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How do symptoms of chronic heart failure influence the burden of treatment experienced by patients?

by

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Thesis for the degree of Doctor of Philosophy

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Abstract

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Chronic heart failure (CHF) is a syndrome of increasing prevalence with invasive symptoms which persist despite optimal medical treatments. Responsibility for CHF management is passed to patients through the assignment of self-care regimens. It is often claimed that patients with CHF fail at self-care engagement and non-adherence is cited as the reason for re-admissions, poor quality of life, and clinical outcomes. Poor engagement in self-care is a possible indication of the overwhelming burden of treatment (BoT). When workload (tasks patients must do to live with and manage their illness) outweighs capacity (internal capabilities and external resources which enable them to do the work) patients become overwhelmed. The role of symptoms on BoT has not been investigated.

Presented in this thesis are six papers, four were accepted for publication, one was submitted for consideration, and the final one will be submitted after the fifth is accepted. Together they identify, describe, and explain the role of CHF symptoms on BoT. The thesis is underpinned by a pragmatic abductive approach utilizing mixed methods. The empirical research is grounded on BoT theory to examine the over-arching research question: How do symptoms of chronic heart failure influence the burden of treatment experienced by patients?

Beginning with an editorial that describes how the major theories of BoT and self-care were brought together to inform the research question. A protocol paper describes the overall design of the empirical research. A qualitative evidence synthesis examines 35 qualitative articles for symptoms interaction with BoT. Next, the results of a cross-sectional survey of patients with CHF (n=333) who completed 3 questionnaires capturing symptoms and BoT are presented. Followed by findings from a sub-sample of survey participants (n=32) who participated in semi-structured interviews to explore the proposed relationship of symptoms with BoT. Finally, a CHF specific BoT theory was developed by integrating all research findings and is presented in a final paper.

The body of research has identified how symptoms of CHF interact with BoT and identified that other factors (illness pathology and identity, task value and performance, and available support structures) alter the relationship between symptoms and BoT. This results in situations where patients may report low burden, despite living lives ruled by the management of CHF.

The collective findings from the research have informed a CHF specific BoT theory. The theory offers an alternative way of viewing CHF patients' engagement with self-care and an alternative way of considering patients with CHF clinically. Incorporating the theory into clinical practice could result in the creation of a minimally disruptive model of care.

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Research Thesis: Declaration of Authorship

Print name: Rosalynn Clara Austin

Title of thesis: How do symptoms of chronic heart failure influence the burden of treatment experienced by patients?

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Parts of this work have been published as:
   Paper 1: Austin, RC, Schoonhoven, L, Kalra, PR, and May, CR. Burden of treatment in chronic heart failure: does symptom burden play a role? British Journal of Cardiac Nursing. 2019; 14(2), 91-93.
   Paper 2: Austin, RC, Schoonhoven, L, Richardson, A, Kalra, PR, and May, CR. How **SYM**ptoms and management tasks in chronic heart failure im**PACT** on a person's life (SYMPACT)? Protocol for a Mixed Methods Study. ESC Heart Failure. 2020 Sep 17; 7(6), pp. 4472– 4477. https://doi.org/10.1002/ehf2.13010.
   Paper 3: Austin, RC, Schoonhoven, L, Clancy, M, Richardson, AR, Kalra, PR, May, CR. Do chronic heart failure symptoms interact with burden of treatment? Qualitative literature systematic review. BMJ Open. 2021; 11**:**e047060. doi: 10.1136/bmjopen-2020-047060.
   Paper 4: Austin, RC, Schoonhoven, L, Koutra, V, Richardson, AR, Kalra, PR, May, CR. SYMptoms in chronic heart failure imPACT on burden of treatment (SYMPACT): a cross-sectional survey. ESC Heart Failure; https://doi.org/10.1002/ehf2.13904.

Paper 5: Austin, RC, Schoonhoven, L, Richardson, AR, Kalra, PR, May, CR. Qualitative interviews with people with heart failure on the interaction between symptoms and self-care work: a sub-sample of SYMPACT survey respondents. ESC Heart failure; submitted 2022 Mar 9.

