





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

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ABSTRACT

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

Design Review of qualitative research studies.

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

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

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

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

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INTRODUCTION

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

Strengths and limitations of this study

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

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

influenced by CHF symptoms or comorbidities, such as cognitive impairment,⁷ anaemia⁸ and fatigue.⁹

Understanding interactions between symptoms and treatment burden in CHF is an important question, which has yet to be explored. It has been proposed that as symptom burden increases, there is a reduction in the affective, cognitive, relational, informational, material and physical capacity of people with long-term conditions. This reduction in capacity is reflected in increases in experienced burden of treatment (BoT), the dynamic modifiable workload delegated to patients.^{10–12} BoT theory¹² 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.^{10–12–16} 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 argued¹⁷ 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.*,¹⁵ we searched CINAHL, EMBASE, MEDLINE, PsycINFO, Scopus and Web of Science. Search strategies are provided (online supplemental material S1). Bibliographies of included articles and relevant review articles were hand searched. Worldwide English language primary qualitative research articles were examined for descriptions of living with, and managing, CHF from the patient perspective. Mixed-method studies were considered for inclusion but required a substantial focus on qualitative methods to be included. Patient experience of heart transplant, end-of-life care, and CHF treatment effects were excluded. Searches were limited to articles published between January 2007 and 20 January 2020 (table 1).

Study selection

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

Table 1 Eligibility criteria for included articles

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

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

Article quality assessment

RA, CRM and LS assessed articles using Critical Appraisal Skills Programme.¹⁹ Papers were scored on the presence of additional participant and CHF characteristics. Articles were grouped into high or medium quality categories. NVivo²⁰ 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.²¹

Quantitative content analysis

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

coded (frequency) and how many articles the node was present in (consistency). Custom NVivo queries were built to count when symptom nodes occurred within the a priori BoT framework which was developed by RA, CRM and LS (online supplemental material S2). Counts of symptom nodes were used to rank the symptoms according to the frequency and consistency of coding in included articles. Sankey diagrams were built using an open-source coding programme, SankeyMATIC.²² 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 Harden²³ methodology for thematic synthesis was used. Stage 1, identification: Extracted data were examined by RA for text referring to symptoms of CHF, forming symptom nodes. A patient and public involvement (PPI) group reviewed the symptom nodes, reorganising and refining the nodes, while simultaneously checking for errors and bias. This process was repeated by a Heart Failure Specialist Nurse (MG). Stage 2, characterisation: Codes in each symptom node were read in context and a descriptive theme created capturing the context associated with that symptom. The constant comparison method²⁴ facilitated an in-depth exploration of the nature of any observed interactions. Stage 3, explain: Descriptive themes were systematically examined, compared with the BoT a priori framework coding. Simultaneously, how each symptom acted on the framework was also coded.

Role of public and patient involvement

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

RESULTS

Results: quantitative content analysis

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

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

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

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

Results: qualitative content analysis

Here interaction is defined as how a CHF symptom impacted on the patient, influencing their self-care engagement and concurrently altering BoT. Constant comparative analysis²⁵ revealed positive (drive) and negative (impede and barrier) interactions between symptoms and BoT. Each of these interactions are considered in turn in the following section. Drive was defined as an interaction where the presence of a symptom meant the patient then positively engaged with an element of their BoT (eg, attend hospital, take medications, etc...). Where Impede was defined as the symptoms making this engagement more difficult and Barrier was defined as symptoms stopping patient engagement in this work.

