,kw.
46. observational method/
47. participant observ\$.ti,ab,kw.
48. humanism/
49. existentialism/
50. (humanistic\$ or existential\$ or experiential\$ or paradigm\$).ti,ab,kw.
51. feminism/
52. (social construct\$ or postmodern\$ or post-modern\$ or poststructural\$ or post-structural\$ or feminis\$ or constructivis\$).ti,ab,kw.
53. action research/
54. (action research or cooperative inquir\$ or co-operative inquir\$).ti,ab,kw.
55. human science.ti,ab,kw.
56. biographical method\$.ti,ab,kw.
57. life world.ti,ab,kw.
58. theoretical saturation.ti,ab,kw.
59. group discussion\$1.ti,ab,kw.
60. direct observation\$.ti,ab,kw.
61. mixed method\$.ti,ab,kw.
62. (observational method\$ or observational approach\$).ti,ab,kw.
63. key informant\$1.ti,ab,kw.
64. field study/
65. field work/
66. (field study or field studies or field research\$ or field work\$ or fieldwork\$).ti,ab,kw.
67. (semi-structured or semistructured or unstructured or un-structured or informal or in-depth or indepth).ti,ab,kw
68. "face-to-face".ti,ab,kw.
69. structured questionnaire/
70. ((guide or structured) adj\$5 (discussion\$1 or questionnaire\$1)).ti,ab,kw.
71. (heidegger\$ or colaizzi\$ or speigelberg\$ or van manen\$ or van kaam\$ or merleau ponty\$ or hussert\$ or giorgi\$ or foucault\$ or corbin\$ or glaser\$).ti,ab,kw.
72. 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71

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3 73. exp patient attitude/  
4 74. attitude/  
5 75. attitude to health/  
6 76. attitude to illness/  
7 77. attitude to life/  
8 78. consumer attitude/  
9 79. exp family attitude/  
10 80. attitude to death/  
11 81. satisfaction/  
12 82. exp emotion/  
13 83. mental stress/  
14 84. exp patient/  
15 85. caregiver/  
16 86. exp psychology/  
17 87. psychological aspect/  
18 88. 84 or 85  
19 89. 86 or 87  
20 90. 88 and 89  
21 91. doctor patient relation/  
22 92. nurse patient relationship/  
23 93. feedback system/  
24 94. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) and (experienc\$ or perspective\$1 or perception\$1 or  
25 opinion\$1 or account or accounts or attitude\$1 or view or views or viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or  
26 disatisf\$ or belief\$1 or believ\$)).ti.  
27 95. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) adj3 (experienc\$ or perspective\$1 or perception\$1 or  
28 opinion\$1 or account or accounts or attitude\$1 or view or views or viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or  
29 disatisf\$ or belief\$1 or believ\$)).ab,kw.  
30 96. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) and (emotion\$ or feeling\$1 or happy or happiness or unhappy  
31 or unhappiness or sad or sadness or anger or angry or anxiet\$ or anxious\$ or worry or worries or worried or worrying or  
32 troubled or troubling or troubles or troublesome or trouble-some or frustrat\$ or stress\$ or distress\$ or embarrass\$ or  
33 empath\$ or accept\$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or  
34 bother\$ or unbother\$ or pleased or displeased\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$ or  
35 confus\$ or hope or hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or  
36 confiden\$ or unconfiden\$)).ti.  
37 97. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) adj3 (emotion\$ or feeling\$1 or happy or happiness or  
38 unhappy or unhappiness or sad or sadness or anger or angry or anxiet\$ or anxious\$ or worry or worries or worried or  
39 worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat\$ or stress\$ or distress\$ or  
40 embarrass\$ or empath\$ or accept\$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or  
41 scared or bother\$ or unbother\$ or pleased or displeased\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$  
42 or confus\$ or hope or hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or  
43 confiden\$ or unconfiden\$)).ab,kw.  
44 98. (life experience\$1 or lived experience\$1 or actual experience\$1 or real experience\$1).ti,ab,kw.  
45 99. 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83 or 90 or 91 or 92 or 93 or 94 or 95 or 96 or 97 or 98  
46 100. 13 and 72 and 99  
47 101. qualitativ\$.ti.  
48 102. qualitative research/  
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- 3 103. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) and experiences).ti.
- 4 104. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) adj2 experienc\$).ti.
- 5 105. 101 or 102 or 103 or 104
- 6 106. 13 and 105
- 7 107. 100 or 106
- 8 108. animal/
- 9 109. animal experiment/
- 10 110. animal model/
- 11 111. animal tissue/
- 12 112. nonhuman/
- 13 113. 108 or 109 or 110 or 111 or 112
- 14 114. human/
- 15 115. 113 not 114
- 16 116. (editorial or letter or conference abstract or conference paper or conference proceeding or conference review).pt.
- 17 117. case report.ti
- 18 118. 107 not (115 or 116 or 117).
- 19 119. limit 118 to (english language and yr="2007 -Current")

**CINAHL plus Full Text (EBSCO interface). Searches run on 04/11/2017, re-tun on Jan 20, 2020.**

- 25
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- 28 S1 "heart failure"
- 29 S2 (MH "heart failure+")
- 30 S3 (MH "cardiac output decreased+")
- 31 S4 (MH "ventricular ejection fraction+")
- 32 S5 (MH "cardiac patients+")
- 33 S6 S1 OR S2 OR S3 OR S4 OR S5
- 34 S7 (MH "Qualitative Studies+")
- 35 S8 TI(qualitativ\*) or AB(qualitativ\*)
- 36 S9 (MH "Interviews+")
- 37 S10 TI(interview\*) or AB(interview\*)
- 38 S11 (MH "Focus Groups")
- 39 S12 TI("focus group\*") or AB("focus group\*")
- 40 S13 TI("grounded theor\*" or "grounded study" or "grounded studies" or "grounded research" or "grounded analys\*") or
- 41 AB("grounded theor\*" or "grounded study" or "grounded studies" or "grounded research" or "grounded analys\*")
- 42 S14 (MH "Phenomenology") OR (MH "Phenomenological Research")
- 43 S15 TI(phenomenol\*) or AB(phenomenol\*)
- 44 S16 TI(ethnograph\* or ethnonurs\* or "ethno-graph\*" or "ethnonurs\*") or AB(ethnograph\* or ethnonurs\* or "ethno-graph\*" or "ethno-
- 45 nurs\*")
- 46 S17 (MH "Storytelling+") OR (MH "Narratives")
- 47 S18 TI(story or stories or storytelling or narrative\* or narration\*) or AB(story or stories or storytelling or narrative\* or narration\*)
- 48 S19 (MH "Open-Ended Questionnaires")
- 49 S20 TI("open-ended" or "open question\*" or text\*) or AB("openended" or "open question\*" or text\*)
- 50 S21 (MH "Discourse Analysis")
- 51 S22 TI("discourse\* analys\*" or "discurs\* analys\*") or AB("discourse\* analys\*" or "discurs\* analys\*")
- 52 S23 (MH "Content Analysis")
- 53 S24 TI("content\* analys\*") or AB("content\* analys\*")
- 54 S25 TI(ethnological) or AB(ethnological)
- 55 S26 (MH "Purposive Sample")
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3 S27 TI("purposive sampl\*") or AB("purposive sampl\*")  
4 S28 (MH "Constant Comparative Method")  
5 S29 TI("constant comparative" or "constant comparison\*") or AB ("constant comparative" or "constant comparison\*")  
6 S30 (MH "Theoretical Sample")  
7 S31 TI("theoretical sampl\*") or AB("theoretical sampl\*")  
8 S32 (MH "Thematic Analysis")  
9 S33 TI(theme\* or thematic\*) or AB(theme\* or thematic\*)  
10 S34 TI(emic or etic or hermeneutic\* or heuristic\* or semiotic\*) or AB(emic or etic or hermeneutic\* or heuristic\* or semiotic\*)  
11 S35 TI("data saturat\*") or AB("data saturat\*")  
12 S36 (MH "Observational Methods+")  
13 S37 TI("participant observ\*") or AB("participant observ\*")  
14 S38 (MH "Humanism")  
15 S39 TI(humanistic\* or existential\* or experiential\* or paradigm\*) or AB(humanistic\* or existential\* or experiential\* or paradigm\*)  
16 S40 (MH "Social Constructionism")  
17 S41 (MH "Postmodernism")  
18 S42 (MH "Feminism+")  
19 S43 TI("social construct\*" or postmodern\* or "post-modern\*" or poststructural\* or "post-structural\*" or feminis\* or constructivis\*) or  
20 AB("social construct\*" or postmodern\* or "post-modern\*" or poststructural\* or "post-structural\*" or feminis\* or constructivis\*)  
21 S44 TI("action research" or "cooperative inquir\*" or "co-operative inquir\*") or AB("action research" or "cooperative inquir\*" or "co-  
22 operative inquir\*")  
23 S45 TI("human science") or AB("human science")  
24 S46 TI("biographical method\*") or AB("biographical method\*")  
25 S47 TI("life world") or AB("life world")  
26 S48 TI("theoretical saturation") or AB("theoretical saturation")  
27 S49 TI("group discussion\*") or AB("group discussion\*")  
28 S50 TI("direct observation\*") or AB("direct observation\*")  
29 S51 TI("mixed method\*") or AB("mixed method\*")  
30 S52 TI("observational method\*" or "observational approach\*") or AB("observational method\*" or "observational approach\*")  
31 S53 TI("key informant\*") or AB("key informant\*")  
32 S54 (MH "Field Studies")  
33 S55 TI("field study" or "field studies" or "field research\*" or "field work\*" or fieldwork\*) or AB("field study" or "field studies" or "field  
34 research\*" or "field work\*" or fieldwork\*)  
35 S56 TI("semi-structured" or semistructured or unstructured or "un-structured" or informal or "in-depth" or indepth) or AB("semi-  
36 structured" or semistructured or unstructured or "un-structured" or informal or "in-depth" or indepth)  
37 S57 TI("face-to-face") or AB("face-to-face")  
38 S58 (MH "Structured Interview Guides")  
39 S59 (MH "Structured Questionnaires")  
40 S60 (MH "Discussion")  
41 S61 TI((guide or structured) N5 (discussion\* or questionnaire\*)) or AB((guide or structured) N5 (discussion\* or questionnaire\*))  
42 S62 TI(heidegger\* or colaizzi\* or speigelberg\* or "van manen\*" or "van kaam\*" or "merleau ponty\*" or husserl\* or giorgi\* or  
43 foucault\* or corbin\* or glaser\*) or AB(heidegger\* or colaizzi\* or speigelberg\* or "van manen\*" or "van kaam\*" or "merleau  
44 ponty\*" or husserl\* or giorgi\* or foucault\* or corbin\* or glaser\*)  
45 S63 S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR  
46 S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36  
47 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR  
48 S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62  
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3 S64 (MH "Consumer Satisfaction") OR (MH "Patient Satisfaction")  
4 S65 (MH "Attitude") OR (MH "Attitude to Death") OR (MH "Attitude to Health") OR (MH "Attitude to Illness") OR (MH "Family  
5 Attitudes+") OR (MH "Patient Attitudes") OR (MH "Personal Satisfaction")  
6  
7 S66 (MH "Patient Compliance+") OR (MH "Treatment Refusal")  
8  
9 S67 (MH "Attitude to Life")  
10  
11 S68 (MH "Health Beliefs")  
12  
13 S69 (MH "Consumer Participation")  
14  
15 S70 (MH "Emotions+")  
16  
17 S71 (MH "Stress, Psychological")  
18  
19 S72 (MH "Caregiver Burden")  
20  
21 S73 (MH "Critical Incident Stress")  
22  
23 S74 (MH "Minority Stress")  
24  
25 S75 (MH "Reality Shock")  
26  
27 S76 (MH "Role Stress")  
28  
29 S77 (MH "Patients+/PF")  
30  
31 S78 (MH "Caregivers/PF")  
32  
33 S79 (MH "Caregiver Support")  
34  
35 S80 (MH "Professional-Patient Relations") OR (MH "PhysicianPatient Relations") OR (MH "Nurse-Patient Relations") OR (MH  
36 "Professional-Family Relations") OR (MH "ProfessionalClient Relations") OR (MH "Patient-Family Relations")  
37  
38 S81 (MH "Empathy")  
39  
40 S82 (MH "Feedback")  
41  
42 S83 TI((patient\* or client\* or user\* or consumer\* or personal) and (experienc\* or perspective\* or perception\* or opinion\* or account  
43 or accounts or attitude\* or view or views or viewpoint\* or satisf\* or unsatisf\* or dissatisf\* or disatisf\* or belie\* or believ\*))  
44  
45 S84 AB((patient\* or client\* or user\* or consumer\* or personal or carer\* or caregiver\* or "care-giver\*" or family\* or families) N3  
46 (experienc\* or perspective\* or perception\* or opinion\* or account or accounts or attitude\* or view or views or viewpoint\* or  
47 satisf\* or unsatisf\* or dissatisf\* or disatisf\* or belie\* or believ\*))  
48  
49 S85 TI((patient\* or client\* or user\* or consumer\* or personal) and (emotion\* or feeling\* or happy or happiness or unhappy or  
50 unhappiness or sad or sadness or anger or angry or anxiet\* or anxious\* or worry or worries or worried or worrying or troubled  
51 or troubling or troubles or troublesome or "trouble-some" or frustrat\* or stress\* or distress\* or embarrass\* or empath\* or  
52 accept\* or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother\$ or  
53 unbother\$ or pleased or displeas\$ or concern\$ or burden\$ or hass\$ or convenien\$ or inconvenien\$ or confus\$ or hope or  
54 hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or confiden\$ or unconfiden\$)).  
55  
56 S86 AB((patient\* or client\* or user\* or consumer\* or personal) N3 (emotion\* or feeling\* or happy or happiness or unhappy or  
57 unhappiness or sad or sadness or anger or angry or anxiet\* or anxious\* or worry or worries or worried or worrying or troubled  
58 or troubling or troubles or troublesome or "troublesome" or frustrat\* or stress\* or distress\* or embarrass\* or empath\* or  
59 accept\* or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother\$ or  
60 unbother\$ or pleased or displeas\$ or concern\$ or burden\$ or hass\$ or convenien\$ or inconvenien\$ or confus\$ or hope or  
hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or confiden\$ or unconfiden\$))  
S87 (MH "Life Experiences")  
S88 TI("life experience\*" or "lived experience\*" or "actual experience\*" or "real experience\*") or AB("life experience\*" or "lived  
experience\*" or "actual experience\*" or "real experience\*")  
S89 S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78  
OR S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88  
S90 S6 AND S63 AND S89  
S91 TI(qualitativ\*)  
S92 (MH "Qualitative Studies")

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3 S93 TI((patient\* or client\* or user\* or consumer\* or personal) and experiences)  
4 S94 TI((patient\* or client\* or user\* or consumer\* or personal) N2 experienc\*)  
5 S95 S91 OR S92 OR S93 OR S94  
6 S96 S6 AND S95  
7 S97 S90 OR S96  
8 S98 PT (commentary or editorial or letter)  
9 S99 TI(case report)  
10  
11  
12 S100 S97 NOT (S98 OR S99) Limiter – Publish date: 20070101-20171131;English Language  
13

