**Title:** Do chronic heart failure symptoms interact with burden of treatment? Qualitative literature 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 devasting 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 arerestricted 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 UK1. Despite major advances in its treatment, many people with CHF experience substantial symptom burden and life-limiting prognosis2-4. The focus of CHF management is increasingly centred on self-care5. 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 outcomes6. 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 impairment7, anaemia8 and fatigue9.

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 patients10-12 . Burden of treatment (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-care10 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, 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 |
|  |  |
| 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 (e.g. paper with a singular focus).  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)  Literature review papers (including qualitative synthesis, meta-synthesis, etc.) |
| Settings: Worldwide |  |
| Date of publication: between January 1, 2007 and Jan 20, 2020 |  |
| Language: English |  |

**Study Selection**

RA screened titles and abstracts, using Covidence18, 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)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 methods21.

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, SankeyMATIC22. 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 23 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 method24 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 2 presents a summative description of included articles.

|  |  |  |
| --- | --- | --- |
|  | | Total |
| 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  Co-morbidities | 8  12 |
|  | Duration of illness  Employment  Education  Marital status  Ethnicity | 18  17  10  21  18 |

|  |  |  |
| --- | --- | --- |
|  | | 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\* |

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

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.

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.

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 (e.g. 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 utilize their capacity to access external resources. Table 3 provides exemplar quotes and figure 3 illustrates the interactions.

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 | 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  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 supplementary data  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  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 |
| Capacity | 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  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 |

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 exacerbation26-50. Symptoms urged patients to access healthcare systems for treatment adjustments or hospital admissions27 28 30 33 35 36 38 43 46-49 51, receive support from social networks26 27 29-32 34 35 37 39-43 45 47 49 52, engage with self-care tasks26-29 32 36 40 45-47 49 50 and make physical environments alterations26 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 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 utilize 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.

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 | Preforming 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 |
| Capacity | 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* |
| Impact | 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.’” 54 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 |

Symptoms made monitoring and management of CHF harder28-31 35-38 40 41 44 46 48 50 51 53 55. Completing specific tasks such as taking medications, attending appointments, and other self-care activities become more difficult in the presence of symptoms27 28 30 34-40 44 46 48-51 53. Further multiple co-morbidities (common in CHF) can create confusion around which illness was responsible for what symptom and which treatment takes priority28 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 life26 28 29 31 32 34-43 46 49-51 53 56 57. Within this context of impaired capability, engagement with lifestyle changes was limited31 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 exacerbated28 37 40 44 48 50. Some reported purposely choosing not to make lifestyle behaviour changes as the effort of these changes outweighed perceived benefits46 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 co-morbidities created confusion hindering baseline understanding of CHF26 29 30 35-37 46-50 55. Treatments for CHF can have iatrogenic effects leading to confusion between disease progression or treatment side effects deterring the evaluation of treatment outcomes28 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 sadness28 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 talking to exercising more difficult26-32 34-38 40 41 45-47 50-53 55-59. Decreases in physical capability often requires patients to recruit others to help with physical tasks, shifting the burden from physical onto emotional through reduced independence26-32 34 36-38 40 42 43 45 47 50-57 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 distress28 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 56 57 60, 2) emotional distress due to being reliant on others to do their work26 29 34 38 41 42 45 56, 3) a grief process around loss of abilities28-31 34 36 37 40 42 45 50-56, and 4) accepting a life-limiting diagnosis27 28 30-32 34 36 37 40 51 52 54 56. 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 belonging26 31 40 45 46 50-52 54; yet, symptoms require reliance on family or friends due to decreased physical capability29 32 34 35 41 45 49 50 53 56 60. There was also a sense that physical limitations meant adapting or giving up recreational and social activities leading to isolation and loneliness28 30 40 50 51 53 54. Interactions with healthcare systems, around symptoms, were reported to cause fatigue, fear, confusion, and depression28 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 with healthcare professionals33 36 47. Healthcare systems were described as costly in terms of energy28 30 50.

Symptoms negatively impacted financial resources draining family finances due to associated healthcare costs, a finding observed in articles from Japan, Iran, Kenya, USA, Pakistan, Italy, United Kingdom, Sweden and Thailand26 28 30 36 40 42 46 52 53. Symptoms also alter a patient’s employability decreasing family incomes and changing family roles26 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 threatened26 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 changes26 28 29 31-36 38-42 45 46 49-57. 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 death26 28-31 35-38 40 42-47 49-53 56 57 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 capacity26 28-31 35-37 40 41 44 50 53 59. Disruptive side -effects of medication meant medications were not taken and/or social activities were restricted28 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 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 utilize 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.

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 | Preforming 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….” 55 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” 37pg. 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 |
| Capacity | 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.” 56 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 |
| Impact | 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.” 54 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. 98 32 |

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 ones26-30 33-38 40-42 44-46 48 50-55 57 60. Assigned complex CHF self-care regimens likely become insurmountable in the face of such symptoms27 38 42 50 51 54. The subjective nature of CHF symptoms can form a barrier to both patients and healthcare providers acting in a timely matter to those symptoms30 33 35 37 38 41 48 54 55. Resulting in delayed treatment seeking and poor illness management30 33 35 38 45 48 51.

Symptoms of CHF appear to form a barrier to patients’ physical, mental, emotional and spiritual abilities27 29 31 32 36 37 40-42 45 50 52-56 58 60. 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 it29 32 37 40-42 45 50 56 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 patients30 35 38 45 47. Symptoms stop patients accessing their social support networks; they retreat from their social support networks fearing embarrassment and becoming burdensome26 28 30 40 42 45 50 52 53 56 60.

Symptoms inhibit patients from performing desired activities, creating a sense of personal worthlessness26 29 30 32 36 37 40-42 45 46 50-52 54-56 59 60.The lack of individual capability alters their role in social support networks, forming a barrier to patients’ relationships and future lives26 28-30 32 33 36 37 40 42 45 46 49-54 56 57. 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 (e.g. 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 align62-65.

*Symptoms as a driver to engagement with self-care* were seen in the minority (<10%) of coded interactions with 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 (e.g. previous negative experiences, perceived barriers to care, misattribution of symptoms, etc.)66 rather than symptoms alone67. Failures in self-care were previously blamed on a patients’ denial of illness or poor health literacy63 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 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 COPD and lung cancer, where lung cancer patients are expected to follow a structure treatment pathway meant less BoT. Where COPD patients 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 difficult65 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 Goncalves, et al. 70, which identified a negative influence between BoT and the pathophysiology of illness across multiple health conditions.

*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 literacy72 73; as well as inadequate healthcare encounters65 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 work74. 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 recognized and verified as true to their experiences across multiple chronic illnesses.

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 health care 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 Harden 23 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.

Figure 1: PRISMA 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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**Author Contributions:** RCA drafted this paper. RCA, LS, and CRM developed the conceptual framework that informed this work. RCA designed the review with support and guidance from CRM, LS, and PRK. RCA assisted by CRM and LS performed the work of the literature searches. MC assisted in the screening of the articles and CRM and LS acted as the arbiter for any disputes. RCA performed the first-line analysis and was guided by CRM, LS, and AR throughout constant comparison analysis. PRA’s and MG checked line by line symptom coding, refined the symptom coding structure, and confirmed the results to be representative of their personal patient experiences. CRM, LS, AR, and PRK critically reviewed the manuscript for intellectual and clinical content. All authors approved the final version of the paper. RCA is the guarantor.

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**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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