Symptoms drive patients to engage with self-care

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

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

Symptoms Impede patient engagement with self-care

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

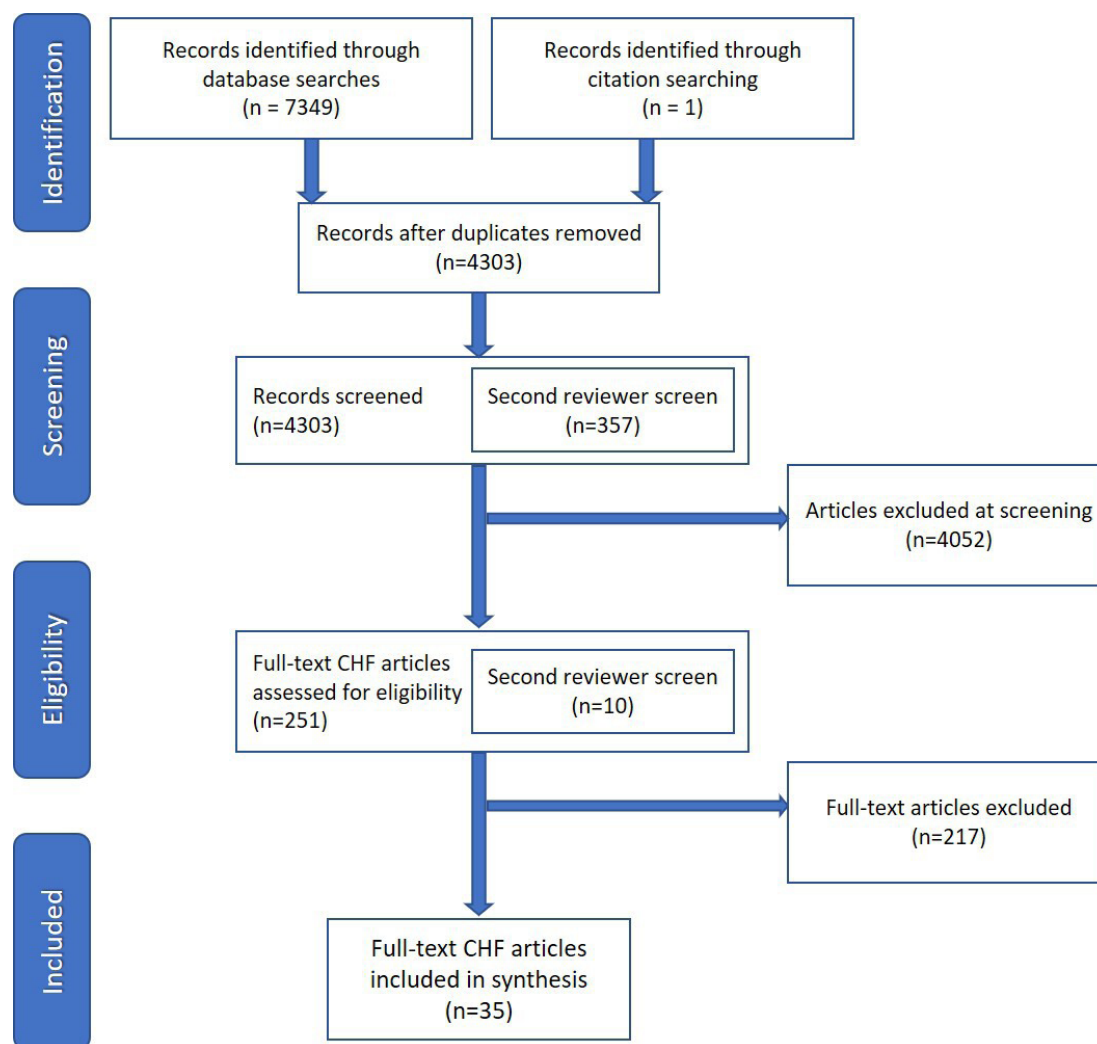


Figure 1 PRISMA flow chart for CHF articles on patient experience. CHF, chronic heart failure; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

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

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

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

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

Symptoms can restrict patients' ability to acquire knowledge around CHF. The sometimes progressive and vague nature of CHF symptoms together with the presence of comorbidities created confusion hindering baseline understanding of CHF.^{26 29 30 35–37 46–50 54} Treatments for CHF can have iatrogenic effects leading to confusion between disease progression or treatment side effects deterring the evaluation of treatment outcomes.^{28 30 35–38 40 50} 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.^{28 30 50}

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

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

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

Continued

Table 2 Continued

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

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

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

talking to exercising more difficult.^{26–32 34–38 40 41 45–47 50–58}

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.^{26–32 34 36–38 40 42 43 45 47 50–56 59 60}

The co-ordination and recruitment of this assistance also increases demand on mental capabilities, with negative affects. We observed reported difficulties in comprehending information, decision making, forgetfulness and psychological distress.^{28 30 31 36–38 40 41 45 47 50–52} Emotional capability appears affected by symptoms in four main ways: (1) physical symptoms directly causing emotional distress,^{28–30 32 34 38 40 45 47 50–53 55 56 60} (2) emotional distress due to being reliant on others to do their work,^{26 29 34 38 41 42 45 55} (3) a grief process around loss of abilities,^{28–31 34 36 37 40 42 45 50–55 59} and (4) accepting a life-limiting diagnosis.^{27 28 30–32 34 36 37 40 51 52 55 59} Symptoms mean patients lose what was and begrudgingly accept a new normal.