14 **PsychINFO (EBSCO interface). Search run 4/Nov/2017, re-run Jan 20, 2020**  
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16  
17 S1 DE heart  
18 S2 DE "heart disorders" OR DE "heart ventricles"  
19 S3 S1 AND S2  
20 S4 "heart failure"  
21 S5 heart N2 failure  
22 S6 S3 OR S4 OR S5  
23 S7 DE "Qualitative Research"  
24 S8 qualitative study  
25 S9 TI qualitativ\* OR AB qualitativ\*  
26 S10 DE "Interviews" OR DE "Intake Interview" OR DE "Interview Schedules" OR DE "Job Applicant Interviews" OR DE  
27 "Psychodiagnostic Interview"  
28 S11 interview  
29 S12 DE "Interviews" OR DE "Interviewing" OR DE "Interviewers"  
30 S13 TI interview\* OR AB interview\*  
31 S14 DE "Group Discussion"  
32 S15 focus group  
33 S16 TI focus group\* OR AB focus group  
34 S17 DE "Grounded Theory"  
35 S18 TI grounded theor\* OR TI grounded study OR TI grounded studies OR TI grounded research OR TI grounded analys\* OR  
36 AB grounded theor\* OR AB grounded study OR AB grounded studies OR AB grounded research OR AB grounded  
37 analys\*  
38 S19 DE "Phenomenology"  
39 S20 TI Phenomenol\*  
40 S21 AB Phenomenol\*  
41 S22 DE "Ethnography"  
42 S23 TI ethnograph\* OR TI ethnonurs\* OR TI ethno-graph\* OR TI ethno-nurs\* OR AB ethnograph\* OR AB ethnonurs\* OR AB  
43 ethno-graph\* OR TI ethno-nurs\*  
44 S24 DE "Storytelling"  
45 S25 DE "Narratives"  
46 S26 TI story OR TI stories OR TI storytelling OR TI narrative\*1 OR TI narration\*1  
47 S27 AB story OR AB stories OR AB storytelling OR AB narrative\*1 OR AB narration\*1  
48 S28 DE "Discourse Analysis"  
49 S29 TI discourse\* analys\* OR TI discours\* analys\* OR AB discourse\* analys\* OR AB discours\* analys\*  
50 S30 DE "Content Analysis"  
51 S31 TI content\* analys\* AND AB content\* analys\*  
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3 S32 DE "Ethnology"  
4 S33 TI ethnological OR AB ethnological  
5 S34 TI purposive sampl\* OR AB purposive sampl\*  
6 S35 TI constant comparative OR TI constant comparison\*1 OR AB constant comparative OR AB constant comparison\*1  
7 S36 TI theoretical sampl\* OR AB theoretical sampl\*  
8 S37 TI theme\* OR TI thematic\* OR AB theme\* OR AB thematic\*  
9 S38 DE "Hermeneutics"  
10 S39 DE "Heuristics" OR DE "Heuristic Modeling"  
11 S40 DE "Semiotics" OR DE "Pragmatics"  
12 S41 TI emic OR TI etic OR TI hermenutic\* OR TI heuristic\* OR TI semiotic\* OR AB emic OR AB etic OR AB hermenutic\* OR  
13 AB heuristic\* OR AB semiotic\*  
14 S42 TI data saturat\* OR AB data saturat\*  
15 S43 DE "Observers"  
16 S44 TI participant observ\* OR AB participant observ\*  
17 S45 DE "Existentialism"  
18 S46 DE "Humanism"  
19 S47 TI humanistic\* OR TI existential\* OR TI experiential\* OR TI paradigm\* OR AB humanistic\* OR AB existential\* OR AB  
20 experiential\* OR AB paradigm\*  
21 S48 DE "Postmodernism"  
22 S49 DE "Feminism"  
23 S50 DE "Structuralism"  
24 S51 DE "Constructivism"  
25 S52 TI social construct\* OR TI postmodern\* OR TI post-modern\* OR TI post-modern\* OR TI post-structural\* OR TI feminis\*  
26 OR TI constructivis\* OR AB social construct\* OR AB postmodern\* OR AB post-modern\* OR AB post-structural\* OR AB  
27 feminis\*  
28 S53 AB constructivis\*  
29 S54 DE "Action Research"  
30 S55 TI action research OR TI cooperative inquir\* OR TI co operative inquir\* OR AB action research OR AB cooperative inquir\*  
31 OR AB co-operative inquir\*  
32 S56 TI human science OR AB human science  
33 S57 TI biographical method\* OR AB biographical method\*  
34 S58 TI life world OR AB life world  
35 S59 TI theoretical saturation OR AB theoretical saturation  
36 S60 TI group discussion\* OR AB group discussion\*  
37 S61 TI direct observation\* OR AB direct observation\*  
38 S62 TI mixed method\* OR AB mixed method\*  
39 S63 DE "Observation Methods"  
40 S64 TI observational method\* OR TI observational approach\* AND AB observational method\* AND AB observational  
41 approach\*  
42 S65 TI key informant\* OR AB key informant\*  
43 S66 field study  
44 S67 TI field study OR TI field studies OR TI field research\* OR TI field work\* OR TI fieldwork\* OR AB field study OR AB field  
45 studies OR AB field research\* OR AB field work\* OR AB fieldwork\*  
46 S68 TI TI semi-structured OR TI semistructured OR TI unstructured OR TI indepth OR AB semi-structured OR AB  
47 semistructured OR AB indepth OR AB in-depth OR TI un-structured OR TI informal OR TI in-depth OR TI unstructured  
48 OR AB un-structured OR AB informal  
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3 S69 TI "face-to-face" OR AB "face-to-face"  
4 S70 TI ( (guide or structured) N5 (discussion\* or questionnaire\*) ) OR AB ( (guide or structured) N5 (discussion\* or  
5 questionnaire\* ) )  
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7 S71 TI ( (heidegger\* or colaizzi\* or speigelberg\* or van manen\* or van kaam\* or merleau ponty\* or husserl\* or giorgi\* or  
8 foucault\* or corbin\* or glaser\*) ) OR AB ( (heidegger\* or colaizzi\* or speigelberg\* or van manen\* or van kaam\* or merleau  
9 ponty\* or husserl\* or giorgi\* or foucault\* or corbin\* or glaser\*) )  
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11 S72 S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21  
12 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35  
13 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49  
14 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63  
15 OR S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70 OR S71  
16  
17 S73 TI qualitativ\*  
18 S74 DE "Qualitative Research"  
19 S75 qualitative study  
20 S76 TI ( (patient\* or client\* or user\* or consumer\* or personal) ) AND TI experiences  
21 S77 TI ((patient\* or client\* or user\* or consumer\* or personal) N2 experienc\*)  
22 S78 S73 OR S74 OR S75  
23 S79 S76 OR S77  
24 S80 S6 AND S72  
25  
26 S81 TI ( (rat or rats or rodent or rodents or mouse or mice or murine or hamster or hamsters or gerbil or gerbils or animal or  
27 animals or dogs or dog or canine or pig or pigs or piglet or piglets or cats or bovine or cow or cows or cattle or sheep or  
28 ewe or ewes or horse or horses or equine or ovine or porcine or monkey or monkeys or primate or primates or rhesus  
29 macaque or rhesus macaques or rabbit or rabbits) ) NOT AF human\*  
30  
31 S82 (chapter or comment/reply or dissertation or editorial or letter)  
32 S83 PT (book or authored book or edited book or dissertation abstract)  
33 S84 (review-book or review-media or review-software & other)  
34 S85 TI case report  
35 S86 S06 AND S78  
36 S87 S06 AND S79  
37 S88 S80 OR S86 OR S87  
38 S89 S81 OR S82 OR S83 OR S84 OR S85  
39 S90 S88 NOT S89 Limiters – Publication Year: 2007-2017; English  
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#### SCOPUS. Search run 4/11/2017, re-run Jan 20, 2020

( TITLE-ABS-

KEY ( ( heart\* OR cardiac OR cardial OR myocardia\* ) W/3 ( failure\* OR decompensat\* OR incompeten\* OR insufficienc\*  
OR dysfunction\* ) ) OR TITLE-ABS-KEY ( "heart failure" W/3 ( congestive OR diastolic OR systolic ) OR ( "preserved  
ejection fraction" OR "reduced ejection fraction" ) ) OR TITLE-ABS-  
KEY ( "CHF" OR "CHF\*s" OR "HF" OR "HFpEF" OR "HFREF" ) AND TITLE-ABS-KEY ( qualitativ\* OR interview\* OR "focus  
group\*" OR "grounded theor\*" OR "grounded study" OR "grounded studies" OR "grounded research" OR "grounded  
analys\*" OR phenomenol\* OR ethnograph\* OR ethnonurs\* OR "ethno-graph\*" OR "ethno-  
nurs\*" OR story OR stories OR storytelling OR narrative\* OR narration\* OR "open ended" OR "open  
question\*" OR text\* OR "discourse\* analys\*" OR "discors\* analys\*" OR "content\* analys\*" OR ethnological OR "purposive  
saml\*" OR "constant comparative" OR "constant comparison\*" OR "theoretical  
saml\*" OR theme\* OR thematic\* OR emic OR etic OR hermeneutic\* OR heuristic\* OR semiotic\* OR "data  
saturat\*" OR "participant observ\*" OR humanistic\* OR existential\* OR experiential\* OR paradigm\* OR "social

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 3 construct\* OR postmodern\* OR "post-modern\*" OR poststructural\* OR "post-  
 4 structural\*" OR feminis\* OR constructivis\* OR "action research" OR "cooperative inquir\*" OR "co-operative  
 5 inquir\*" OR "human science" OR "biographical method\*" OR "life world" OR "theoretical saturation" OR "group  
 6 discussion\*" OR "direct observation\*" OR "mixed method\*" OR "observational method\*" OR "observational  
 7 approach\*" OR "key informant\*" OR "field study" OR "field studies" OR "field research\*" OR "field  
 8 work\*" OR fieldwork\* OR "semi-structured" OR "semistructured" OR "unstructured" OR informal OR "in-  
 9 depth" OR indepth OR "face-to-face" OR heidegger\* OR colaizzi\* OR speigelberg\* OR "van manen\*" OR "van  
 10 kaam\*" OR "merleau ponty\*" OR husserl\* OR giorgi\* OR foucault\* OR corbin\* OR glaser\*) OR TITLE-ABS-  
 11 KEY (guide OR structured) W/5 (discussion\* OR questionnaire\*) AND TITLE (patient\* OR client\* OR user\* OR consum  
 12 er\* OR personal OR carer\* OR caregiver\* OR "care-  
 13 giver\*" OR family\* OR families) AND (experienc\* OR perspective\* OR perception\* OR opinion\* OR account OR account  
 14 s OR attitude\* OR view OR views OR viewpoint\* OR satisf\* OR unsatisf\* OR dissatisf\* OR disatisf\* OR believ\* OR belie  
 15 v\*) OR ABS (patient\* OR client\* OR user\* OR consumer\* OR personal OR carer\* OR caregiver\* OR "care-  
 16 giver\*" OR family\* OR families) W/3 (experienc\* OR perspective\* OR perception\* OR opinion\* OR account OR accounts  
 17 OR attitude\* OR view OR views OR viewpoint\* OR satisf\* OR unsatisf\* OR dissatisf\* OR disatisf\* OR believ\* OR believ  
 18 \*) OR KEY (patient\* OR client\* OR user AND \* OR consumer\* OR personal OR carer\* OR caregiver\* OR "care-  
 19 giver\*" OR family\* OR families) W/3 (experienc\* OR perspective\* OR perception\* OR opinion\* OR account OR accounts  
 20 OR attitude\* OR view OR views OR viewpoint\* OR satisf\* OR unsatisf\* OR dissatisf\* OR disatisf\* OR believ\* OR believ  
 21 \*) OR TITLE (patient\* OR client\* OR user\* OR consumer\* OR personal) AND (emotion\* OR feeling\* OR happy OR h  
 22 appiness OR unhappy OR unhappiness OR sad OR sadness OR anger OR angry OR anxiet\* OR anxious\* OR worry O  
 23 R worries OR worried OR worrying OR troubled OR troubling OR troubles OR troublesome OR "trouble-  
 24 some" OR frustrat\* OR stress\* OR distress\* OR embarrass\* OR empath\* OR accept\* OR alone OR lonely OR lonelines  
 25 s OR fear OR fears OR fearing OR feared OR afraid OR scary OR scared OR bother\* OR unbother\* OR pleased OR  
 26 displeased\* OR concern\* OR burden\* OR hassl AND \* OR convenien\* OR inconvenien\* OR confus\* OR hope OR hopel  
 27 ess OR hopeful OR trust OR trusts OR mistrust\* OR distrust\* OR entrust\* OR trusting OR trusted OR confiden\* OR un  
 28 confiden\*) OR ABS (patient\* OR client\* OR user\* OR consumer\* OR personal OR carer\* OR caregiver\* OR "care-  
 29 giver\*" OR family\* OR families) W/3 (emotion\* OR feeling\* OR happy OR happiness OR unhappy OR unhappiness OR  
 30 sad OR sadness OR anger OR angry OR anxiet\* OR anxious\* OR worry OR worries OR worried OR worrying OR trou  
 31 bled OR troubling OR troubles OR troublesome OR "trouble-  
 32 some" OR frustrat\* OR stress\* OR distress\* OR embarrass\* OR empath\* OR accept\* OR alone OR lonely OR lonelines  
 33 s OR fear OR fears OR fearing OR feared OR afraid OR scary OR scared OR bother\* OR unbother\* OR pleased OR  
 34 displeased\* OR concern\* OR burden\* OR hassl AND \* OR convenien\* OR inconvenien\* OR confus\* OR hope OR hopel  
 35 ess OR hopeful OR trust OR trusts OR mistrust\* OR distrust\* OR entrust\* OR trusting OR trusted OR confiden\* OR un  
 36 confiden\*) OR KEY (patient\* OR client\* OR user\* OR consumer\* OR personal OR carer\* OR caregiver\* OR "caregiver\*" OR  
 37 family\* OR families) W/3 (emotion\* OR feeling\* OR happy OR happiness OR unhappy OR unhappiness OR sad O  
 38 R sadness OR anger OR angry OR anxiet\* OR anxious\* OR worry OR worries OR worried OR worrying OR troubled O  
 39 R troubling OR troubles OR troublesome OR "trouble-  
 40 some" OR frustrat\* OR stress\* OR distress\* OR embarrass\* OR empath\* OR accept\* OR alone OR lonely OR lonelines  
 41 s OR fear OR fears OR fearing OR feared OR afraid OR scary OR scared OR bother\* OR unbother\* OR pleased OR  
 42 displeased\* OR concern\* OR burden\* OR hassl AND \* OR convenien\* OR inconvenien\* OR confus\* OR hope OR hopel  
 43 ess OR hopeful OR trust OR trusts OR mistrust\* OR distrust\* OR entrust\* OR trusting OR trusted OR confiden\* OR un  
 44 confiden\*) OR TITLE-ABS-KEY ("life experience\*" OR "lived experience\*" OR "actual experience\*" OR "real  
 45 experience\*") AND (title-abs-  
 46 KEY ((heart\* OR cardiac OR cardial OR myocardia\*) W/3 (failure\* OR decompensat\* OR incompeten\* OR insufficienc\*  
 47 OR dysfunction\*)) OR TITLE-ABS-KEY ("heart failure" W/3 (congestive OR diastolic OR systolic) OR ("preserved  
 48 ejection fraction" OR "reduced ejection fraction")) OR TITLE-ABS-  
 49 KEY ("CHF" OR "CHFs" OR "HF" OR "HFpEF" OR "HFREF") AND TITLE (qualitativ\*) OR KEY (qualitativ\*) OR TITLE ( OR  
 50 patient\* OR client\* OR user\* OR consumer\* OR personal) AND {experiences} AND NOT INDEX (medline) AND ORIG-  
 51 LOAD-DATE AFT 20171104  
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## Web of Science Core Collection: Citation Indices. Search run 4/Nov/2017, re-run Jan 20, 2020.

*Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=2007-2017*

- # 1 **TOPIC:** ("heart failure")
- # 2 **TS=**((heart\* OR cardiac OR cardial OR myocardial) near/2 (failure\* OR decompensat\* OR incompetenc\* OR insufficien\* OR dysfunction\*))
- # 3 **TOPIC:** ("diastolic heart failure" OR "systolic heart failure")
- # 4 **TOPIC:** ("congestive heart failure")
- # 5 **TOPIC:** (CHF ORCHFs OR HF OR HFpEF OR HFrEF)
- # 6 #5 OR #4 OR #3 OR #2 OR #1
- # 7 **TOPIC:** (qualitativ\*)
- # 8 **TOPIC:** (interview\*)
- # 9 **TOPIC:** ("focus group\*\*")
- # 10 **TOPIC:** ("grounded theor\*\*" or "grounded study" or "grounded studies" or "grounded research" or "grounded analys\*\*")
- # 11 **TOPIC:** (phenomenol\*)
- # 12 **TOPIC:** (ethnograph\* or ethnonurs\* or "ethno-graph\*\*" or "ethno-nurs\*\*")
- # 13 **TOPIC:** (story or stories or storytelling or narrative\* or narration\*)
- # 14 **TOPIC:** ("open-ended" or "open question\*\*" or text\*)
- #15 **TOPIC:** ("discourse\* analys\*\*" or "discors\* analys\*\*")
- #16 **TOPIC:** ("content\* analys\*\*")
- #17 **TOPIC:** ("ethnological")
- #18 **TOPIC:** ("purposive sampl\*\*")
- #19 **TOPIC:** ("constant comparative" or "constant comparison\*\*")
- #20 **TOPIC:** ("theoretical sampl\*\*")
- #21 **TOPIC:** (theme\* or thematic\*)
- #22 **TOPIC:** ("emic" or "etic" or hermeneutic\* or heuristic\* or semiotic\*)
- #23 **TOPIC:** ("data saturat\*\*")
- #24 **TOPIC:** ("participant observ\*\*")
- #25 **TOPIC:** (humanistic\* or existential\* or experiential\* or paradigm\*)
- #26 **TOPIC:** ("social construct\*\*" or postmodern\* or "post-modern\*\*" or poststructural\* or "post-structural\*\*" or feminis\* or constructivis\*)
- #27 **TOPIC:** ("action research" or "cooperative inquir\*\*" or "co-operative inquir\*\*")
- #28 **TOPIC:** ("human science")
- #29 **TOPIC:** ("biographical method\*\*")
- #30 **TOPIC:** ("life world")
- #31 **TOPIC:** ("theoretical saturation")
- #32 **TOPIC:** ("group discussion\*\*")
- #33 **TOPIC:** ("direct observation\*\*")
- #34 **TOPIC:** ("mixed method\*\*")
- #35 **TOPIC:** ("observational method\*\*" or "observational approach\*\*")
- #36 **TOPIC:** ("key informant\*\*")
- #37 **TOPIC:** ("field study" or "field studies" or "field research\*\*" or "field work\*\*" or fieldwork\*)
- #38 **TOPIC:** ("semi-structured" or "semistructured" or "unstructured" or "un-structured" or "informal" or "indepth" or "indepth")
- #39 **TOPIC:** ("face-to-face")
- #40 **TOPIC:** (("guide" or "structured") near/5 (discussion\* or questionnaire\*))
- #41 **TOPIC:** (TOPIC: (heidgger\* or colaizzi\* or speigelberg\* or "van manen\*\*" or "van kaam\*\*" or "merleau ponty\*\*" or husserl\* or giorgi\* or foucault\* or corbin\* or glaser\*))
- #42 #41 OR #40 OR #39 OR #38 OR #37 OR #36 OR #35 OR #34 OR #33 OR #32 OR #31 OR #30 OR #29 OR #28 OR #27 OR #26 OR #25 OR #24 OR #23 OR #22 OR #21 OR #20 OR #19 OR #18 OR #17 OR #16 OR #15 OR #14 OR #13 OR #12 OR #11 OR #10 OR #9 OR #8 OR #7