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

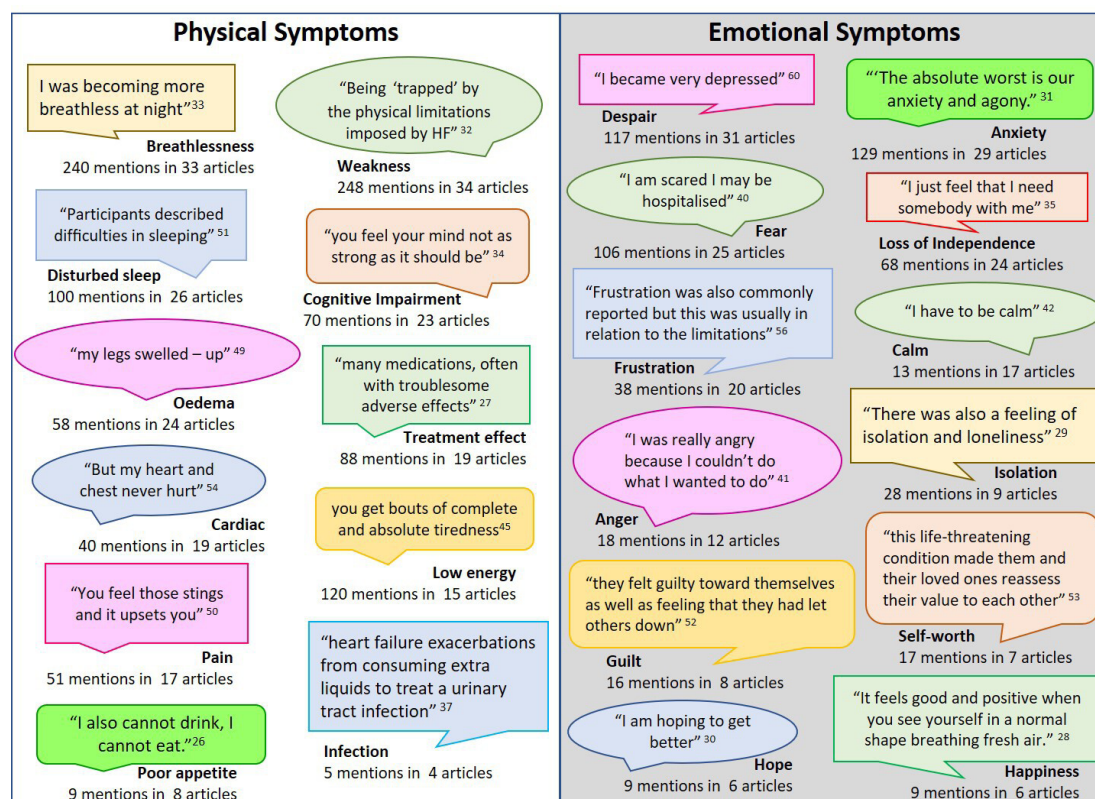


Figure 2 Symptom terms found in included articles: name of symptom node in bold font with example quote in speech bubble. Counts of frequency consistency of coding are provided. HF, heart failure.

with healthcare professionals.^{33 36 47} Healthcare systems were described as costly in terms of energy.^{28 30 50}

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

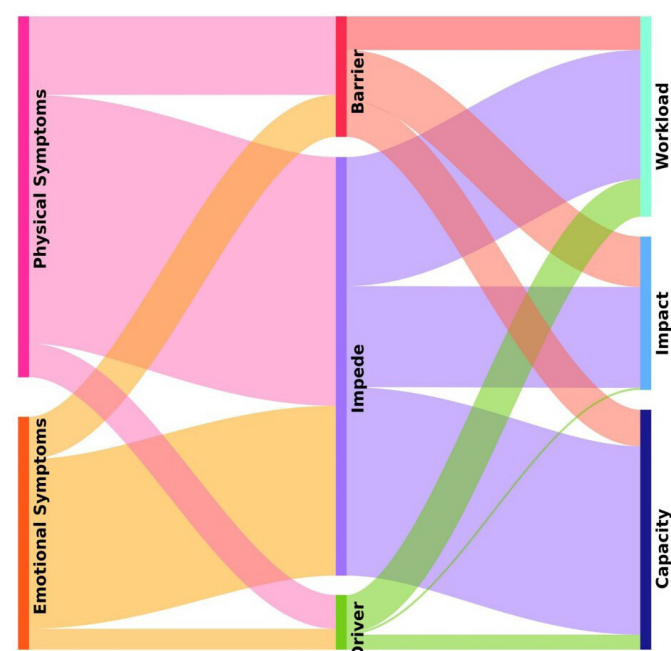


Figure 3 Sankey diagram of symptoms and the type of interaction they have with burden of treatment. Thickness of the flow bars represents the frequency of that interaction being coded in the analysis.

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

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

Symptoms create a barrier to patient engagement with self-care

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

Table 3 Symptoms drive patients to engage with self-care

Construct	Themes with exemplar quotes
Workload	<p>In asking for help from social support networks (n=15) 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.'²⁶ pg. E13</p> <p>In asking for help from healthcare professionals (n=13) 'Well if I got them now, the symptoms I get now if I'd have got them years ago I would be going to see my doctor, but as it is now over the years, I more or less know how far it can go. I'll know when it's gone too far and then I'll ring a doctor or an ambulance....' (patient 36).²⁷ pg. 2 online supplemental data</p> <p>Preforming tasks of CHF self-care; activities of daily living, illness management, lifestyle changes (n=12) '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.'²⁸ pg. 588</p> <p>Gaining knowledge around CHF; baseline understanding, and evaluating outcomes (n=7) '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.'²⁹ pg. 2042</p>
Capacity	<p>To utilize individual capacity; physical, mental, emotional, spiritual (n=8) '... acute onset breathlessness caused significant anxiety and triggered a decision to seek emergency care.'³⁰ pg. 3</p> <p>To utilize external resources; healthcare system, support networks, financial resources, physical environment (n=15) '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.'³¹ pg. 197</p>

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

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

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

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

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

support networks fearing embarrassment and becoming burdensome.^{26 28 30 40 42 45 50 52 53 55 60}

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

DISCUSSION

Statement of findings

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

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

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

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

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

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

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

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

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

Construct	Themes with exemplar quotes
Workload	<p>Performing tasks of CHF self-care (n=20): Activities of daily living (n=12): 'Tired, tired, tired, when I sit and watch TV my eyes just fall down....'⁵⁴ pg. 634 Specific illness management tasks (n=11): 'The treatment regimen is so complex I cannot figure it all out myself. I do not have the energy or the ability to manage it all. (P 6 NYHA II)'⁵⁰ pg. 1787 Gaining knowledge around CHF; understand illness and evaluating outcomes (n=9) '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'³⁷ pg. 138 In asking for help from social support networks or healthcare professional (n=7) '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)'⁵¹ pg. 77</p>
Capacity	<p>To utilize individual abilities (n=18): Physical (n=16): 'My friends have invited me over to France a couple of times and I've said that I couldn't manage it, getting in a car, driving over and driving back again. I've said I just can't do it.' P9.⁵⁵ pg.195 Emotional (n=6): 'It affected me emotionally, I became very depressed, I had bouts of depression. At one time I sort of gave up on life... one of the common emotion is frustration. I used to be able to do this thing you know, I used to be able to go out, to handle such situations; now I cannot.' (57 years, male, Chinese, married, FG3)'⁶⁰ pg.94 Mental (n=3): 'Decision-making problems lead to impairment in self-care, failure in the timely reporting of the symptoms of disease severity, disability, frequent hospitalisation, decreased QOL and increased mortality rate, which indicates the importance of evaluating cognitive impairment in patients with HF.'⁴⁰ pg.827 Spiritual (n=2): 'The discipline and practice of Islam was mentioned in relation to knowledge and understanding about diet, exercise and general health... an inability to conduct ritual ablutions before daily prayers proved to be distressing for some patients, as did not being able to prostrate during prayer.'⁵³ pg. 277 To utilize external resources (n=14) Support networks (n=11) 'A 62-year-old woman in NYHA class II reported 'I have friends but I can't go on holiday with them anymore. They recently went on holiday for 8–10 days and invited me, but I couldn't go because I feel tired and walking is more and more difficult for me.'⁴² pg. 267 Healthcare system (n=5) 'However, some respondents were less positive about primary care professionals. A number of respondents reported an apparent delay in diagnosis by their GP, which had negative effects on their relationship. 'That was while the doctors were saying chest infections... so they weren't spotting the fluid.' KP5 'Oh it's your asthma, here....he didn't even examine me....it's only when my legs started, my ankles started swelling and we insisted.' KP4'³⁵ pg.5</p>
Impact	<p>Disruption to self-ability: change of what a patient could do (n=19) '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.'⁵⁹ pg. 159 Disruption to role: change of a patient identity (n=19) 'Because my status was very serious when I was first diagnosed, my husband and I ... were advised to no longer ... try to become pregnant. My heart was too weak to go through childbirth. I was sad, but I understood. It wasn't fair to bring a child into the world with ... such a very sick mommy ... Being a childless mother is a fallout of my CHF.' pg. 98³²</p>

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

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

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

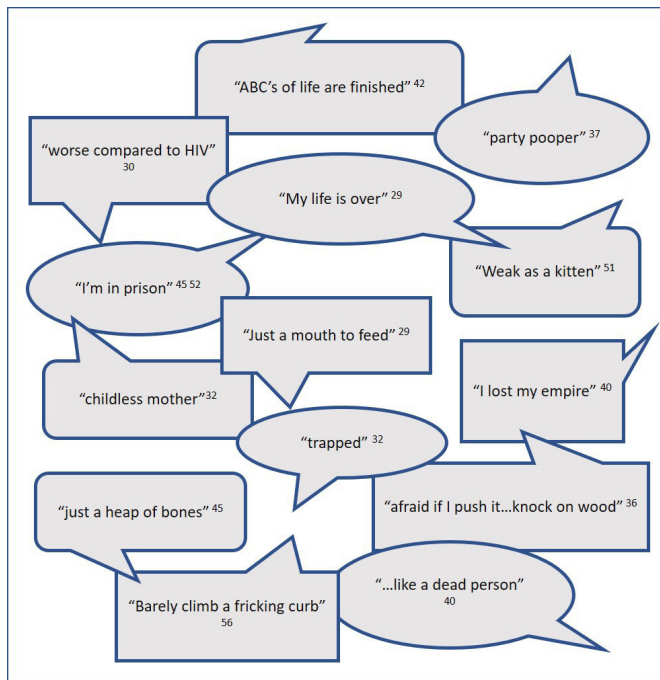


Figure 4 Exemplar metaphors used in description of how symptoms form barriers to engagement in desired activities and their perceived role.

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

as perceived benefits are so low. This affectively inhibits patients from engaging in self-care. Previous reviews on living with heart failure appear to neglect highlighting the importance of symptoms on capacity to do this work instead focusing on patients' poor adaptation to their illness and its impact on their lives⁶⁸ and their health literacy^{72 73}; as well as inadequate healthcare encounters.^{65 72 73}

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

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

Strengths and weakness of the study

Our review is the first to explore qualitative literature on patients' experiences of CHF with respect to the interactions of symptoms with BoT. It builds on the foundation of BoT theory¹⁵ with specific consideration for CHF patients. It characterises the types of symptom interaction with patient engagement in the context of BoT; which our PPI group recognised and verified as true to their experiences across multiple chronic illnesses.