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3 #43 **TOPIC:** (((patient\* or client\* or user\* or consumer\* or "personal") and (experienc\* or perspective\* or perception\* or  
4 opinion\* or "account" or "accounts" or attitude\* or "view" or "views" or viewpoint\* or satisf\* or unsatisf\* or dissatisf\* or disatisf\* or  
5 belief\* or believ\*)))
- 6 #44 **TITLE:** (((patient\* or client\* or user\* or consumer\* or "personal") and (experienc\* or perspective\* or perception\* or  
7 opinion\* or "account" or "accounts" or attitude\* or "view" or "views" or viewpoint\* or satisf\* or unsatisf\* or dissatisf\* or disatisf\* or  
8 belief\* or believ\*)))
- 9 #45 TI=((patient\* or client\* or user\* or consumer\* or "personal") and (emotion\* or feeling\* or "happy" or "happiness" or  
10 "unhappy" or "unhappiness" or "sad" or "sadness" or "anger" or "angry" or anxiet\* or anxious\* or "worry" or "worries" or "worried" or  
11 "worrying" or "troubled" or "troubling" or "troubles" or "troublesome" or "troublesome" or frustrat\* or stress\* or distress\* or  
12 embarrass\* or empath\* or accept\* or "alone" or "lonely" or "loneliness" or "fear" or "fears" or "fearing" or "feared" or "afraid" or  
13 "scary" or "scared" or bother\* or unbother\* or "pleased" or "displeased" or concern\* or burden\* or hassl\* or convenien\* or  
14 inconvenien\* or confus\* or "hope" or "hopeless" or "hopeful" or "trust" or "trusts" or mistrust\* or distrust\* or entrust\* or "trusting" or  
15 "trusted" or confiden\* or unconfiden\*))
- 16 #46 TS=((patient\* or client\* or user\* or consumer\* or "personal") near/3 (emotion\* or feeling\* or "happy" or "happiness" or  
17 "unhappy" or "unhappiness" or "sad" or "sadness" or "anger" or "angry" or anxiet\* or anxious\* or "worry" or "worries" or "worried" or  
18 "worrying" or "troubled" or "troubling" or "troubles" or "troublesome" or "troublesome" or frustrat\* or stress\* or distress\* or  
19 embarrass\* or empath\* or accept\* or "alone" or "lonely" or "loneliness" or "fear" or "fears" or "fearing" or "feared" or "afraid" or  
20 "scary" or "scared" or bother\* or unbother\* or "pleased" or "displeased" or concern\* or burden\* or hassl\* or convenien\* or  
21 inconvenien\* or confus\* or "hope" or "hopeless" or "hopeful" or "trust" or "trusts" or mistrust\* or distrust\* or entrust\* or "trusting" or  
22 "trusted" or confiden\* or unconfiden\*))
- 23 #47 **TOPIC:** (("life experience\*" or "lived experience\*" or "actual experience\*" or "real experience\*"))
- 24 #48 #47 OR #46 OR #45 OR #44 OR #43
- 25 #49 #48 AND #42 AND #6
- 26 #50 **TITLE:** ((qualitativ\*))
- 27 #51 **TITLE:** (((patient\* or client\* or user\* or consumer\* or "personal") and "experiences"))
- 28 #52 **TITLE:** (((patient\* or client\* or user\* or consumer\* or "personal") near/2 experienc\*))
- 29 #53 #52 OR #51 OR #50
- 30 #54 #53 AND #6
- 31 #55 (#54 OR #49) **AND DOCUMENT TYPES:** (Article OR Abstract of Published Item OR Art Exhibit Review OR Bibliography  
32 OR Biographical-Item OR Book OR Book Chapter OR Book Review OR Chronology OR Correction OR Correction, Addition OR  
33 Dance Performance Review OR Data Paper OR Database Review OR Discussion OR Excerpt OR Fiction, Creative Prose OR Film  
34 Review OR Hardware Review OR Item About an Individual OR Meeting Summary OR Music Performance Review OR Music Score  
35 OR Music Score Review OR News Item OR Note OR Poetry OR Proceedings Paper OR Record Review OR Reprint OR Review  
36 OR Script OR Software Review OR TV Review, Radio Review OR TV Review, Radio Review Video OR Theater Review)
- 37 #56 **TITLE:** (("case report"))
- 38 #57 **TITLE:** (((("rat" or "rats" or "rodent" or "rodents" or "mouse" or "mice" or "murine" or "hamster" or "hamsters" or "gerbil" or  
39 "gerbils" or "animal" or "animals" or "dogs" or "dog" or "canine" or "pig" or "pigs" or "piglet" or "piglets" or "cats" or "bovine" or "cow"  
40 or "cows" or "cattle" or "sheep" or "ewe" or "ewes" or "horse" or "horses" or "equine" or "ovine" or "porcine" or "monkey" or  
41 "monkeys" or "primate" or "primates" or "rhesus macaque" or "rhesus macaques" or "rabbit" or "rabbits"))) **NOT TOPIC:** ((human\*))
- 42 #58 #54 OR #49
- 43 #59 (#58 NOT (#57 OR #56))
- 44 #60 (#55 AND #59) **AND LANGUAGE:** (English)
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<b>Supplemental Material 3: A priori framework of Burden of Treatment</b>		
Primary construct	Secondary construct	Definition
Workload	In asking for help	Activate support: ask for support network to help with or take over the work
		Seek help: Refer for healthcare practitioners for advice or to increase level of care
	Gaining knowledge of CHF	Baseline knowledge: What does CHF look like and feel like
		Understand what works: What to do in response to a symptom, when to seek help.
		Evaluate outcomes: monitor symptoms, did the treatment work
	Performing tasks of CHF management	Lifestyle changes: exercise, diet, balance lifestyle
		Medication management: obtaining and filling prescriptions, taking medications, navigate healthcare system
		Specific illness task: attend regular appointments, daily weights, fluid management
	Capacity	Utilize abilities
External resources		What helps the patient: financial, social support network, healthcare system, physical environment, spirituality
Impact	Changes to self	Discontinuation of what the patient did and what was normal for them.
	Change to role	Discontinuation of the role the patient, alteration in who they believed they were
	Negative consequences of treatments	Things that make it hard to do what healthcare providers have recommended



Author(s)	Year	Journal	Title (abbreviated)
Ahmad et al. <sup>58</sup>	2016	<i>J Card Fail</i>	Comparing Perspectives ... Heart Failure Management
Allen et al. <sup>32</sup>	2009	<i>Prog Cardiovasc Nurs</i>	The lived experience of ... III heart failure: a pilot study
Andersson et al. <sup>55</sup>	2012	<i>Br J Community Nurs</i>	Living with heart failure ... a qualitative patient study
Attenburrow <sup>33</sup>	2016	<i>Br J Cardiac Nurs</i>	Live for the day with atrial fibrillation plus heart failure
Chiaranai <sup>26</sup>	2014	<i>J Cardiovas Nurs</i>	A phenomenological study of .... of living with heart failure
Cortis and Williams <sup>34</sup>	2007	<i>Int Nurs Rev</i>	Palliative and supportive needs ... adults with heart failure
Falk et al. <sup>31</sup>	2007	<i>Eur J Cardiovasc Nurs</i>	Keeping the maintenance ... in spite of chronic heart failure
Fry et al. <sup>35</sup>	2016	<i>BMC Fam Pract</i>	The implications of living with heart failure ... analysis
Gallacher et al. <sup>27</sup>	2011	<i>Ann Fam Med</i>	Understanding patients' experiences ... NPT
Gowani et. al. <sup>28</sup>	2017	<i>Br J Cardiac Nurs</i>	Living with heart Failure: Karachi exploratory study
Gwaltney et al. <sup>59</sup>	2012	<i>Br J Cardiology</i>	Hearing ... the heart failure patient ... qualitative interviews
Heo et al. <sup>36</sup>	2019	<i>Western J Nurs Res</i>	Patients' beliefs about causes and consequences ... symptoms
Holden et al. <sup>37</sup>	2015	<i>Appl Ergon</i>	The patient work system ... heart failure patients ... caregivers
Hopp et al. <sup>54</sup>	2012	<i>Soc Work Health Care</i>	Life Disruption ... American Elders With Advanced Heart Failure
Kimani et al. <sup>30</sup>	2018	<i>BMC Palliative Care</i>	Multidimensional needs of patients ... serial interview study
Mahoney-Davis et al. <sup>56</sup>	2017	<i>Br J Cardiac Nurs</i>	Examining the emotional and ... of people with heart failure
Malhotra et al. <sup>60</sup>	2016	<i>Proc Singapore Healthcare</i>	Living with heart failure ... patients from Singapore
Mangoloan Shahrababaki et al. <sup>38</sup>	2017	<i>J Clin Nurs</i>	The sliding context of health ... patients with heart failure ...
Ming et al. <sup>39</sup>	2011	<i>J Public Health</i>	Perspectives of heart failure patients ... from a qualitative study
Moshki et. al. <sup>40</sup>	2019	<i>OA Macedonian J Med Sci</i>	Dark or Bright half of the moon: ...quality of life
Nordfonn et al. <sup>50</sup>	2019	<i>J Clin Nurs</i>	Patients' experience with heart failure ... burden of treatment
Nordgren et al. <sup>52</sup>	2007	<i>Qual Health Res</i>	Living with ... heart failure as a middle-aged person
Paton et al. <sup>41</sup>	2007	<i>Can J Cardiovasc Nurs</i>	Recalibrating time and space ... living with heart failure
Pattenden et al. <sup>53</sup>	2007	<i>Eur J Cardiovasc Nurs</i>	Living with heart failure; patient and carer perspectives
Paturzo et al. <sup>42</sup>	2016	<i>Ann Ig</i>	The lived experience ... heart failure: a phenomenological study
Piamjariyakul et al. <sup>43</sup>	2012	<i>Appl Nurs Res</i>	Part I: heart failure home management ... perspectives
Rerkluenrit et al. <sup>49</sup>	2009	<i>Thai J Nurs Res</i>	Self-care among Thai people with heart failure
Retrum et al. <sup>44</sup>	2013	<i>Circulation</i>	Patient-identified factors related to heart failure readmissions
Ryan and Farrelly <sup>45</sup>	2009	<i>Eur J Cardiovasc Nurs</i>	Living with an unfixable heart ... with advanced heart failure
Sano et al. <sup>46</sup>	2018	<i>Int J Nurs Prac</i>	Self management of congestive heart failure ... in Japan
Seah et al. <sup>57</sup>	2016	<i>J Transcult Nurs</i>	Experiences of Patients Living With Heart Failure ... Study
Tenner <sup>47</sup>	2018	<i>JACC Heart Fail</i>	Everybody has a story, and I'm lucky!
Walthall et al. <sup>29</sup>	2017	<i>J Clin Nurs</i>	Living with ... in chronic heart failure: a qualitative study
Walthall et al. <sup>51</sup>	2019	<i>Contemporary Nurse</i>	Patients experience of ... advanced heart failure
Woda et al. <sup>48</sup>	2015	<i>J Community Health Nurs</i>	Self-Care Behaviors ... Americans Living with Heart Failure



# PRISMA 2009 Checklist

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Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	3-4
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	2
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	4
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4-5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplementary material 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	4
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	4-5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	4-5 & 24
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	4-5 & 21-22
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	4
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	4-5



# PRISMA 2009 Checklist

Page 1 of 2

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	21-22
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	6-8
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	6-8
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	21-22
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	n/a
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	6-19
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	21-22
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	19-21
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	21-22
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	23
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	24

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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Page 2 of 2

For peer review only - <http://bmjopen.bmj.com/site/about/guidelines.xhtml>

# BMJ Open

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

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-047060.R1
Article Type:	Original research
Date Submitted by the Author:	28-Apr-2021
Complete List of Authors:	Austin, Rosalynn; Portsmouth Hospitals University NHS Trust; University of Southampton, School of Health Sciences, Faculty of Environmental and Life Sciences Schoonhoven, Lisette; University Medical Center Utrecht, Julius Center for Health Sciences and Primary Care; University of Southampton, School of Health Sciences Clancy, Mike; University Hospital Southampton NHS Foundation Trust; University of Southampton, School of Health Sciences, Faculty of Environmental and Life Sciences Richardson, Alison; University of Southampton, School of Health Sciences, Faculty of Environmental and Life Sciences; University Hospital Southampton NHS Foundation Trust Kalra, Paul R; Portsmouth Hospitals University NHS Trust, Cardiology; University of Portsmouth May, Carl; London School of Hygiene and Tropical Medicine Faculty of Epidemiology and Population Health; National Institute for Health Research (NIHR), Applied Research Collaboration (ARC) North Thames
<b>Primary Subject Heading</b>:	Cardiovascular medicine
Secondary Subject Heading:	Evidence based practice, Health services research, Nursing, Patient-centred medicine, Qualitative research
Keywords:	Heart failure < CARDIOLOGY, Cardiomyopathy < CARDIOLOGY, Adult cardiology < CARDIOLOGY, QUALITATIVE RESEARCH, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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3 **Title:** Do chronic heart failure symptoms interact with burden of treatment? Qualitative literature  
4 systematic review.  
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**Abstract (current 298):**

*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, PsychINFO, Scopus, and Web of Science were searched between January 2007 -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 CHF patients. 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 (i.e. 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.

*Prospero Registration:* CRD42017077487

**ARTICLE SUMMARY: STRENGTHS AND LIMITATIONS**

- This is the first systematic literature review to explore the role of symptoms in burden of treatment in chronic heart failure.
- 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 chronic heart failure patient population.
- The innovative methods to visually illustrate the qualitative data, allows the reader to observe the depth and breadth of the themes outline 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.



## INTRODUCTION

Chronic heart failure (CHF) is increasing in prevalence, it is now estimated there are just 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 behaviour 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 co-morbidities, 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, the dynamic modifiable workload delegated to patients<sup>10-12</sup>. Burden of treatment (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, PsychINFO, Scopus, and Web of Science. Search strategies are provided (*LINK Supplemental material: S1\_Complete search strategies*). 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 January 20, 2020 (Table 1).

*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

<p>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</p>	<p>Qualitative studies not reporting on general or holistic lived experience (e.g. paper with a singular focus).</p> <p>Reports of intervention effectiveness, e.g. where the focus is on the treatment effect or service delivery rather than the patients experience (RCT's, healthcare organization or delivery)</p> <p>Literature review papers (including qualitative synthesis, meta-synthesis, etc.)</p>
<p>Settings: Worldwide</p> <p>Date of publication: between January 1, 2007 and Jan 20, 2020</p> <p>Language: English</p>	

### 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. 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 Program (CASP)<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 summarized 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 (*Link Supplemental material 2: BoT Framework BMJ*). 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 program, 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 one, 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, reorganizing and refining the nodes, whilst simultaneously checking for errors and bias. This process was repeated by a Heart Failure Specialist Nurse (MG). *Stage two, characterization*: 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 three, explain*: Descriptive themes were systematically examined, compared to the BoT a priori framework coding. Simultaneously, how each symptom acted on the framework was also coded.

### Role of Public and Patient Involvement

	Total
<b>Location</b>	
North America	11
Asia	9
Europe	14
Africa	1
<b>Methodological Approach</b>	
Qualitative Approach	16
Phenomenology	6
Secondary Analysis	3
Hermeneutic	2
Mixed Methods	1
Constructivist	2
Anthropologic	1
Grounded Theory	2
Patient Narrative	2
<b>Methods</b>	
Interview	30
Focus group	3
Patient Narrative	2
<b>Published participant characteristics</b>	

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 Nov 4, 2017 and repeated on Jan 1, 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 (Supplemental material: S3\_IncludedArticles). Table 2 presents a summative description of included articles.