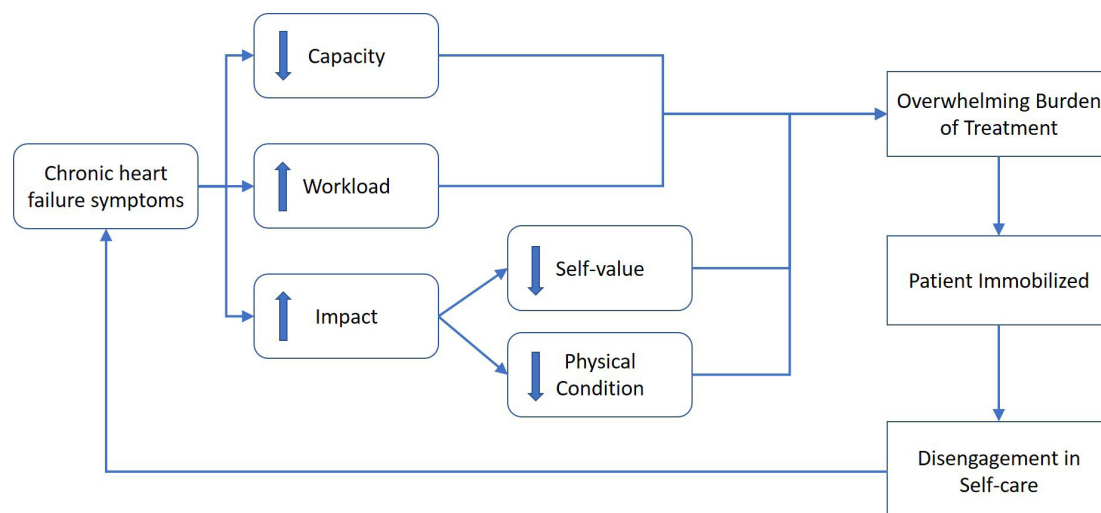


Figure 5 Initial model of CHF symptoms interaction with bot theory primary constructs. CHF, chronic heart failure.

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

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

Strengthening our analysis by using matrix queries, in Nvivo, to facilitate comparative pattern analysis as well as textual comparison,⁷⁵ confirmed the patterns observed in the constant comparison process and provided the data to create visual illustrations of these complex interactions. Our coding analysis strategy, has precedent, as it was a refinement of Thomas and Harden²³ methodology for thematic synthesis, which used a three stage coding process. We adapted their third stage to follow Gallacher *et al.*¹⁴ work which takes second stage codes (characterise) and compares them against an a priori framework helping to explain the observations.

Future work

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

CONCLUSIONS AND CLINICAL IMPLICATIONS

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

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

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- 75 Bazeley P, Jackson K. Using coding queries to further analysis.. In: *Qualitative data analysis with Nvivo*. 2 edn. Sage, 2013: 242–69.
- 76 Austin RC, Schoonhoven L, Richardson A. How do SYMPToms and management tasks in chronic heart failure imPACT a person's life (SYMFACT)? Protocol for a mixed-methods study. *ESC Heart Fail* 2020;17:4472–7.

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-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.
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 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. ethnnonursing research/
25. (ethnograph\$ or ethnnonurs\$ 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/
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) adj5 (discussion\$1 or questionnaire\$1)).ti,ab,kw.
71. (heidegger\$ or colaizzi\$ or speigelberg\$ or van manen\$ or van kaam\$ or merleau ponty\$ or husserl\$ 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
73. exp patient attitude/
74. attitude/
75. attitude to health/
76. attitude to illness/
77. attitude to life/
78. consumer attitude/
79. exp family attitude/
80. attitude to death/
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/

94. ((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.
95. ((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,kw.
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 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.
97. ((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,kw.
98. (life experience\$1 or lived experience\$1 or actual experience\$1 or real experience\$1).ti,ab,kw.
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
100. 13 and 72 and 99
101. qualitativ\$.ti.
102. qualitative research/
103. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) and experiences).ti.
104. ((patient\$1 or client\$1 or user\$1 or consumer\$1 or personal) adj2 experienc\$).ti.
105. 101 or 102 or 103 or 104
106. 13 and 105
107. 100 or 106
108. animal/
109. animal experiment/
110. animal model/
111. animal tissue/
112. nonhuman/
113. 108 or 109 or 110 or 111 or 112
114. human/
115. 113 not 114
116. (editorial or letter or conference abstract or conference paper or conference proceeding or conference review).pt.
117. case report.ti
118. 107 not (115 or 116 or 117).
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.

- S1 "heart failure"
- S2 (MH "heart failure+")
- S3 (MH "cardiac output decreased+")
- S4 (MH "ventricular ejection fraction+")
- S5 (MH "cardiac patients+")
- S6 S1 OR S2 OR S3 OR S4 OR S5
- S7 (MH "Qualitative Studies+")
- S8 TI(qualitativ*) or AB(qualitativ*)
- S9 (MH "Interviews+")
- S10 TI(interview*) or AB(interview*)
- S11 (MH "Focus Groups")
- S12 TI("focus group*") or AB("focus group*")
- S13 TI("grounded theor*" or "grounded study" or "grounded studies" or "grounded research" or "grounded analys*") or AB("grounded theor*" or "grounded study" or "grounded studies" or "grounded research" or "grounded analys*")
- S14 (MH "Phenomenology") OR (MH "Phenomenological Research")
- S15 TI(phenomenol*) or AB(phenomenol*)
- S16 TI(ethnograph* or ethnouns* or "ethno-graph*" or "ethnonurs*") or AB(ethnograph* or ethnouns* or "ethno-graph*" or "ethnonurs*")
- S17 (MH "Storytelling+") OR (MH "Narratives")
- S18 TI(story or stories or storytelling or narrative* or narration*) or AB(story or stories or storytelling or narrative* or narration*)
- S19 (MH "Open-Ended Questionnaires")
- S20 TI("open-ended" or "open question*" or text*) or AB("openended" or "open question*" or text*)
- S21 (MH "Discourse Analysis")
- S22 TI("discourse* analys*" or "discurs* analys*") or AB("discourse* analys*" or "discurs* analys*")
- S23 (MH "Content Analysis")

- S24 TI("content* analys*") or AB("content* analys*")
S25 TI(ethnological) or AB(ethnological)
S26 (MH "Purposive Sample")
S27 TI("purposive sampl*") or AB("purposive sampl*")
S28 (MH "Constant Comparative Method")
S29 TI("constant comparative" or "constant comparison*") or AB ("constant comparative" or "constant comparison*")
S30 (MH "Theoretical Sample")
S31 TI("theoretical sampl*") or AB("theoretical sampl*")
S32 (MH "Thematic Analysis")
S33 TI(theme* or thematic*) or AB(theme* or thematic*)
S34 TI(emic or etic or hermeneutic* or heuristic* or semiotic*) or AB(emic or etic or hermeneutic* or heuristic* or semiotic*)
S35 TI("data saturat*") or AB("data saturat*")
S36 (MH "Observational Methods+")
S37 TI("participant observ*") or AB("participant observ*")
S38 (MH "Humanism")
S39 TI(humanistic* or existential* or experiential* or paradigm*) or AB(humanistic* or existential* or experiential* or paradigm*)
S40 (MH "Social Constructionism")
S41 (MH "Postmodernism")
S42 (MH "Feminism+")
S43 TI("social construct*" or postmodern* or "post-modern*" or poststructural* or "post-structural*" or feminis* or constructivis*) or AB("social construct*" or postmodern* or "post-modern*" or poststructural* or "post-structural*" or feminis* or constructivis*)
S44 TI("action research" or "cooperative inquir*" or "co-operative inquir*") or AB("action research" or "cooperative inquir*" or "co-operative inquir*")
S45 TI("human science") or AB("human science")
S46 TI("biographical method*") or AB("biographical method*")
S47 TI("life world") or AB("life world")
S48 TI("theoretical saturation") or AB("theoretical saturation")
S49 TI("group discussion*") or AB("group discussion*")
S50 TI("direct observation*") or AB("direct observation*")
S51 TI("mixed method*") or AB("mixed method*")
S52 TI("observational method*" or "observational approach*") or AB("observational method*" or "observational approach*")
S53 TI("key informant*") or AB("key informant*")
S54 (MH "Field Studies")
S55 TI("field study" or "field studies" or "field research*" or "field work*" or fieldwork*) or AB("field study" or "field studies" or "field research*" or "field work*" or fieldwork*)
S56 TI("semi-structured" or semistructured or unstructured or "un-structured" or informal or "in-depth" or indepth) or AB("semi-structured" or semistructured or unstructured or "un-structured" or informal or "in-depth" or indepth)
S57 TI("face-to-face") or AB("face-to-face")
S58 (MH "Structured Interview Guides")
S59 (MH "Structured Questionnaires")
S60 (MH "Discussion")
S61 TI((guide or structured) N5 (discussion* or questionnaire*)) or AB((guide or structured) N5 (discussion* or questionnaire*))
S62 TI(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 AB(heidegger* or colaizzi* or speigelberg* or "van manen*" or "van kaam*" or "merleau ponty*" or husserl* or giorgi* or foucault* or corbin* or glaser*)
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 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 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 S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62
S64 MH "Consumer Satisfaction") OR (MH "Patient Satisfaction")
S65 (MH "Attitude") OR (MH "Attitude to Death") OR (MH "Attitude to Health") OR (MH "Attitude to Illness") OR (MH "Family Attitudes+") OR (MH "Patient Attitudes") OR (MH "Personal Satisfaction")
S66 (MH "Patient Compliance+") OR (MH "Treatment Refusal")
S67 (MH "Attitude to Life")
S68 (MH "Health Beliefs")
S69 (MH "Consumer Participation")
S70 (MH "Emotions+")
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")

S83 TI((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 belief* or believ*))

S84 AB((patient* or client* or user* or consumer* or personal or carer* or caregiver* or "care-giver*" or family* or families) N3 (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 belief* or believ*))

S85 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 "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\$)).

S86 AB((patient* or client* or user* or consumer* or personal) N3 (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\$))

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")

S93 TI((patient* or client* or user* or consumer* or personal) and experiences)

S94 TI((patient* or client* or user* or consumer* or personal) N2 experienc*)

S95 S91 OR S92 OR S93 OR S94

S96 S6 AND S95

S97 S90 OR S96

S98 PT (commentary or editorial or letter)

S99 TI(case report)

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

S1 DE heart

S2 DE "heart disorders" OR DE "heart ventricles"

S3 S1 AND S2

S4 "heart failure"

S5 heart N2 failure

S6 S3 OR S4 OR S5

S7 DE "Qualitative Research"

S8 qualitative study

S9 TI qualitativ* OR AB qualitativ*

S10 DE "Interviews" OR DE "Intake Interview" OR DE "Interview Schedules" OR DE "Job Applicant Interviews" OR DE "Psychodiagnostic Interview"

S11 interview

S12 DE "Interviews" OR DE "Interviewing" OR DE "Interviewers"

S13 TI interview* OR AB interview*

S14 DE "Group Discussion"

S15 focus group

S16 TI focus group* OR AB focus group

S17 DE "Grounded Theory"