NYHA Class	21
Ejection Fraction	9
Aetiology of CHF	8
Co-morbidities	12
Duration of illness	18
Employment	17
Education	10
Marital status	21
Ethnicity	18

Table 2 (a & b): Characteristics of included articles

		Total
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*
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*

a) Summarised articles characteristics. (n) represents number of papers with that characteristic.

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.

b) Summarized participant descriptives for included articles. (n) represented the number of participants. NYHA: New York Heart Association, CHF: Chronic Heart Failure. \* Numbers presented are the sums of published data, characteristics were not consistently published across all articles.

Figure 3 illustrates how coded symptoms interacted with coded elements of BoT framework. The width of the connectors represents how frequently these codes interacted during a visual

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3 representation of the prevalence of each type of interaction observed in the data. CHF symptoms  
4 appeared to drive (9.2% of codes, n=238), impede (70.5% of codes, n=1823) or form a barrier to  
5 patients' engagement with elements of BoT (20.3% of codes, n=525). Suggesting that symptoms  
6 rarely encourage patients to engage with self-care. Predominantly, symptoms make self-care more  
7 difficult and can stop patients from engaging with self-care.  
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### 15 **Results: qualitative content analysis**

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

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

Construct	Themes with exemplar quotes
Workload	<p>In asking for help from social support networks (n=15)  <i>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."</i><sup>26</sup> pg. E13</p> <p>In asking for help from healthcare professionals (n=13)  <i>"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...."</i> (patient 36).<sup>27</sup> pg. 2 online supplementary data</p> <p>Performing tasks of CHF self-care; activities of daily living, illness management, lifestyle changes (n=12)  <i>"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."</i><sup>28</sup> pg. 588</p> <p>Gaining knowledge around CHF; baseline understanding, and evaluating outcomes (n=7)  <i>"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."</i><sup>29</sup> pg. 2042</p>
Capacity	<p>To utilize individual capacity; physical, mental, emotional, spiritual (n=8)  <i>"... acute onset breathlessness caused significant anxiety and triggered a decision to seek emergency care."</i><sup>30</sup> pg. 3</p> <p>To utilize external resources; healthcare system, support networks, financial resources, physical environment (n=15)  <i>"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."</i><sup>31</sup> pg. 197</p>

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3 Symptoms can encourage patients to engage in the tasks of CHF self-care; from seeking urgent help  
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5 from healthcare services to adapting activities of daily living to limiting symptom exacerbation<sup>26-50</sup>.

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7 Symptoms urged patients to access healthcare systems for treatment adjustments or hospital  
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9 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>,  
10  
11 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>.

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14 Symptoms compelled patients to recruit help from their social networks. Family and friends assumed  
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16 tasks without being asked, that were beyond patient capacity. They also provided emotional support  
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18 to patients. Without help from friends and family patients felt managing their illness was more  
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20 difficult.  
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24 Symptoms Impede patient engagement with self-care  
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28 Symptoms of CHF are acknowledged as burdensome, this type of interaction was coded *impede*,  
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30 meaning symptoms made self-care more difficult. Symptoms appear to impede patients' ability to  
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32 engage with their self-care. Symptoms appeared to hinder patients in the following areas: (1)  
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34 workload in performing the tasks of CHF self-care, (2) workload in gaining knowledge of CHF, (3)  
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36 capacity to utilize physical, emotional, mental, and spiritual abilities, (4) capacity to access external  
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38 resources, and (5) impact of changes to patient self and role. Table 4 provides exemplar quotes and  
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40 figure 3 illustrates the interactions.  
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Table 4: Symptoms as impede patients in engaging with self-care. 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

Construct	Themes with exemplar quotes
Workload	<p>Preforming tasks of CHF self-care (N=31):</p> <p>Activities of daily living (n=20): <i>"I can be just sitting, watching TV. And all of a sudden I get to breathing hard, you know."</i><sup>36</sup> pg. 1632</p> <p>Specific illness management tasks (n=23): <i>"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)"</i><sup>53</sup> pg. 275</p> <p>Lifestyle changes (n=7): <i>"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."</i><sup>46</sup> pg. 4</p> <p>Gaining knowledge around CHF; baseline understanding, and evaluating outcomes (n=21)</p> <p><i>"I thought the signs were related to my prostate or lung problem, I never thought it was my heart."</i><sup>38</sup> pg. 3602</p> <p>In asking for help from social support networks or healthcare professional (n=15)</p> <p><i>"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."</i><sup>52</sup> pg. 7</p>
Capacity	<p>To utilize individual abilities (n=29):</p> <p>Physical (n=27): <i>"I liked my garden and I used to come out and potter. I can't do that now..."</i> (P7)<sup>34</sup> pg. 266</p> <p>Emotional (n=25): <i>"some very dark days over the years" and that much of the depression was caused by physical limitations."</i><sup>32</sup> pg. 99</p> <p>Mental (n=13): <i>"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)."</i><sup>40</sup> pg. 826</p> <p>Spiritual (n=7): <i>"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)"</i><sup>45</sup> pg. 227</p> <p>To utilize external resources (n=24)</p> <p>Support networks (n=20): <i>"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)"</i><sup>50</sup> pg. 1787</p> <p>Healthcare system (n=9): <i>"To see a doctor, you have to wait for an hour. This is very tiring."</i><sup>28</sup> pg. 588</p> <p>Financial resources (n=9): <i>"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.'"</i><sup>42</sup> pg. 266</p> <p>Physical environment (n=9): <i>"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."</i><sup>41</sup> pg. 10</p>

Construct	Themes with exemplar quotes
Impact	<p>Disruption to self-ability: change of what a patient could do (n=25)  <i>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</i></p> <p>Disruption to role: change of a patient identity (n=24)  <i>“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>54</sup> pg. 159</i></p> <p>Disruption to adherence: changes in self due to treatments or self-care regimens making adherence more difficult (n=14)  <i>“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</i></p>

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3 Symptoms made monitoring and management of CHF harder<sup>28-31 35-38 40 41 44 46 48 50 51 53 55</sup>. Completing  
4 specific tasks such as taking medications, attending appointments, and other self-care activities  
5 become more difficult in the presence of symptoms<sup>27 28 30 34-40 44 46 48-51 53</sup>. Further multiple co-  
6 morbidity (common in CHF) can create confusion around which illness was responsible for what  
7 symptom and which treatment takes priority<sup>28 33 35 37 40 41 46 47 53</sup>.

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10 Symptoms made daily activities like housework, leisure activities, sexual intimacy, and personal  
11 hygiene more difficult restricting patients' holistic participation in life<sup>26 28 29 31 32 34-43 46 49-51 53 56 57</sup>.

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14 Within this context of impaired capability, engagement with lifestyle changes was limited<sup>31 36 39 40 43 46</sup>  
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51<sup>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>.

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Symptoms can restrict patients' ability to acquire knowledge around CHF. The sometimes  
progressive and vague nature of CHF symptoms together with the presence of co-morbidities  
created confusion hindering baseline understanding of CHF<sup>26 29 30 35-37 46-50 55</sup>. Treatments for CHF can  
have iatrogenic effects leading to confusion between disease progression or treatment side effects  
detering 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>.

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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 talking to exercising more difficult<sup>26-32 34-38 40 41 45-47 50-53 55-59</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 50-57 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,

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3 forgetfulness and psychological distress<sup>28 30 31 36-38 40 41 45 47 50-52</sup>. Emotional capability appears affected  
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5 by symptoms in four main ways: 1) physical symptoms directly causing emotional distress<sup>28-30 32 34 38</sup>  
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7 <sup>40 45 47 50-53 56 57 60</sup>, 2) emotional distress due to being reliant on others to do their work<sup>26 29 34 38 41 42 45 56</sup>,  
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9 3) a grief process around loss of abilities<sup>28-31 34 36 37 40 42 45 50-56</sup>, and 4) accepting a life-limiting  
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11 diagnosis<sup>27 28 30-32 34 36 37 40 51 52 54 56</sup>. Symptoms mean patients lose what was and begrudgingly accept a  
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13 new normal.  
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17 Symptoms appear to impede a patient's willingness to access capacity building external resources,  
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19 such as, social support networks and healthcare systems. Patients' ability to access their social  
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21 networks is hindered by creating emotional distress and a lack of belonging<sup>26 31 40 45 46 50-52 54</sup>; yet,  
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23 symptoms require reliance on family or friends due to decreased physical capability<sup>29 32 34 35 41 45 49 50 53</sup>  
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25 <sup>56 60</sup>. There was also a sense that physical limitations meant adapting or giving up recreational and  
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27 social activities leading to isolation and loneliness<sup>28 30 40 50 51 53 54</sup>. Interactions with healthcare  
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29 systems, around symptoms, were reported to cause fatigue, fear, confusion, and depression<sup>28 30 36 50</sup>  
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31 <sup>53</sup>. The ambiguous nature of CHF symptoms saw healthcare professionals sometimes mis-diagnose  
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33 patients'; providing patients with wrong information, adding further confusion and harming  
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35 relationship's with healthcare professionals<sup>33 36 47</sup>. Healthcare systems were described as costly in  
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37 terms of energy<sup>28 30 50</sup>.  
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43 Symptoms negatively impacted financial resources draining family finances due to associated  
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45 healthcare costs, a finding observed in articles from Japan, Iran, Kenya, USA, Pakistan, Italy, United  
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47 Kingdom, Sweden and Thailand<sup>26 28 30 36 40 42 46 52 53</sup>. Symptoms also alter a patient's employability  
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49 decreasing family incomes and changing family roles<sup>26 28 30 36 40 42 46 52 53</sup>. Unaffordable healthcare and  
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51 treatments meant that symptoms were ignored by patients until the symptoms were unbearable or  
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53 that their lives were threatened<sup>26 28 30 40</sup>.  
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57 Symptoms impact on an individual's capabilities, altering their role within social networks, through a  
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59 reduction in performing desired activities. The lack of ability to engage in tasks like housework or  
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3 baking may seem trivial, but patients experience grief, frustration, anxiety at these changes<sup>26 28 29 31-36</sup>  
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5 38-42 45 46 49-57. If those alterations are central to their identity, then the impact of symptoms may  
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7 extend to their perceived role in their social networks. Symptoms can strip the ability to provide for  
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9 family, care for children, and/or accepting the possibility of an early death<sup>26 28-31 35-38 40 42-47 49-53 56 57 60</sup>.  
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11 CHF treatments and self-care regimens designed to help patients were often recorded as disruptions  
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13 thwarting patients' engagement in their self-care or causing further negative impact on capacity<sup>26 28-</sup>  
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15 31 35-37 40 41 44 50 53 59. Disruptive side-effects of medication meant medications were not taken and/or  
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17 social activities were restricted<sup>28 35-37 40 50</sup>.  
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22 Symptoms create a barrier to patient engagement with self-care  
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26 Finally, the presence of CHF symptoms appears to form a barrier to patients doing the work of  
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28 illness. Symptoms appeared to hinder patients in the following areas: (1) workload in performing  
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30 tasks of CHF management, (2) workload in gaining knowledge of CHF syndrome, (3) capacity to  
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32 utilize physical, emotional, mental, and spiritual abilities, (3) individual capacity to access external  
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34 resources, , and (4) impact of changes to self and role. Table 5 provides exemplar quotes and figure  
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36 3 illustrates the interactions.  
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Table 5: Symptoms as a barrier to patients in engaging with self-care. 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.

Construct	Themes with exemplar quotes
Workload	<p>Performing tasks of CHF self-care (n=20):</p> <p>Activities of daily living (n=12): <i>"Tired, tired, tired, when I sit and watch TV my eyes just fall down..."</i><sup>55</sup> pg. 634</p> <p>Specific illness management tasks (n=11): <i>"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)"</i><sup>50</sup> pg. 1787</p> <p>Gaining knowledge around CHF; understand illness and evaluating outcomes (n=9)</p> <p><i>"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."79/M/Mix"</i><sup>37</sup>pg. 138</p> <p>In asking for help from social support networks or healthcare professional (n=7)</p> <p><i>"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)"</i><sup>51</sup> pg. 77</p>
Capacity	<p>To utilize individual abilities (n=18):</p> <p>Physical (n=16): <i>"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."</i><sup>56</sup> pg.195</p> <p>Emotional (n=6): <i>"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)"</i><sup>60</sup> pg.94</p> <p>Mental (n=3): <i>"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."</i><sup>40</sup> pg.827</p> <p>Spiritual (n=2): <i>"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."</i><sup>53</sup> pg. 277</p> <p>To utilize external resources (n=14)</p> <p>Support networks (n=11)</p> <p><i>"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.'"</i><sup>42</sup> pg. 267</p> <p>Healthcare system (n=5)</p> <p><i>"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"</i><sup>35</sup> pg.5</p>

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Construct	Themes with exemplar quotes
Impact	<p>Disruption to self-ability: change of what a patient could do (n=19)  <i>"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."</i><sup>54</sup> pg. 159</p> <p>Disruption to role: change of a patient identity (n=19)  <i>"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."</i> pg. 98<sup>32</sup></p>

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3 Symptoms can stop patients from engaging in the work of illness, from daily tasks to specific illness  
4 management tasks. Persistent and severe symptoms turn simple tasks into impossible ones<sup>26-30 33-38 40-  
5 42 44-46 48 50-55 57 60</sup>. Assigned complex CHF self-care regimens likely become insurmountable in the face  
6 of such symptoms<sup>27 38 42 50 51 54</sup>. The subjective nature of CHF symptoms can form a barrier to both  
7 patients and healthcare providers acting in a timely matter to those symptoms<sup>30 33 35 37 38 41 48 54 55</sup>.  
8 Resulting in delayed treatment seeking and poor illness management<sup>30 33 35 38 45 48 51</sup>.

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10 Symptoms of CHF appear to form a barrier to patients' physical, mental, emotional and spiritual  
11 abilities<sup>27 29 31 32 36 37 40-42 45 50 52-56 58 60</sup>. The limitation in abilities creates a substantial deficit in their  
12 individual capacity, appearing to erode agency immobilizing patients, who then suffer with CHF  
13 rather than living with it<sup>29 32 37 40-42 45 50 56 60</sup>.

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15 Symptoms also create a barrier to patients' accessing external resources. When symptoms were not  
16 correctly considered or interpreted by the healthcare professionals leading to negative feelings and  
17 mistrust from patients<sup>30 35 38 45 47</sup>. Symptoms stop patients accessing their social support networks;  
18 they retreat from their social support networks fearing embarrassment and becoming burdensome<sup>26  
19 28 30 40 42 45 50 52 53 56 60</sup>.

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21 Symptoms inhibit patients from performing desired activities, creating a sense of personal  
22 worthlessness<sup>26 29 30 32 36 37 40-42 45 46 50-52 54-56 59 60</sup>. The lack of individual capability alters their role in  
23 social support networks, forming a barrier to patients' relationships and future lives<sup>26 28-30 32 33 36 37 40 42  
24 45 46 49-54 56 57</sup>. The loss of perceived roles in social support networks has high cost. The power of the  
25 metaphors (see figure 4) used in patients' description of this interaction demonstrates the high  
26 degree of impact of symptoms on patient identity.

## DISCUSSION

### Statement of Findings



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

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22 *Symptoms as a driver to engagement with self-care* were seen in the minority (<10%) of coded  
23 interactions with our BoT framework. This was unexpected as it is generally assumed that symptoms  
24 are the impetus for patients to engage with self-care. This finding, has parallels to the body of work  
25 relating to CHF patients' delaying in seeking healthcare support due to multiple influencing factors  
26 (e.g. previous negative experiences, perceived barriers to care, misattribution of symptoms, etc.)<sup>66</sup>  
27 rather than symptoms alone<sup>67</sup>. Failures in self-care were previously blamed on a patients' denial of  
28 illness or poor health literacy<sup>63 68</sup> rather than as this work suggests symptoms having a more complex  
29 interaction with patient engagement with healthcare services.