S18 TI grounded theor* OR TI grounded study OR TI grounded studies OR TI grounded research OR TI grounded analys* OR AB grounded theor* OR AB grounded study OR AB grounded studies OR AB grounded research OR AB grounded analys*

S19 DE "Phenomenology"

S20 TI Phenomenol*

S21 AB Phenomenol*

S22 DE "Ethnography"

S23 TI ethnograph* OR TI ethnonurs* OR TI ethno-graph* OR TI ethno-nurs* OR AB ethnograph* OR AB ethnonurs* OR AB ethno-graph* OR TI ethno-nurs*

S24 DE "Storytelling"

S25 DE "Narratives"

S26 TI story OR TI stories OR TI storytelling OR TI narrative*1 OR TI narration*1

S27 AB story OR AB stories OR AB storytelling OR AB narrative*1 OR AB narration*1

S28 DE "Discourse Analysis"

S29 TI discourse* analys* OR TI discours* analys* OR AB discourse* analys* OR AB discours* analys*
 S30 DE "Content Analysis"
 S31 TI content* analys* AND AB content* analys*
 S32 DE "Ethnology"
 S33 TI ethnological OR AB ethnological
 S34 TI purposive sampl* OR AB purposive sampl*
 S35 TI constant comparative OR TI constant comparison*1 OR AB constant comparative OR AB constant comparison*1
 S36 TI theoretical sampl* OR AB theoretical sampl*
 S37 TI theme* OR TI thematic* OR AB theme* OR AB thematic*
 S38 DE "Hermeneutics"
 S39 DE "Heuristics" OR DE "Heuristic Modeling"
 S40 DE "Semiotics" OR DE "Pragmatics"
 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 AB heuristic* OR AB semiotic*
 S42 TI data saturat* OR AB data saturat*
 S43 DE "Observers"
 S44 TI participant observ* OR AB participant observ*
 S45 DE "Existentialism"
 S46 DE "Humanism"
 S47 TI humanistic* OR TI existential* OR TI experiential* OR TI paradigm* OR AB humanistic* OR AB existential* OR AB experiential* OR AB paradigm*
 S48 DE "Postmodernism"
 S49 DE "Feminism"
 S50 DE "Structuralism"
 S51 DE "Constructivism"
 S52 TI social construct* OR TI postmodern* OR TI post-modern* OR TI post-modern* OR TI post-structural* OR TI feminis* OR TI constructivis* OR AB social construct* OR AB postmodern* OR AB post-modern* OR AB post-structural* OR AB feminis*
 S53 AB constructivis*
 S54 DE "Action Research"
 S55 TI action research OR TI cooperative inquir* OR TI co operative inquir* OR AB action research OR AB cooperative inquir* OR AB co-operative inquir*
 S56 TI human science OR AB human science
 S57 TI biographical method* OR AB biographical method*
 S58 TI life world OR AB life world
 S59 TI theoretical saturation OR AB theoretical saturation
 S60 TI group discussion* OR AB group discussion*
 S61 TI direct observation* OR AB direct observation*
 S62 TI mixed method* OR AB mixed method*
 S63 DE "Observation Methods"
 S64 TI observational method* OR TI observational approach* AND AB observational method* AND AB observational approach*
 S65 TI key informant* OR AB key informant*
 S66 field study
 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 studies OR AB field research* OR AB field work* OR AB fieldwork*
 S68 TI TI semi-structured OR TI semistructured OR TI unstructured OR TI indepth OR AB semi-structured OR AB semistructured OR AB indepth OR AB in-depth OR TI un-structured OR TI informal OR TI in-depth OR TI unstructured OR AB un-structured OR AB informal
 S69 TI "face-to-face" OR AB "face-to-face"
 S70 TI ((guide or structured) N5 (discussion* or questionnaire*)) OR AB ((guide or structured) N5 (discussion* or questionnaire*))
 S71 TI ((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 AB ((heidegger* or colaizzi* or speigelberg* or van manen* or van kaam* or merleau ponty* or husserl* or giorgi* or foucault* or corbin* or glaser*))
 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 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 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 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 OR S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70 OR S71
 S73 TI qualitativ*
 S74 DE "Qualitative Research"
 S75 qualitative study
 S76 TI ((patient* or client* or user* or consumer* or personal)) AND TI experiences
 S77 TI ((patient* or client* or user* or consumer* or personal) N2 experienc*)
 S78 S73 OR S74 OR S75
 S79 S76 OR S77
 S80 S6 AND S72
 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 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 AF human*

S82 (chapter or comment/reply or dissertation or editorial or letter)

S83 PT (book or authored book or edited book or dissertation abstract)

S84 (review-book or review-media or review-software & other)

S85 TI case report

S86 S06 AND S78

S87 S06 AND S79

S88 S80 OR S86 OR S87

S89 S81 OR S82 OR S83 OR S84 OR S85

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 cardinal 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
er* OR personal OR carer* OR caregiver* OR "care-giver*" OR family* OR families) AND (experienc* OR perspective* OR perception* OR opinion* OR account OR account
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displeased* OR concern* OR burden* OR hassl AND * OR convenien* OR inconvenien* OR confus* OR hope OR hopel
ess OR hopeful OR trust OR trusts OR mistrust* OR distrust* OR entrust* OR trusting OR trusted OR confiden* OR un
confiden*) OR TITLE-ABS-KEY ("life experience*" OR "lived experience*" OR "actual experience*" OR "real
experience*") AND (title-
abs- KEY ((heart* OR cardiac OR cardinal 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 insufficien* OR dysfunction*))
- # 3 **TOPIC:** ("diastolic heart failure" OR "systolic heart failure")
- # 4 **TOPIC:** ("congestive heart failure")
- # 5 **TOPIC:** (CHF ORCHF* 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 ethnonsurs* 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:** (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 belief* 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 belief* 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*"))