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41 *Symptoms impede engagement with self-care* was coded in 70.5% interactions within our BoT  
42 framework. The work of managing CHF was made more difficult not only in increasing task difficulty  
43 due to decreased capacity, but also through how symptoms are considered by healthcare  
44 professionals. The work of Lippiett, et al.<sup>11</sup> described how different patient clinical pathways  
45 influenced BoT in COPD and lung cancer, where lung cancer patients are expected to follow a  
46 structure treatment pathway meant less BoT. Where COPD patients are expected to be engaged  
47 with self-care meant greater BoT. Deficits in CHF healthcare service delivery has previously been  
48 observed to make the work of self-care more difficult<sup>65 69</sup>. The high prevalence of this type of  
49 interaction within the framework suggests an intrinsic relationship with symptoms. Thus,  
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3 emphasising importance of considering symptoms as more than an indicator for disease progression  
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5 or treatment effectiveness, by healthcare professionals when assigning self-care work to patients.  
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7 Adding to the work of Goncalves, et al. <sup>70</sup>, which identified a negative influence between BoT and the  
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9 pathophysiology of illness across multiple health conditions.  
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13 *Symptoms as a barrier to engagement with self-care* was coded in 20.3% of the interactions within  
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15 our BoT framework. If CHF symptoms removed patients' capacity, an unsurmountable illness  
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17 workload can be created. Similarly, Yu, et al. <sup>64</sup>, reported in older adults with CHF the work around  
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19 symptom monitoring contributed to patients' physical and mental exhaustion; meaning poor self-  
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21 care or reliance on social support systems. The high workload of CHF patients is similar to the  
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23 exhausting and invasive BoT that Roberti, et al. <sup>71</sup> noted in chronic kidney disease. From a patient  
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25 perspective, symptoms strip their capacity and increase their workload creating overwhelming BoT.  
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27 For them the effort of attempting to do the work assigned by healthcare professionals is not worth  
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29 the physical effort or emotional stress as perceived benefits are so low. This affectively inhibits  
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31 patients from engaging in self-care. Previous reviews on living with heart failure appear to neglect  
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33 highlighting the importance of symptoms on capacity to do this work instead focusing on patients'  
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35 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  
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37 inadequate healthcare encounters<sup>65 72 73</sup>.  
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43 A preliminary model describing how symptoms interact with BoT has been developed (see figure 5).  
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45 Symptoms in CHF can erode patient agency through a complex interaction of symptoms decreasing  
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47 capacity and increasing workload. This in turn leads to a loss of self-value and physical  
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49 deconditioning, which together can inhibit a patients' ability to engage with self-care regimens due  
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51 to perceived overwhelming BoT.  
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55 Current research on self-care in CHF focuses on the assumption of patient self-efficacy, which  
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57 assumes given the right approach, intervention, and education a patient will have the capacity to  
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3 engage in self-care regimens which will positively impact clinical outcomes. Recent revisions to the  
4 theory of self-care in CHF includes the consideration of symptom monitoring and management as a  
5 part of patients' self-care work<sup>74</sup>. However, the theory of self-care in CHF has yet to examine how  
6 symptoms might impact on the patients' agency to perform self-care. To the best of our knowledge,  
7 no empirical work has yet explored the observed interaction between symptoms, self-care  
8 engagement in CHF, and how that influences BoT.  
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### 16 **Strengths and weakness of the study**

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18 Our review is the first to explore qualitative literature on patients' experiences of CHF with respect  
19 to the interactions of symptoms with BoT. It builds on the foundation of BoT theory<sup>15</sup> with specific  
20 consideration for CHF patients. It characterises the types of symptom interaction with patient  
21 engagement in the context of BoT; which our PPI group recognized and verified as true to their  
22 experiences across multiple chronic illnesses.  
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31 Using BoT as a framework was a strength, leading to the original observation of CHF symptoms  
32 forming a barrier to patient engagement with BoT and self-care. Hinting at the possibility of an  
33 alternative explanation for why health care professionals may perceive high levels of non-adherence  
34 in CHF patients.  
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41 A strength of the synthesis of qualitative research, is that conclusions drawn were viewed through  
42 multiple theoretical, epistemological, and ontological stance of the included studies' authors as well  
43 as the authors of this review. Thus, commonalities observed are stronger due to heterogeneity of  
44 their context but could also be a limitation as the multiple interpretations may have altered the  
45 'true' view of the original data. The review was restricted by the choice of published quotes from  
46 the included articles, our conclusions formed by using data from published primary studies to  
47 develop explanatory ideas the original researcher did not intend. Only English language articles were  
48 included.  
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3 Strengthening our analysis by using matrix queries, in Nvivo, to facilitate comparative pattern  
4 analysis as well as textual comparison <sup>75</sup>, confirmed the patterns observed in the constant  
5 comparison process and provided the data to create visual illustrations of these complex  
6 interactions. Our coding analysis strategy, has precedent, as it was a refinement of Thomas and  
7 Harden <sup>23</sup> methodology for thematic synthesis, which used a three stage coding process. We  
8 adapted their third stage to follow Gallacher, et al. <sup>14</sup> work which takes second stage codes  
9 (characterise) and compares them against an a priori framework helping to explain the observations.  
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### 20 **Future work**

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23 The role of symptoms in CHF and their interaction with patient engagement in self-care are not well  
24 understood and need more research. The authors are currently conducting empirical research to  
25 better understand this concept <sup>76</sup>.  
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### 30 **CONCLUSIONS AND CLINICAL IMPLICATIONS**

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34 Our synthesis suggests that relying on patients' symptom experience as the impetus for them to  
35 seek healthcare support may not be as successful as currently assumed. Examination of symptom  
36 interaction with BoT in CHF has demonstrated a complex relationship. CHF symptoms appear to  
37 negatively interact with patients' engagement with self-care regimens, including healthcare  
38 interactions, through the creation of overwhelming BoT. Symptoms increase patients' illness  
39 workload simultaneously decreasing their capacity, with a detrimental impact on their lives. This  
40 interaction of symptoms suggests that patients with CHF may not be as poor at self-care as reported  
41 in current literature. CHF symptoms have an integral role in patient BoT predominately acting to  
42 impede patients' efforts to engage in self-care. Healthcare professionals need to carefully consider  
43 patients' capacity and current workloads when altering patient self-care regimens, as reducing  
44 workload may improve patient outcomes and improve engagement with self-care. The results of this  
45 review postulate that patients previously being blamed for poor self-care may be suffering from  
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3 overwhelming BoT of which symptoms, which are modifiable are a major contributor. Our findings  
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5 call for more research underpinned by BoT in CHF; exploring changes CHF service delivery and  
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7 interventions to enhance patient self-care by focusing on their experiences.  
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11 *Figure 1: PRISMA Flowchart for CHF articles on patient experience. CHF, chronic heart failure; PRISMA, Preferred Reporting*  
12 *Items for Systematic Reviews and MetaAnalyses.*

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15 *Figure 2: Symptom terms found in included articles: Name of Symptom node in bold font with example quote in speech*  
16 *bubble. Counts of frequency consistency of coding are provided.*

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

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

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28 *Figure 5: Initial model of CHF symptoms interaction with BoT theory primary constructs. BoT, Burden of Treatment*

29  
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36

37  
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51  
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53 framework that informed this work. RCA designed the review with support and guidance from CRM,  
54 LS, and PRK. RCA assisted by CRM and LS performed the work of the literature searches. MC assisted  
55 in the screening of the articles and CRM and LS acted as the arbiter for any disputes. RCA performed  
56 the first-line analysis and was guided by CRM, LS, and AR throughout constant comparison analysis.  
57 PRA's and MG checked line by line symptom coding, refined the symptom coding structure, and  
58 confirmed the results to be representative of their personal patient experiences. CRM, LS, AR, and  
59 PRK critically reviewed the manuscript for intellectual and clinical content. All authors approved the  
60 final version of the paper. RCA is the guarantor.

**Patient consent:** Not required

**Any checklist and flow diagram for the appropriate reporting statement:**

PRIMSA2009Checklist\_Austin.doc

**A data sharing statement:** Data presented in this work was taken from previously published articles.

**Supplemental data:** 1) Complete search strategies, 2) A priori BoT framework, and 3) list of included articles

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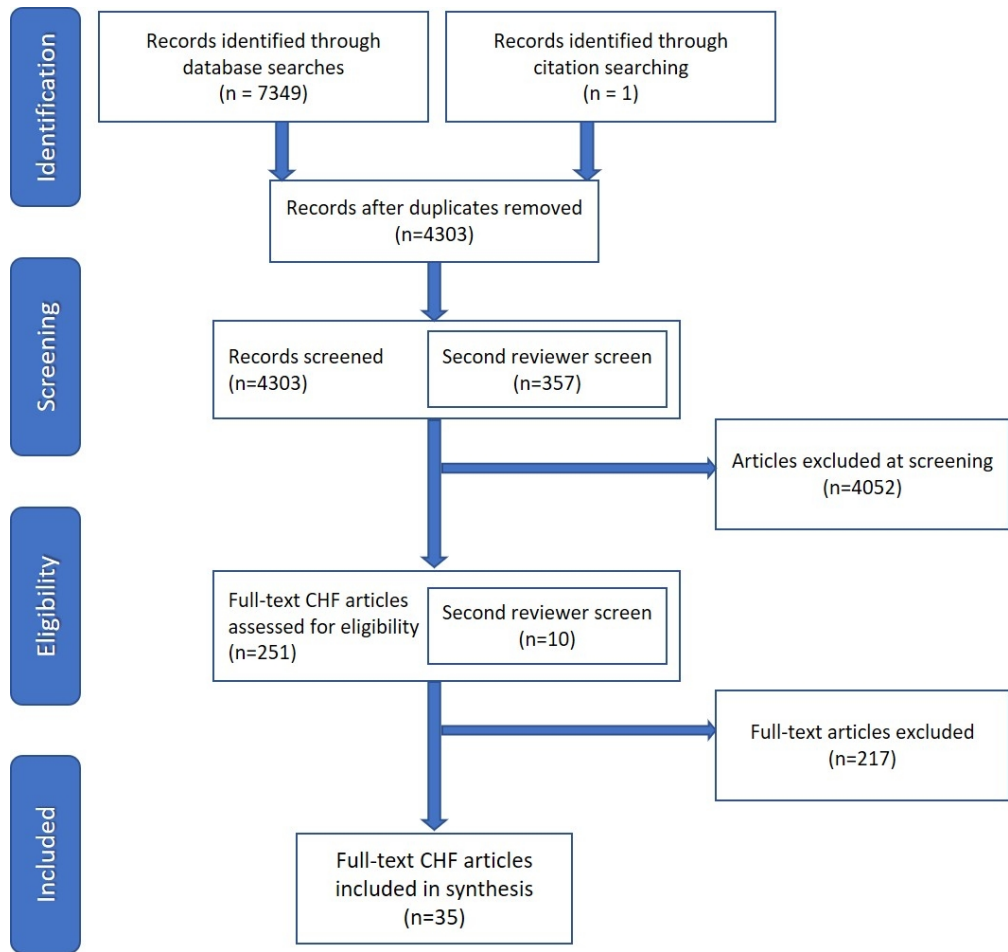


Figure 1: PRISMA Flowchart for CHF articles on patient experience. CHF, chronic heart failure; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta Analyses.

178x169mm (150 x 150 DPI)

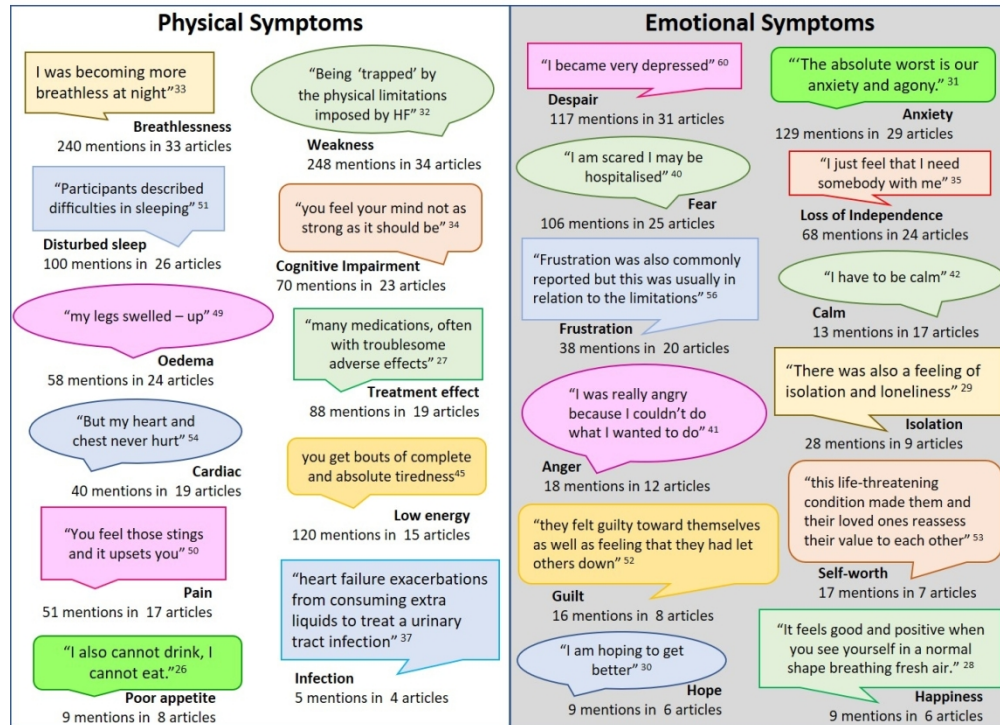


Figure 2: Symptom terms found in included articles: Name of Symptom node in bold font with example quote in speech bubble. Counts of frequency consistency of coding are provided.

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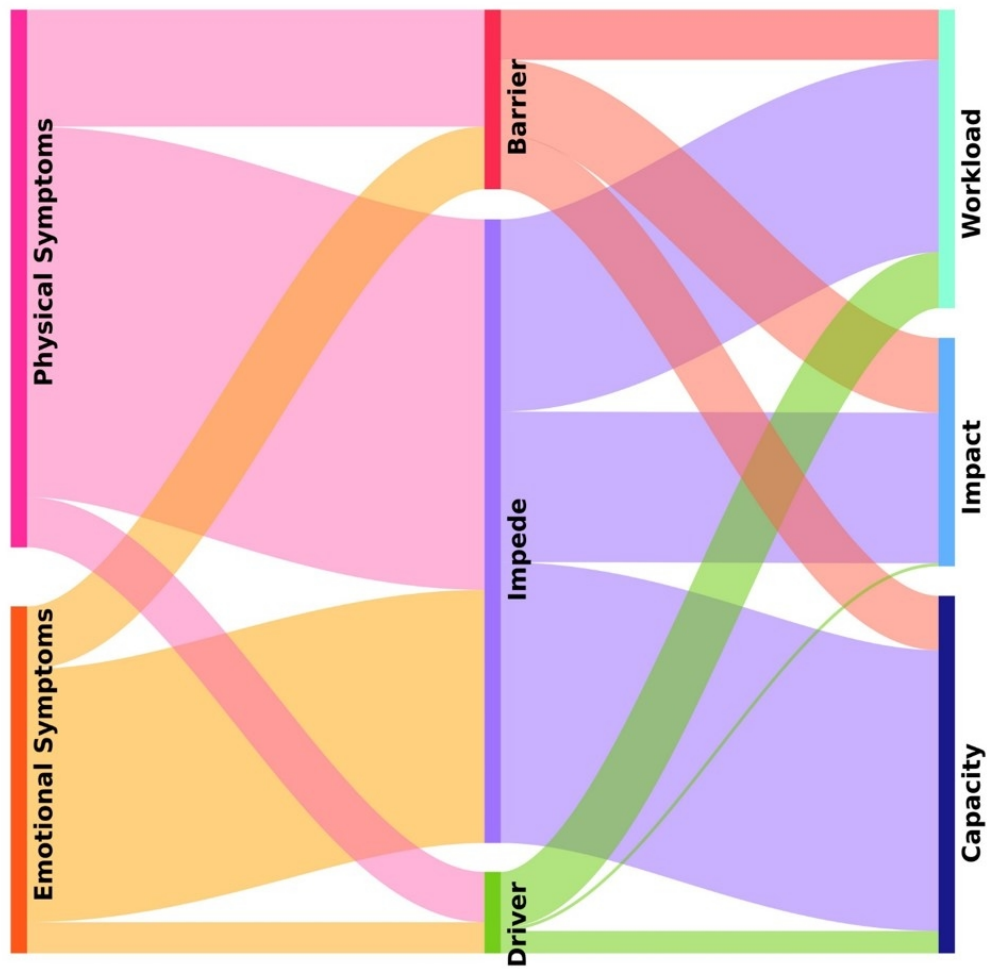


Figure 3: Sankey diagram of symptoms and the type of interaction they have with Burden of treatment. Thickness of the flow bars represents the frequency of that interaction being coded in the analysis.