#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)

Supplemental Material 3: A priori framework of Burden of Treatment		
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	What can the patient do: physical, emotional, and mental capability, socialisation
	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. ⁵⁸	2016	<i>J Card Fail</i>	Comparing Perspectives ... Heart Failure Management
Allen et al. ³²	2009	<i>Prog Cardiovasc Nurs</i>	The lived experience of ... III heart failure: a pilot study
Andersson et al. ⁵⁵	2012	<i>Br J Community Nurs</i>	Living with heart failure ... a qualitative patient study
Attenburrow ³³	2016	<i>Br J Cardiac Nurs</i>	Live for the day with atrial fibrillation plus heart failure
Chiaranai ²⁶	2014	<i>J Cardiovas Nurs</i>	A phenomenological study of of living with heart failure
Cortis and Williams ³⁴	2007	<i>Int Nurs Rev</i>	Palliative and supportive needs ... adults with heart failure
Falk et al. ³¹	2007	<i>Eur J Cardiovasc Nurs</i>	Keeping the maintenance ... in spite of chronic heart failure
Fry et al. ³⁵	2016	<i>BMC Fam Pract</i>	The implications of living with heart failure ... analysis
Gallacher et al. ²⁷	2011	<i>Ann Fam Med</i>	Understanding patients' experiences ... NPT
Gowani et. al. ²⁸	2017	<i>Br J Cardiac Nurs</i>	Living with heart Failure: Karachi exploratory study
Gwaltney et al. ⁵⁹	2012	<i>Br J Cardiology</i>	Hearing ... the heart failure patient ... qualitative interviews
Heo et al. ³⁶	2019	<i>Western J Nurs Res</i>	Patients' beliefs about causes and consequences ... symptoms
Holden et al. ³⁷	2015	<i>Appl Ergon</i>	The patient work system ... heart failure patients ... caregivers
Hopp et al. ⁵⁴	2012	<i>Soc Work Health Care</i>	Life Disruption ... American Elders With Advanced Heart Failure
Kimani et al. ³⁰	2018	<i>BMC Palliative Care</i>	Multidimensional needs of patients ... serial interview study
Mahoney-Davis et al. ⁵⁶	2017	<i>Br J Cardiac Nurs</i>	Examining the emotional and ... of people with heart failure
Malhotra et al. ⁶⁰	2016	<i>Proc Singapore Healthcare</i>	Living with heart failure ... patients from Singapore
Mangoloan Shahrabaki et al. ³⁸	2017	<i>J Clin Nurs</i>	The sliding context of health ... patients with heart failure ...
Ming et al. ³⁹	2011	<i>J Public Health</i>	Perspectives of heart failure patients ... from a qualitative study
Moshki et. al. ⁴⁰	2019	<i>OA Macedonian J Med Sci</i>	Dark or Bright half of the moon: ...quality of life
Nordfonn et al. ⁵⁰	2019	<i>J Clin Nurs</i>	Patients' experience with heart failure ... burden of treatment
Nordgren et al. ⁵²	2007	<i>Qual Health Res</i>	Living with ... heart failure as a middle-aged person
Paton et al. ⁴¹	2007	<i>Can J Cardiovasc Nurs</i>	Recalibrating time and space ... living with heart failure
Pattenden et al. ⁵³	2007	<i>Eur J Cardiovasc Nurs</i>	Living with heart failure; patient and carer perspectives
Paturzo et al. ⁴²	2016	<i>Ann Ig</i>	The lived experience ... heart failure: a phenomenological study
Piamjariyakul et al. ⁴³	2012	<i>Appl Nurs Res</i>	Part I: heart failure home management ... perspectives
Rerkluenrit et al. ⁴⁹	2009	<i>Thai J Nurs Res</i>	Self-care among Thai people with heart failure
Retrum et al. ⁴⁴	2013	<i>Circulation</i>	Patient-identified factors related to heart failure readmissions
Ryan and Farrelly ⁴⁵	2009	<i>Eur J Cardiovasc Nurs</i>	Living with an unfixable heart ... with advanced heart failure
Sano et al. ⁴⁶	2018	<i>Int J Nurs Prac</i>	Self management of congestive heart failure ... in Japan
Seah et al. ⁵⁷	2016	<i>J Transcult Nurs</i>	Experiences of Patients Living With Heart Failure ... Study
Tenner ⁴⁷	2018	<i>JACC Heart Fail</i>	Everybody has a story, and I'm lucky!
Walthall et al. ²⁹	2017	<i>J Clin Nurs</i>	Living with ... in chronic heart failure: a qualitative study
Walthall et al. ⁵¹	2019	<i>Contemporary Nurse</i>	Patients experience of ... advanced heart failure
Woda et al. ⁴⁸	2015	<i>J Community Health Nurs</i>	Self-Care Behaviors ... Americans Living with Heart Failure