159x156mm (150 x 150 DPI)



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

166x170mm (150 x 150 DPI)

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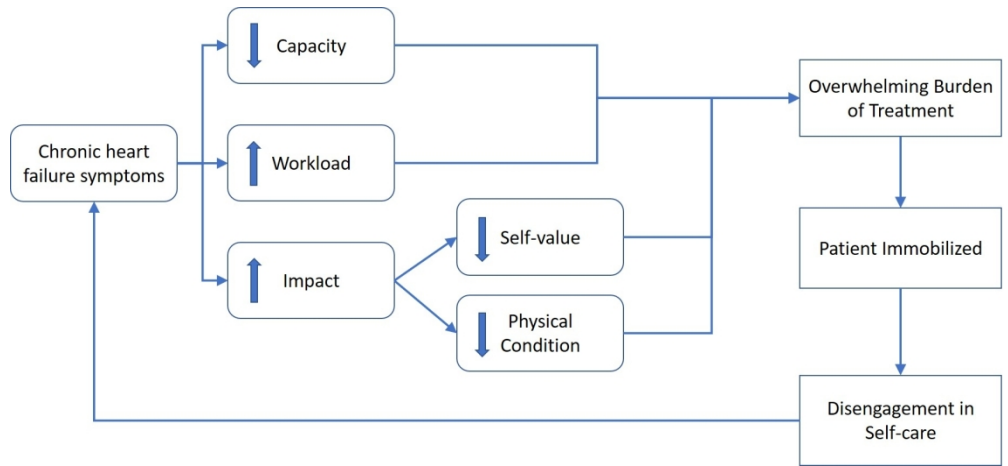


Figure 5: Initial model of CHF symptoms interaction with BoT theory primary constructs. BoT, Burden of Treatment

314x144mm (150 x 150 DPI)



## Literature Synthesis Search strategies

**MEDLINE (Ovid interface) Ovid MEDLINE (R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE (R) Daily and Ovid MEDLINE (R) 1946 to Present. Search run on 4/Nov/2017, re-run Jan 20, 2020**

1. Heart failure.af.
2. (Heart failure, diastolic or heart failure, systolic).af
3. ((heart\$ or cardiac or cardial or myocardial) adj3 decompensat\$).af.
4. ((heart\$ or cardiac or cardial or myocardial) adj3 failure\$).af.
5. ((heart\$ or cardiac or cardial or myocardial) adj3 incompetenc\$).af.
6. ((heart\$ or cardiac or cardial or myocardial) adj3 insufficienc\$).af.
7. ((heart\$ or cardiac or cardial or myocardial) adj3 (standstill or stand-still)).af.
8. (CHF or CHF\$ or HF).af.
9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
10. exp Qualitative Research/
11. qualitativ\$.ti,ab,kf.
12. Interviews as Topic/
13. interview\$.ti,ab,kf.
14. Focus Groups/
15. Grounded Theory/
16. (grounded theor\$ or grounded stud\$ or grounded research or grounded analys\$).ti,ab,kf.
17. focus group\$1.ti,ab,kf.
18. phenomenol\$.ti,ab,kf.
19. (ethnograph\$ or ethnours\$ or ethno-graph\$ or ethno-nurs\$).ti,ab,kf.
20. (story or stories or storytelling or narrative\$1).ti,ab,kf.
21. (open-ended or open question\$ or text\$).ti,ab,kf.
22. Narration/
23. Personal Narratives/
24. Personal Narratives as Topic/
25. (discourse\$ analys\$ or discours\$ analys\$).ti,ab,kf.
26. Content\$ analys\$.ti,ab,kf.
27. ethnological.ti,ab,kf.
28. purposive sampl\$.ti,ab,kf.
29. (constant comparative or constant comparison\$1).ti,ab,kf.
30. theoretical sampl\$.ti,ab,kf.
31. (theme\$ or thematic\$).ti,ab,kf.
32. (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).ti,ab,kf.
33. data saturat\$.ti,ab,kf.
34. participant observ\$.ti,ab,kf.
35. exp Humanism/
36. (humanistic\$ or existential\$ or experiential\$ or paradigm\$).ti,ab,kf.
37. Postmodernism/
38. (social construct\$ or postmodern\$ or post-modern\$ or poststructural\$ or post-structural\$ or feminis\$ or constructivis\$).ti,ab,kf.
39. (action resesarch or cooperative inquir\$ or co-operative inquir\$ or coproduct& or co-product\$).ti,ab,kf.
40. biographical method\$.ti,ab,kf.
41. human science.ti,ab,kf.
42. life world.ti,ab,kf.
43. theoretical saturat\$.ti,ab,kf.
44. mixed method\$.ti,ab,kf.
45. (observational method\$ or observational approach\$).ti,ab,kf.
46. key informant\$1.ti,ab,kf.
47. (field study or field studies or field research\$ or field work\$ or fieldwork\$).ti,ab,kf.
48. (semi-structured or semistructured or unstructured or un-structured or informal or in-depth or indepth).ti,ab,kf.
49. "face-to-face".ti,ab,kf.
50. ((guide or structure) adj5 (disscusion\$1 or questionnaire\$1)).ti,ab,kf.
51. (heidegger\$ or colaizzi\$ or speigelberg\$ or van manen\$ or van kaam\$ or merleau ponty\$ or husserl\$ or giorgi\$ or foucault\$ or corbin\$ or glasser\$).ti,ab,kf
52. 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51
53. Consumer Behavior/
54. Attitude/
55. exp Attitude to Health/
56. Attitude to Death/
57. Personal Satisfaction/
58. exp Emotions/
59. Stress, Psychological/
60. exp Patients/px [Psychology]
61. Caregivers/px [Psychology]
62. Professional-Patient Relations/
63. Nurse-Patient Relations/
64. Physician-Patient Relations/



65. Professional-Family Relations/
66. Empathy/
67. Feedback/
68. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) and (experienc\$ or perspective\$1 or perception\$1 or opinion\$1 or account or accounts or attitude\$1 or view or views or viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or disatisf\$ or belief\$1 or believ\$)).ti.
69. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) adj3 (experienc\$ or perspective\$1 or perception\$1 or opinion\$1 or account or accounts or attitude\$1 or view or views or viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or disatisf\$ or belief\$1 or believ\$)).ab,kf.
70. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) and (emotion\$ or feeling\$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet\$ or anxious\$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat\$ or stress\$ or distress\$ or embarrass\$ or empath\$ or accept\$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother\$ or unbother\$ or pleased or displeased\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$ or confus\$ or hope or hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or confiden\$ or unconfiden\$)).ti.
71. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) adj3 (emotion\$ or feeling\$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet\$ or anxious\$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat\$ or stress\$ or distress\$ or embarrass\$ or empath\$ or accept\$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother\$ or unbother\$ or pleased or displeased\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$ or confus\$ or hope or hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or confiden\$ or unconfiden\$)).ab,kf.
72. (life experience\$1 or lived experience\$1 or actual experience\$1 or real experience\$1).ti,ab,kf.
73. 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72
74. 9 and 52 and 73
75. qualitativ\$.ti.
76. Qualitative Research/
77. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) and experiences).ti.
78. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) adj2 experienc\$).ti.
79. 75 or 76 or 77 or 78
80. 9 and 79
81. 74 or 80
82. exp animals/ not humans/
83. (news or comment or editorial or letter or case reports or randomized controlled trial).pt.
84. case-report.ti.
85. 81 not (82 or 83 or 84)
86. limit 81 to (english language and yr="2007 -Current")

**EMBASE (Ovid interface) EMBASE Classic + EMBASE 1947 to Week 45. Search run on 4/Nov/2017, re-run on Jan 20, 2020**

1. exp heart failure/
2. heart failure with preserved ejection fraction/
3. exp heart failure with reduced ejection fraction/
4. congestive heart failure/
5. (heart failure diastolic or heart failure systolic).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]
6. ((heart\$ or cardiac or cardial or myocardial) adj3 decompensat\$).mp.
7. ((heart\$ or cardiac or cardial or myocardial) adj3 failure\$).mp.
8. ((heart\$ or cardiac or cardial or myocardial) adj3 incompetenc\$).mp.
9. ((heart\$ or cardiac or cardial or myocardial) adj3 insufficienc\$).mp.
10. ((heart\$ or cardiac or cardial or myocardial) adj3 dysfunction\$).mp.
11. (((heart\$ or cardiac or cardial or myocardial) adj3 standstill) or stand-still).mp.
12. (CHF or CHFs or HF or HFpEF or HFREF).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]
13. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14. exp qualitative research/
15. qualitativ\$.ti,ab,kw.
16. exp interview/
17. interview\$.ti,ab,kw.
18. focus group\$1.ti,ab,kw.
19. grounded theory/
20. (grounded theor\$ or grounded study or grounded studies or grounded research or grounded analys\$).ti,ab,kw.
21. phenomenology/
22. phenomenol\$.ti,ab,kw.
23. ethnography/
24. ethnnonursing research/
25. (ethnograph\$ or ethnnonurs\$ or ethno-graph\$ or ethno-nurs\$).ti,ab,kw.
26. verbal communication/
27. narrative/

- 1
- 2
- 3 28. storytelling/
- 4 29. (story or stories or storytelling or narrative\$1 or narration\$1).ti,ab,kw.
- 5 30. open ended questionnaire/
- 6 31. (open-ended or open question\$ or text\$).ti,ab,kw.
- 7 32. discourse analysis/
- 8 33. (discourse\$ analys\$ or discurs\$ analys\$).ti,ab,kw.
- 9 34. content analysis/
- 10 35. content\$ analys\$.ti,ab,kw.
- 11 36. ethnological.ti,ab,kw.
- 12 37. purposive sample/
- 13 38. purposive sampl\$.ti,ab,kw.
- 14 39. (constant comparative or constant comparison\$1).ti,ab,kw.
- 15 40. theoretical sample/
- 16 41. theoretical sampl\$.ti,ab,kw.
- 17 42. thematic analysis/
- 18 43. (theme\$ or thematic\$).ti,ab,kw.
- 19 44. (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).ti,ab,kw.
- 20 45. data saturat\$.ti,ab,kw.
- 21 46. observational method/
- 22 47. participant observ\$.ti,ab,kw.
- 23 48. humanism/
- 24 49. existentialism/
- 25 50. (humanistic\$ or existential\$ or experiential\$ or paradigm\$).ti,ab,kw.
- 26 51. feminism/
- 27 52. (social construct\$ or postmodern\$ or post-modern\$ or poststructural\$ or post-structural\$ or feminis\$ or
- 28 constructivis\$).ti,ab,kw.
- 29 53. action research/
- 30 54. (action research or cooperative inquir\$ or co-operative inquir\$).ti,ab,kw.
- 31 55. human science.ti,ab,kw.
- 32 56. biographical method\$.ti,ab,kw.
- 33 57. life world.ti,ab,kw.
- 34 58. theoretical saturation.ti,ab,kw.
- 35 59. group discussion\$1.ti,ab,kw.
- 36 60. direct observation\$.ti,ab,kw.
- 37 61. mixed method\$.ti,ab,kw.
- 38 62. (observational method\$ or observational approach\$).ti,ab,kw.
- 39 63. key informant\$1.ti,ab,kw.
- 40 64. field study/
- 41 65. field work/
- 42 66. (field study or field studies or field research\$ or field work\$ or fieldwork\$).ti,ab,kw.
- 43 67. (semi-structured or semistructured or unstructured or un-structured or informal or in-depth or indepth).ti,ab,kw
- 44 68. "face-to-face".ti,ab,kw.
- 45 69. structured questionnaire/
- 46 70. ((guide or structured) adj5 (discussion\$1 or questionnaire\$1)).ti,ab,kw.
- 47 71. (heidegger\$ or colaizzi\$ or speigelberg\$ or van manen\$ or van kaam\$ or merleau ponty\$ or husserl\$ or giorgi\$ or
- 48 foucault\$ or corbin\$ or glaser\$).ti,ab,kw.
- 49 72. 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or
- 50 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or
- 51 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71
- 52 73. exp patient attitude/
- 53 74. attitude/
- 54 75. attitude to health/
- 55 76. attitude to illness/
- 56 77. attitude to life/
- 57 78. consumer attitude/
- 58 79. exp family attitude/
- 59 80. attitude to death/
- 60 81. satisfaction/
82. exp emotion/
83. mental stress/
84. exp patient/
85. caregiver/
86. exp psychology/
87. psychological aspect/
88. 84 or 85
89. 86 or 87
90. 88 and 89
91. doctor patient relation/
92. nurse patient relationship/
93. feedback system/

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3 94. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) and (experienc\$ or perspective\$1 or perception\$1 or  
4 opinion\$1 or account or accounts or attitude\$1 or view or views or viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or  
5 disatisf\$ or believ\$1 or believ\$)).ti.  
6 95. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) adj3 (experienc\$ or perspective\$1 or perception\$1 or  
7 opinion\$1 or account or accounts or attitude\$1 or view or views or viewpoint\$1 or satisf\$ or unsatisf\$ or dissatisf\$ or  
8 disatisf\$ or believ\$1 or believ\$)).ab,kw.  
9 96. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) and (emotion\$ or feeling\$1 or happy or happiness or unhappy  
10 or unhappiness or sad or sadness or anger or angry or anxiet\$ or anxious\$ or worry or worries or worried or worrying or  
11 troubled or troubling or troubles or troublesome or trouble-some or frustrat\$ or stress\$ or distress\$ or embarrass\$ or  
12 empath\$ or accept\$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or  
13 bother\$ or unbother\$ or pleased or displeased\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$ or  
14 confus\$ or hope or hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or  
15 confiden\$ or unconfiden\$)).ti.  
16 97. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) adj3 (emotion\$ or feeling\$1 or happy or happiness or  
17 unhappy or unhappiness or sad or sadness or anger or angry or anxiet\$ or anxious\$ or worry or worries or worried or  
18 worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat\$ or stress\$ or distress\$ or  
19 embarrass\$ or empath\$ or accept\$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or  
20 scared or bother\$ or unbother\$ or pleased or displeased\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$  
21 or confus\$ or hope or hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or  
22 confiden\$ or unconfiden\$)).ab,kw.  
23 98. (life experience\$1 or lived experience\$1 or actual experience\$1 or real experience\$1).ti,ab,kw.  
24 99. 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83 or 90 or 91 or 92 or 93 or 94 or 95 or 96 or 97 or 98  
25 100. 13 and 72 and 99  
26 101. qualitativ\$.ti.  
27 102. qualitative research/  
28 103. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) and experiences).ti.  
29 104. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) adj2 experienc\$).ti.  
30 105. 101 or 102 or 103 or 104  
31 106. 13 and 105  
32 107. 100 or 106  
33 108. animal/  
34 109. animal experiment/  
35 110. animal model/  
36 111. animal tissue/  
37 112. nonhuman/  
38 113. 108 or 109 or 110 or 111 or 112  
39 114. human/  
40 115. 113 not 114  
41 116. (editorial or letter or conference abstract or conference paper or conference proceeding or conference review).pt.  
42 117. case report.ti  
43 118. 107 not (115 or 116 or 117).  
44 119. limit 118 to (english language and yr="2007 -Current")

### CINAHL plus Full Text (EBSCO interface). Searches run on 04/11/2017, re-tun on Jan 20, 2020.

- 45 S1 "heart failure"  
46 S2 (MH "heart failure+")  
47 S3 (MH "cardiac output decreased+")  
48 S4 (MH "ventricular ejection fraction+")  
49 S5 (MH "cardiac patients+")  
50 S6 S1 OR S2 OR S3 OR S4 OR S5  
51 S7 (MH "Qualitative Studies+")  
52 S8 TI(qualitativ\*) or AB(qualitativ\*)  
53 S9 (MH "Interviews+")  
54 S10 TI(interview\*) or AB(interview\*)  
55 S11 (MH "Focus Groups")  
56 S12 TI("focus group\*") or AB("focus group\*")  
57 S13 TI("grounded theor\*" or "grounded study" or "grounded studies" or "grounded research" or "grounded analys\*") or  
58 AB("grounded theor\*" or "grounded study" or "grounded studies" or "grounded research" or "grounded analys\*")  
59 S14 (MH "Phenomenology") OR (MH "Phenomenological Research")  
60 S15 TI(phenomenol\*) or AB(phenomenol\*)  
61 S16 TI(ethnograph\* or ethnonurs\* or "ethno-graph\*" or "ethnonurs\*") or AB(ethnograph\* or ethnonurs\* or "ethno-graph\*" or "ethno-  
62 nurs\*")  
63 S17 (MH "Storytelling+") OR (MH "Narratives")  
64 S18 TI(story or stories or storytelling or narrative\* or narration\*) or AB(story or stories or storytelling or narrative\* or narration\*)  
65 S19 (MH "Open-Ended Questionnaires")  
66 S20 TI("open-ended" or "open question\*" or text\*) or AB("openended" or "open question\*" or text\*)  
67 S21 (MH "Discourse Analysis")  
68 S22 TI("discourse\* analys\*" or "discurs\* analys\*") or AB("discourse\* analys\*" or "discurs\* analys\*")  
69 S23 (MH "Content Analysis")

- 1  
2  
3 S24 TI("content\* analys\*") or AB("content\* analys\*")  
4 S25 TI(ethnological) or AB(ethnological)  
5 S26 (MH "Purposive Sample")  
6 S27 TI("purposive sampl\*") or AB("purposive sampl\*")  
7 S28 (MH "Constant Comparative Method")  
8 S29 TI("constant comparative" or "constant comparison\*") or AB ("constant comparative" or "constant comparison\*")  
9 S30 (MH "Theoretical Sample")  
10 S31 TI("theoretical sampl\*") or AB("theoretical sampl\*")  
11 S32 (MH "Thematic Analysis")  
12 S33 TI(theme\* or thematic\*) or AB(theme\* or thematic\*)  
13 S34 TI(emic or etic or hermeneutic\* or heuristic\* or semiotic\*) or AB(emic or etic or hermeneutic\* or heuristic\* or semiotic\*)  
14 S35 TI("data saturat\*") or AB("data saturat\*")  
15 S36 (MH "Observational Methods+")  
16 S37 TI("participant observ\*") or AB("participant observ\*")  
17 S38 (MH "Humanism")  
18 S39 TI(humanistic\* or existential\* or experiential\* or paradigm\*) or AB(humanistic\* or existential\* or experiential\* or paradigm\*)  
19 S40 (MH "Social Constructionism")  
20 S41 (MH "Postmodernism")  
21 S42 (MH "Feminism+")  
22 S43 TI("social construct\*" or postmodern\* or "post-modern\*" or poststructural\* or "post-structural\*" or feminis\* or constructivis\*) or  
23 AB("social construct\*" or postmodern\* or "post-modern\*" or poststructural\* or "post-structural\*" or feminis\* or constructivis\*)  
24 S44 TI("action research" or "cooperative inquir\*" or "co-operative inquir\*") or AB("action research" or "cooperative inquir\*" or "co-  
25 operative inquir\*")  
26 S45 TI("human science") or AB("human science")  
27 S46 TI("biographical method\*") or AB("biographical method\*")  
28 S47 TI("life world") or AB("life world")  
29 S48 TI("theoretical saturation") or AB("theoretical saturation")  
30 S49 TI("group discussion\*") or AB("group discussion\*")  
31 S50 TI("direct observation\*") or AB("direct observation\*")  
32 S51 TI("mixed method\*") or AB("mixed method\*")  
33 S52 TI("observational method\*" or "observational approach\*") or AB("observational method\*" or "observational approach\*")  
34 S53 TI("key informant\*") or AB("key informant\*")  
35 S54 (MH "Field Studies")  
36 S55 TI("field study" or "field studies" or "field research\*" or "field work\*" or fieldwork\*) or AB("field study" or "field studies" or "field  
37 research\*" or "field work\*" or fieldwork\*)  
38 S56 TI("semi-structured" or semistructured or unstructured or "un-structured" or informal or "in-depth" or indepth) or AB("semi-  
39 structured" or semistructured or unstructured or "un-structured" or informal or "in-depth" or indepth)  
40 S57 TI("face-to-face") or AB("face-to-face")  
41 S58 (MH "Structured Interview Guides")  
42 S59 (MH "Structured Questionnaires")  
43 S60 (MH "Discussion")  
44 S61 TI((guide or structured) N5 (discussion\* or questionnaire\*)) or AB((guide or structured) N5 (discussion\* or questionnaire\*))  
45 S62 TI(heidegger\* or colaizzi\* or speigelberg\* or "van manen\*" or "van kaam\*" or "merleau ponty\*" or husserl\* or giorgi\* or  
46 foucault\* or corbin\* or glaser\*) or AB(heidegger\* or colaizzi\* or speigelberg\* or "van manen\*" or "van kaam\*" or "merleau  
47 ponty\*" or husserl\* or giorgi\* or foucault\* or corbin\* or glaser\*)  
48 S63 S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR  
49 S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36  
50 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR  
51 S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62  
52 S64 MH "Consumer Satisfaction") OR (MH "Patient Satisfaction")  
53 S65 (MH "Attitude") OR (MH "Attitude to Death") OR (MH "Attitude to Health") OR (MH "Attitude to Illness") OR (MH "Family  
54 Attitudes+") OR (MH "Patient Attitudes") OR (MH "Personal Satisfaction")  
55 S66 (MH "Patient Compliance+") OR (MH "Treatment Refusal")  
56 S67 (MH "Attitude to Life")  
57 S68 (MH "Health Beliefs")  
58 S69 (MH "Consumer Participation")  
59 S70 (MH "Emotions+")  
60 S71 (MH "Stress, Psychological")  
S72 (MH "Caregiver Burden")  
S73 (MH "Critical Incident Stress")  
S74 (MH "Minority Stress")  
S75 (MH "Reality Shock")  
S76 (MH "Role Stress")  
S77 (MH "Patients+/PF")  
S78 (MH "Caregivers+/PF")  
S79 (MH "Caregiver Support")  
S80 (MH "Professional-Patient Relations") OR (MH "PhysicianPatient Relations") OR (MH "Nurse-Patient Relations") OR (MH  
"Professional-Family Relations") OR (MH "ProfessionalClient Relations") OR (MH "Patient-Family Relations")  
S81 (MH "Empathy")  
S82 (MH "Feedback")

1  
2  
3 S83 TI((patient\* or client\* or user\* or consumer\* or personal) and (experienc\* or perspective\* or perception\* or opinion\* or account  
4 or accounts or attitude\* or view or views or viewpoint\* or satisf\* or unsatisf\* or dissatisf\* or disatisf\* or belief\* or believ\*))  
5 S84 AB((patient\* or client\* or user\* or consumer\* or personal or carer\* or caregiver\* or "care-giver\*" or family\* or families) N3  
6 (experienc\* or perspective\* or perception\* or opinion\* or account or accounts or attitude\* or view or views or viewpoint\* or  
7 satisf\* or unsatisf\* or dissatisf\* or disatisf\* or belief\* or believ\*))  
8 S85 TI((patient\* or client\* or user\* or consumer\* or personal) and (emotion\* or feeling\* or happy or happiness or unhappy or  
9 unhappiness or sad or sadness or anger or angry or anxiet\* or anxious\* or worry or worries or worried or worrying or troubled  
10 or troubling or troubles or troublesome or "trouble-some" or frustrat\* or stress\* or distress\* or embarrass\* or empath\* or  
11 accept\* or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother\$ or  
12 unbother\$ or pleased or displeas\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$ or confus\$ or hope or  
13 hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or confiden\$ or unconfiden\$)).  
14 S86 AB((patient\* or client\* or user\* or consumer\* or personal) N3 (emotion\* or feeling\* or happy or happiness or unhappy or  
15 unhappiness or sad or sadness or anger or angry or anxiet\* or anxious\* or worry or worries or worried or worrying or troubled  
16 or troubling or troubles or troublesome or "troublesome" or frustrat\* or stress\* or distress\* or embarrass\* or empath\* or  
17 accept\* or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother\$ or  
18 unbother\$ or pleased or displeas\$ or concern\$ or burden\$ or hassl\$ or convenien\$ or inconvenien\$ or confus\$ or hope or  
19 hopeless or hopeful or trust or trusts or mistrust\$ or distrust\$ or entrust\$ or trusting or trusted or confiden\$ or unconfiden\$))  
20 S87 (MH "Life Experiences")  
21 S88 TI("life experience\*" or "lived experience\*" or "actual experience\*" or "real experience\*") or AB("life experience\*" or "lived  
22 experience\*" or "actual experience\*" or "real experience\*")  
23 S89 S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78  
24 OR S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88  
25 S90 S6 AND S63 AND S89  
26 S91 TI(qualitativ\*)  
27 S92 (MH "Qualitative Studies")  
28 S93 TI((patient\* or client\* or user\* or consumer\* or personal) and experiences)  
29 S94 TI((patient\* or client\* or user\* or consumer\* or personal) N2 experienc\*)  
30 S95 S91 OR S92 OR S93 OR S94  
31 S96 S6 AND S95  
32 S97 S90 OR S96  
33 S98 PT (commentary or editorial or letter)  
34 S99 TI(case report)  
35 S100 S97 NOT (S98 OR S99) Limiter – Publish date: 20070101-20171131;English Language

### PsychINFO (EBSCO interface). Search run 4/Nov/2017, re-run Jan 20, 2020

36 S1 DE heart  
37 S2 DE "heart disorders" OR DE "heart ventricles"  
38 S3 S1 AND S2  
39 S4 "heart failure"  
40 S5 heart N2 failure  
41 S6 S3 OR S4 OR S5  
42 S7 DE "Qualitative Research"  
43 S8 qualitative study  
44 S9 TI qualitativ\* OR AB qualitativ\*  
45 S10 DE "Interviews" OR DE "Intake Interview" OR DE "Interview Schedules" OR DE "Job Applicant Interviews" OR DE  
46 "Psychodiagnostic Interview"  
47 S11 interview  
48 S12 DE "Interviews" OR DE "Interviewing" OR DE "Interviewers"  
49 S13 TI interview\* OR AB interview\*  
50 S14 DE "Group Discussion"  
51 S15 focus group  
52 S16 TI focus group\* OR AB focus group  
53 S17 DE "Grounded Theory"  
54 S18 TI grounded theor\* OR TI grounded study OR TI grounded studies OR TI grounded research OR TI grounded analys\* OR  
55 AB grounded theor\* OR AB grounded study OR AB grounded studies OR AB grounded research OR AB grounded  
56 analys\*  
57 S19 DE "Phenomenology"  
58 S20 TI Phenomenol\*  
59 S21 AB Phenomenol\*  
60 S22 DE "Ethnography"  
61 S23 TI ethnograph\* OR TI ethnonurs\* OR TI ethno-graph\* OR TI ethno-nurs\* OR AB ethnograph\* OR AB ethnonurs\* OR AB  
62 ethno-graph\* OR TI ethno-nurs\*  
63 S24 DE "Storytelling"  
64 S25 DE "Narratives"  
65 S26 TI story OR TI stories OR TI storytelling OR TI narrative\*1 OR TI narration\*1  
66 S27 AB story OR AB stories OR AB storytelling OR AB narrative\*1 OR AB narration\*1  
67 S28 DE "Discourse Analysis"



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3 S29 TI discourse\* analys\* OR TI discours\* analys\* OR AB discourse\* analys\* OR AB discours\* analys\*  
4 S30 DE "Content Analysis"  
5 S31 TI content\* analys\* AND AB content\* analys\*  
6 S32 DE "Ethnology"  
7 S33 TI ethnological OR AB ethnological  
8 S34 TI purposive sampl\* OR AB purposive sampl\*  
9 S35 TI constant comparative OR TI constant comparison\*1 OR AB constant comparative OR AB constant comparison\*1  
10 S36 TI theoretical sampl\* OR AB theoretical sampl\*  
11 S37 TI theme\* OR TI thematic\* OR AB theme\* OR AB thematic\*  
12 S38 DE "Hermeneutics"  
13 S39 DE "Heuristics" OR DE "Heuristic Modeling"  
14 S40 DE "Semiotics" OR DE "Pragmatics"  
15 S41 TI emic OR TI etic OR TI hermenutic\* OR TI heuristic\* OR TI semiotic\* OR AB emic OR AB etic OR AB hermenutic\* OR  
16 AB heuristic\* OR AB semiotic\*  
17 S42 TI data saturat\* OR AB data saturat\*  
18 S43 DE "Observers"  
19 S44 TI participant observ\* OR AB participant observ\*  
20 S45 DE "Existentialism"  
21 S46 DE "Humanism"  
22 S47 TI humanistic\* OR TI existential\* OR TI experiential\* OR TI paradigm\* OR AB humanistic\* OR AB existential\* OR AB  
23 experiential\* OR AB paradigm\*  
24 S48 DE "Postmodernism"  
25 S49 DE "Feminism"  
26 S50 DE "Structuralism"  
27 S51 DE "Constructivism"  
28 S52 TI social construct\* OR TI postmodern\* OR TI post-modern\* OR TI post-modern\* OR TI post-structural\* OR TI feminis\*  
29 OR TI constructivis\* OR AB social construct\* OR AB postmodern\* OR AB post-modern\* OR AB post-structural\* OR AB  
30 feminis\*  
31 S53 AB constructivis\*  
32 S54 DE "Action Research"  
33 S55 TI action research OR TI cooperative inquir\* OR TI co operative inquir\* OR AB action research OR AB cooperative inquir\*  
34 OR AB co-operative inquir\*  
35 S56 TI human science OR AB human science  
36 S57 TI biographical method\* OR AB biographical method\*  
37 S58 TI life world OR AB life world  
38 S59 TI theoretical saturation OR AB theoretical saturation  
39 S60 TI group discussion\* OR AB group discussion\*  
40 S61 TI direct observation\* OR AB direct observation\*  
41 S62 TI mixed method\* OR AB mixed method\*  
42 S63 DE "Observation Methods"  
43 S64 TI observational method\* OR TI observational approach\* AND AB observational method\* AND AB observational  
44 approach\*  
45 S65 TI key informant\* OR AB key informant\*  
46 S66 field study  
47 S67 TI field study OR TI field studies OR TI field research\* OR TI field work\* OR TI fieldwork\* OR AB field study OR AB field  
48 studies OR AB field research\* OR AB field work\* OR AB fieldwork\*  
49 S68 TI TI semi-structured OR TI semistructured OR TI unstructured OR TI indepth OR AB semi-structured OR AB  
50 semistructured OR AB indepth OR AB in-depth OR TI un-structured OR TI informal OR TI in-depth OR TI unstructured  
51 OR AB un-structured OR AB informal  
52 S69 TI "face-to-face" OR AB "face-to-face"  
53 S70 TI ( (guide or structured) N5 (discussion\* or questionnaire\* ) ) OR AB ( (guide or structured) N5 (discussion\* or  
54 questionnaire\* ) )  
55 S71 TI ( (heidegger\* or colaizzi\* or speigelberg\* or van manen\* or van kaam\* or merleau ponty\* or husserl\* or giorgi\* or  
56 foucault\* or corbin\* or glaser\* ) ) OR AB ( (heidegger\* or colaizzi\* or speigelberg\* or van manen\* or van kaam\* or merleau  
57 ponty\* or husserl\* or giorgi\* or foucault\* or corbin\* or glaser\* ) )  
58 S72 S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21  
59 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35  
60 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49  
61 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63  
62 OR S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70 OR S71  
63 S73 TI qualitativ\*  
64 S74 DE "Qualitative Research"  
65 S75 qualitative study  
66 S76 TI ( (patient\* or client\* or user\* or consumer\* or personal) ) AND TI experiences  
67 S77 TI ((patient\* or client\* or user\* or consumer\* or personal) N2 experienc\*))  
68 S78 S73 OR S74 OR S75  
69 S79 S76 OR S77  
70 S80 S6 AND S72  
71 S81 TI ( (rat or rats or rodent or rodents or mouse or mice or murine or hamster or hamsters or gerbil or gerbils or animal or  
72 animals or dogs or dog or canine or pig or pigs or piglet or piglets or cats or bovine or cow or cows or cattle or sheep or

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3 ewe or ewes or horse or horses or equine or ovine or porcine or monkey or monkeys or primate or primates or rhesus  
4 macaque or rhesus macaques or rabbit or rabbits) ) NOT AF human\*  
5 S82 (chapter or comment/reply or dissertation or editorial or letter)  
6 S83 PT (book or authored book or edited book or dissertation abstract)  
7 S84 (review-book or review-media or review-software & other)  
8 S85 TI case report  
9 S86 S06 AND S78  
10 S87 S06 AND S79  
11 S88 S80 OR S86 OR S87  
12 S89 S81 OR S82 OR S83 OR S84 OR S85  
13 S90 S88 NOT S89 Limiters – Publication Year: 2007-2017; English

## SCOPUS. Search run 4/11/2017, re-run Jan 20, 2020

( TITLE-ABS-  
KEY (( heart\* OR cardiac OR cardial OR myocardia\* ) W/3 ( failure\* OR decompensat\* OR incompeten\* OR insufficienc\*  
OR dysfunction\* )) ) OR TITLE-ABS-KEY ( "heart failure" W/3 ( congestive OR diastolic OR systolic ) OR ( "preserved  
ejection fraction" OR "reduced ejection fraction" ) ) OR TITLE-ABS-  
KEY ( "CHF" OR "CHF\*s" OR "HF" OR "HFpEF" OR "HFrEF" ) AND TITLE-ABS-KEY ( qualitativ\* OR interview\* OR "focus  
group\*" OR "grounded theor\*" OR "grounded study" OR "grounded studies" OR "grounded research" OR "grounded  
analys\*" OR phenomenol\* OR ethnograph\* OR ethnonurs\* OR "ethno-graph\*" OR "ethno-  
nurs\*" OR story OR stories OR storytelling OR narrative\* OR narration\* OR "open ended" OR "open  
question\*" OR text\* OR "discourse\* analys\*" OR "discors\* analys\*" OR "content\* analys\*" OR ethnological OR "purposive  
sampl\*" OR "constant comparative" OR "constant comparison\*" OR "theoretical  
sampl\*" OR theme\* OR thematic\* OR emic OR etic OR hermeneutic\* OR heuristic\* OR semiotic\* OR "data  
saturat\*" OR "participant observ\*" OR humanistic\* OR existential\* OR experiential\* OR paradigm\* OR "social  
construct\*" OR postmodern\* OR "post-modern\*" OR poststructural\* OR "post-  
structural\*" OR feminis\* OR constructivis\* OR "action research" OR "cooperative inquir\*" OR "co-operative  
inquir\*" OR "human science" OR "biographical method\*" OR "life world" OR "theoretical saturation" OR "group  
discussion\*" OR "direct observation\*" OR "mixed method\*" OR "observational method\*" OR "observational  
approach\*" OR "key informant" OR "field study" OR "field studies" OR "field research\*" OR "field  
work\*" OR fieldwork\* OR "semi- structured" OR "semistructured" OR "unstructured" OR informal OR "in-  
depth" OR indepth OR "face-to-face" OR heidegger\* OR colaizzi\* OR speigelberg\* OR "van manen\*" OR "van  
kaam\*" OR "merleau ponty\*" OR husserl\* OR giorgi\* OR foucault\* OR corbin\* OR glaser\* ) OR TITLE-ABS-  
KEY ( guide OR structured ) W/5 ( discussion\* OR questionnaire\* ) AND TITLE ( patient\* OR client\* OR user\* OR consum  
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giver\*" OR family\* OR families ) AND ( experienc\* OR perspective\* OR perception\* OR opinion\* OR account OR account  
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\* ) OR TITLE ( patient\* OR client\* OR user\* OR consumer\* OR personal ) AND ( emotion\* OR feeling\* OR happy OR h  
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confiden\* ) OR TITLE-ABS-KEY ( "life experience\*" OR "lived experience\*" OR "actual experience\*" OR "real  
experience\*" ) AND ( title-  
abs- KEY ( ( heart\* OR cardiac OR cardial OR myocardia\* ) W/3 ( failure\* OR decompensat\* OR incompeten\* OR insuffici  
enc\* OR dysfunction\* )) ) OR TITLE-ABS-KEY ( "heart failure" W/3 ( congestive OR diastolic OR systolic ) OR ( "preserved  
ejection fraction" OR "reduced ejection fraction" ) ) OR TITLE-ABS-  
KEY ( "CHF" OR "CHF\*s" OR "HF" OR "HFpEF" OR "HFrEF" ) AND TITLE ( qualitativ\* ) OR KEY ( qualitativ\* ) OR TITLE (

patient\* OR client\* OR user\* OR consumer\* OR personal ) AND {experiences} AND NOT INDEX ( medline ) AND ORIG-LOAD-DATE AFT 20171104

## Web of Science Core Collection: Citation Indices. Search run 4/Nov/2017, re-run Jan 20, 2020.

Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=2007-2017

- # 1 TOPIC: ("heart failure")
- # 2 TS=((heart\* OR cardiac OR cardial OR myocardial) near/2 (failure\* OR decompensat\* OR incompetenc\* OR insufficent\* OR dysfunction\*))
- # 3 TOPIC: ("diastolic heart failure" OR "systolic heart failure")
- # 4 TOPIC: ("congestive heart failure")
- # 5 TOPIC: (CHF ORCHFs OR HF OR HFpEF OR HFrEF)
- # 6 #5 OR #4 OR #3 OR #2 OR #1
- # 7 TOPIC: (qualitativ\*)
- # 8 TOPIC: (interview\*)
- # 9 TOPIC: ("focus group\*\*")
- # 10 TOPIC: ("grounded theor\*" or "grounded study" or "grounded studies" or "grounded research" or "grounded analys\*\*")
- # 11 TOPIC: (phenomenol\*)
- # 12 TOPIC: (ethnograph\* or ethnonurs\* or "ethno-graph\*" or "ethno-nurs\*\*")
- # 13 TOPIC: (story or stories or storytelling or narrative\* or narration\*)
- # 14 TOPIC: ("open-ended" or "open question\*" or text\*)
- # 15 TOPIC: ("discourse\* analys\*" or "discors\* analys\*\*")
- # 16 TOPIC: ("content\* analys\*\*")
- # 17 TOPIC: ("ethnological")
- # 18 TOPIC: ("purposive sampl\*\*")
- # 19 TOPIC: ("constant comparative" or "constant comparison\*\*")
- # 20 TOPIC: ("theoretical sampl\*\*")
- # 21 TOPIC: (theme\* or thematic\*)
- # 22 TOPIC: ("emic" or "etic" or hermeneutic\* or heuristic\* or semiotic\*)
- # 23 TOPIC: ("data saturat\*\*")
- # 24 TOPIC: ("participant observ\*\*")
- # 25 TOPIC: (humanistic\* or existential\* or experiential\* or paradigm\*)
- # 26 TOPIC: ("social construct\*\*" or postmodern\* or "post-modern\*" or poststructural\* or "post-structural\*" or feminis\* or constructivis\*)
- # 27 TOPIC: ("action research" or "cooperative inquir\*" or "co-operative inquir\*\*")
- # 28 TOPIC: ("human science")
- # 29 TOPIC: ("biographical method\*\*")
- # 30 TOPIC: ("life world")
- # 31 TOPIC: ("theoretical saturation")
- # 32 TOPIC: ("group discussion\*\*")
- # 33 TOPIC: ("direct observation\*\*")
- # 34 TOPIC: ("mixed method\*\*")
- # 35 TOPIC: ("observational method\*" or "observational approach\*\*")
- # 36 TOPIC: ("key informant\*\*")
- # 37 TOPIC: ("field study" or "field studies" or "field research\*\*" or "field work\*\*" or fieldwork\*)
- # 38 TOPIC: ("semi-structured" or "semistructured" or "unstructured" or "un-structured" or "informal" or "indepth" or "indepth")
- # 39 TOPIC: ("face-to-face")
- # 40 TOPIC: (("guide" or "structured") near/5 (discussion\* or questionnaire\*\*))
- # 41 TOPIC: (TOPIC: (heidegger\* or colaizzi\* or speigelberg\* or "van manen\*" or "van kaam\*" or "merleau ponty\*" or husserl\* or giorgi\* or foucault\* or corbin\* or glaser\*\*))
- # 42 #41 OR #40 OR #39 OR #38 OR #37 OR #36 OR #35 OR #34 OR #33 OR #32 OR #31 OR #30 OR #29 OR #28 OR #27 OR #26 OR #25 OR #24 OR #23 OR #22 OR #21 OR #20 OR #19 OR #18 OR #17 OR #16 OR #15 OR #14 OR #13 OR #12 OR #11 OR #10 OR #9 OR #8 OR #7
- # 43 TOPIC: (((patient\* or client\* or user\* or consumer\* or "personal") and (experienc\* or perspective\* or perception\* or opinion\* or "account" or "accounts" or attitude\* or "view" or "views" or viewpoint\* or satisf\* or unsatisf\* or dissatisf\* or disatisf\* or believ\* or believ\*\*))
- # 44 TITLE: (((patient\* or client\* or user\* or consumer\* or "personal") and (experienc\* or perspective\* or perception\* or opinion\* or "account" or "accounts" or attitude\* or "view" or "views" or viewpoint\* or satisf\* or unsatisf\* or dissatisf\* or disatisf\* or believ\* or believ\*\*))
- # 45 TI=((patient\* or client\* or user\* or consumer\* or "personal") and (emotion\* or feeling\* or "happy" or "happiness" or "unhappy" or "unhappiness" or "sad" or "sadness" or "anger" or "angry" or anxiet\* or anxious\* or "worry" or "worries" or "worried" or "worrying" or "troubled" or "troubling" or "troubles" or "troublesome" or "troublesome" or frustrat\* or stress\* or distress\* or embarrass\* or empath\* or accept\* or "alone" or "lonely" or "loneliness" or "fear" or "fears" or "fearing" or "feared" or "afraid" or "scary" or "scared" or bother\* or unbother\* or "pleased" or "displeased" or concern\* or burden\* or hassl\* or convenien\* or inconvenien\* or confus\* or "hope" or "hopeless" or "hopeful" or "trust" or "trusts" or mistrust\* or distrust\* or entrust\* or "trusting" or "trusted" or confiden\* or unconfiden\*\*))
- # 46 TS=((patient\* or client\* or user\* or consumer\* or "personal") near/3 (emotion\* or feeling\* or "happy" or "happiness" or "unhappy" or "unhappiness" or "sad" or "sadness" or "anger" or "angry" or anxiet\* or anxious\* or "worry" or "worries" or "worried" or "worrying" or "troubled" or "troubling" or "troubles" or "troublesome" or "troublesome" or frustrat\* or stress\* or distress\* or embarrass\* or empath\* or accept\* or "alone" or "lonely" or "loneliness" or "fear" or "fears" or "fearing" or "feared" or "afraid" or "scary" or "scared" or bother\* or unbother\* or "pleased" or "displeased" or concern\* or burden\* or hassl\* or convenien\* or inconvenien\* or confus\* or "hope" or "hopeless" or "hopeful" or "trust" or "trusts" or mistrust\* or distrust\* or entrust\* or "trusting" or "trusted" or confiden\* or unconfiden\*\*))
- # 47 TOPIC: (("life experience\*" or "lived experience\*" or "actual experience\*" or "real experience\*\*"))



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#48 #47 OR #46 OR #45 OR #44 OR #43  
 #49 #48 AND #42 AND #6  
 #50 **TITLE:** ((qualitativ\*))  
 #51 **TITLE:** (((patient\* or client\* or user\* or consumer\* or "personal") and "experiences\*))  
 #52 **TITLE:** (((patient\* or client\* or user\* or consumer\* or "personal") near/2 experienc\*))  
 #53 #52 OR #51 OR #50  
 #54 #53 AND #6  
 #55 (#54 OR #49) **AND DOCUMENT TYPES:** (Article OR Abstract of Published Item OR Art Exhibit Review OR Bibliography OR Biographical-Item OR Book OR Book Chapter OR Book Review OR Chronology OR Correction OR Correction, Addition OR Dance Performance Review OR Data Paper OR Database Review OR Discussion OR Excerpt OR Fiction, Creative Prose OR Film Review OR Hardware Review OR Item About an Individual OR Meeting Summary OR Music Performance Review OR Music Score OR Music Score Review OR News Item OR Note OR Poetry OR Proceedings Paper OR Record Review OR Reprint OR Review OR Script OR Software Review OR TV Review, Radio Review OR TV Review, Radio Review Video OR Theater Review)  
 #56 **TITLE:** (("case report"))  
 #57 **TITLE:** (((("rat" or "rats" or "rodent" or "rodents" or "mouse" or "mice" or "murine" or "hamster" or "hamsters" or "gerbil" or "gerbils" or "animal" or "animals" or "dogs" or "dog" or "canine" or "pig" or "pigs" or "piglet" or "piglets" or "cats" or "bovine" or "cow" or "cows" or "cattle" or "sheep" or "ewe" or "ewes" or "horse" or "horses" or "equine" or "ovine" or "porcine" or "monkey" or "monkeys" or "primate" or "primates" or "rhesus macaque" or "rhesus macaques" or "rabbit" or "rabbits")))) **NOT TOPIC:** ((human\*))  
 #58 #54 OR #49  
 #59 (#58 NOT (#57 OR #56))  
 #60 (#55 AND #59) **AND LANGUAGE:** (English)

<b>Supplemental Material 3: A priori framework of Burden of Treatment</b>		
Primary construct	Secondary construct	Definition
Workload	In asking for help	Activate support: ask for support network to help with or take over the work
		Seek help: Refer for healthcare practitioners for advice or to increase level of care
	Gaining knowledge of CHF	Baseline knowledge: What does CHF look like and feel like
		Understand what works: What to do in response to a symptom, when to seek help.
		Evaluate outcomes: monitor symptoms, did the treatment work
	Performing tasks of CHF management	Lifestyle changes: exercise, diet, balance lifestyle
		Medication management: obtaining and filling prescriptions, taking medications, navigate healthcare system
		Specific illness task: attend regular appointments, daily weights, fluid management
	Capacity	Utilize abilities
External resources		What helps the patient: financial, social support network, healthcare system, physical environment, spirituality
Impact	Changes to self	Discontinuation of what the patient did and what was normal for them.
	Change to role	Discontinuation of the role the patient, alteration in who they believed they were
	Negative consequences of treatments	Things that make it hard to do what healthcare providers have recommended

Author(s)	Year	Journal	Title (abbreviated)
Ahmad et al. <sup>58</sup>	2016	<i>J Card Fail</i>	Comparing Perspectives ... Heart Failure Management
Allen et al. <sup>32</sup>	2009	<i>Prog Cardiovasc Nurs</i>	The lived experience of ... III heart failure: a pilot study
Andersson et al. <sup>55</sup>	2012	<i>Br J Community Nurs</i>	Living with heart failure ... a qualitative patient study
Attenburrow <sup>33</sup>	2016	<i>Br J Cardiac Nurs</i>	Live for the day with atrial fibrillation plus heart failure
Chiaranai <sup>26</sup>	2014	<i>J Cardiovas Nurs</i>	A phenomenological study of .... of living with heart failure
Cortis and Williams <sup>34</sup>	2007	<i>Int Nurs Rev</i>	Palliative and supportive needs ... adults with heart failure
Falk et al. <sup>31</sup>	2007	<i>Eur J Cardiovasc Nurs</i>	Keeping the maintenance ... in spite of chronic heart failure
Fry et al. <sup>35</sup>	2016	<i>BMC Fam Pract</i>	The implications of living with heart failure ... analysis
Gallacher et al. <sup>27</sup>	2011	<i>Ann Fam Med</i>	Understanding patients' experiences ... NPT
Gowani et. al. <sup>28</sup>	2017	<i>Br J Cardiac Nurs</i>	Living with heart Failure: Karachi exploratory study
Gwaltney et al. <sup>59</sup>	2012	<i>Br J Cardiology</i>	Hearing ... the heart failure patient ... qualitative interviews
Heo et al. <sup>36</sup>	2019	<i>Western J Nurs Res</i>	Patients' beliefs about causes and consequences ... symptoms
Holden et al. <sup>37</sup>	2015	<i>Appl Ergon</i>	The patient work system ... heart failure patients ... caregivers
Hopp et al. <sup>54</sup>	2012	<i>Soc Work Health Care</i>	Life Disruption ... American Elders With Advanced Heart Failure
Kimani et al. <sup>30</sup>	2018	<i>BMC Palliative Care</i>	Multidimensional needs of patients ... serial interview study
Mahoney-Davis et al. <sup>56</sup>	2017	<i>Br J Cardiac Nurs</i>	Examining the emotional and ... of people with heart failure
Malhotra et al. <sup>60</sup>	2016	<i>Proc Singapore Healthcare</i>	Living with heart failure ... patients from Singapore
Mangoloan Shahrababaki et al. <sup>38</sup>	2017	<i>J Clin Nurs</i>	The sliding context of health ... patients with heart failure ...
Ming et al. <sup>39</sup>	2011	<i>J Public Health</i>	Perspectives of heart failure patients ... from a qualitative study
Moshki et. al. <sup>40</sup>	2019	<i>OA Macedonian J Med Sci</i>	Dark or Bright half of the moon: ...quality of life
Nordfonn et al. <sup>50</sup>	2019	<i>J Clin Nurs</i>	Patients' experience with heart failure ... burden of treatment
Nordgren et al. <sup>52</sup>	2007	<i>Qual Health Res</i>	Living with ... heart failure as a middle-aged person
Paton et al. <sup>41</sup>	2007	<i>Can J Cardiovasc Nurs</i>	Recalibrating time and space ... living with heart failure
Pattenden et al. <sup>53</sup>	2007	<i>Eur J Cardiovasc Nurs</i>	Living with heart failure; patient and carer perspectives
Paturzo et al. <sup>42</sup>	2016	<i>Ann Ig</i>	The lived experience ... heart failure: a phenomenological study
Piamjariyakul et al. <sup>43</sup>	2012	<i>Appl Nurs Res</i>	Part I: heart failure home management ... perspectives
Rerkluenrit et al. <sup>49</sup>	2009	<i>Thai J Nurs Res</i>	Self-care among Thai people with heart failure
Retrum et al. <sup>44</sup>	2013	<i>Circulation</i>	Patient-identified factors related to heart failure readmissions
Ryan and Farrelly <sup>45</sup>	2009	<i>Eur J Cardiovasc Nurs</i>	Living with an unfixable heart ... with advanced heart failure
Sano et al. <sup>46</sup>	2018	<i>Int J Nurs Prac</i>	Self management of congestive heart failure ... in Japan
Seah et al. <sup>57</sup>	2016	<i>J Transcult Nurs</i>	Experiences of Patients Living With Heart Failure ... Study
Tenner <sup>47</sup>	2018	<i>JACC Heart Fail</i>	Everybody has a story, and I'm lucky!
Walthall et al. <sup>29</sup>	2017	<i>J Clin Nurs</i>	Living with ... in chronic heart failure: a qualitative study
Walthall et al. <sup>51</sup>	2019	<i>Contemporary Nurse</i>	Patients experience of ... advanced heart failure
Woda et al. <sup>48</sup>	2015	<i>J Community Health Nurs</i>	Self-Care Behaviors ... Americans Living with Heart Failure



# PRISMA 2009 Checklist

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Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	3-4
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	2
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	4
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4-5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Supplementary material 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	4
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	4-5
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	4-5 & 24
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	4-5 & 21-22
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	4
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	4-5



# PRISMA 2009 Checklist

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Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	21-22
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	6-8
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	6-8
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	21-22
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	n/a
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	6-19
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	21-22
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	19-21
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	21-22
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	23
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	24

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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