Paper 6: Austin, RC, Schoonhoven, L, Richardson, AR, Kalra, PR, May, CR. A condition specific theory of treatment burden in heart failure and a translational clinical model. *Will be submitted to JAHA after paper 5 is accepted.*

8. The doctoral project supervisors Professor Carl May, Professor Lisette Schoonhoven, Professor Paul Kalra, and Professor Alison Richardson oversaw the design, conduct, and write-up for the thesis and the papers presented (where their names are listed). Co-author contributions, other than supervisors, are outlined in the author contribution sections in the individual papers. The patient research ambassador group at the Portsmouth hospitals university trust provided patient and public involvement throughout the thesis. Their contributions are outlined in the publications and the thesis's final chapter.
9. I designed, conducted the research, analysed the data, and wrote both the thesis and papers here included. Professor Carl May, Professor Lisette Schoonhoven, Professor Paul Kalra, and Professor Alison Richardson provided supervision, advice, and comments. They challenged and guided me throughout my doctoral studies.

Signature: .... Date:...........................

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Definitions and Abbreviations

ACE-I	Angiotensin-converting enzyme inhibitors
ARB	Angiotensin receptor blockers
ARC	Applied research collaboration
ARNi	Angiotensin receptor neprilysin inhibitors
BANCC	British association for nursing in cardiovascular care
BMI	Body mass index
BNP	B-type natriuretic peptide
BoT	Burden of Treatment, concept which describes the dynamic concepts of *workload* (tasks, time and energy required to manage a health condition), *capacity* (individual factors that may influence a person's ability to engage and complete that work) and the resultant *impact* (effect of the workload on the individual's sense of self and their role in society)
Capacity	The combination of internal capabilities together with accessible and available external resources. Where internal capabilities were defined as physical, mental, emotional and spiritual abilities and external resources as social, financial, environmental, and accessible healthcare services.
CASP	Critical appraisal skills programme
CHF	Chronic Heart Failure: an individual diagnosed with any type of heart failure for a minimum of six months
CI	confidence interval
COPD	Chronic obstructive pulmonary disorder
CPR	Cardiopulmonary resuscitation
CRN	Clinical research network
CRT	Cardiac resynchronization therapy
eCRF	Electronic case report form
GP	General practitioners

Definitions and Abbreviations

HCS	Healthcare services
HCP	Healthcare professionals
HFmrEF	Heart failure with mildly reduced left ventricular ejection fraction
HFpEF	Heart Failure with preserved (left ventricular) ejection fraction
HFrEF	Heart Failure with reduced (left ventricular) ejection fraction
HFSN	Heart failure specialist nurse
HFSS	Heart failure symptom survey
HR-QoL	Health related quality of life
ICD	Implantable cardioverter-defibrillator
Impact	The alteration of oneself or their role due to the capacity to engage in workload.
IQR	Interquartile range
ITU	Intensive therapies unit
LVEF	Left ventricular ejection fraction
MLHFQ	Minnesota living with heart failure questionnaire
MRA	Mineralocorticoid receptor agonist
MRI	Magnetic resonance imaging
MTBQ	Multimorbidity treatment burden questionnaire
NCD	Non-communicable disease
NHS	National Health Service
NICE	National institute for health and care excellence
NIHR	National institute for health and research
NT-proBNP	N-terminal pro-B-type natriuretic peptide
NYHA	New York Heart Association
PETS	Patient experience of treatment and self-management
PhD	Doctor of Philosophy
PPI	Patient and public involvement
PRISMA	Preferred reporting items for systematic reviews and meta-analysis

QoL	Quality of life
RCT	Randomised control trial
SD	Standard deviation
Self-care	Tasks both assigned to and assumed by patients and includes tasks typically included in self-care maintenance, monitoring, and management, as defined in the theory of self-care in chronic illness.
SGLT2i	Sodium glucose co-transporter 2 inhibitor
SPSS	Statistical Package for Social Sciences
SYMPACT	Research study acronym: How do SYMptoms and management tasks in chronic heart failure imPACT on a person's life?
TBQ	Treatment burden questionnaire
UK	United Kingdom
Workload	The self-care, treatment, and illness work combined with the work of recruiting and negotiating additional support

Chapter 1 Introduction

The introductory chapter of this thesis is an overview of the background concepts, theories utilised, and methodology. First, a background of the clinical context of chronic heart failure and current treatment pathways is provided. As the focus of this thesis is around the work that patients perform in living with and managing chronic illness the background on these concepts is also provided. Second, the three main theories which underpin the thesis and research work are introduced. The introduction chapter ends with an overview of the thesis outline, methodology, and justification of research methods.

1.1 Background: heart failure

Heart failure is defined as a syndrome related to an insufficiency of the heart structure or function to deliver adequate oxygenated blood to the tissues which require oxygen to function. Patients typically present with symptoms such as breathlessness, fatigue, and oedema McMurray, Adamopoulos, Anker (1). In 2018, Conrad, Judge, Tran (2) reported that in the past 12 years heart failure prevalence had increased by 23% in the United Kingdom (UK). Prevalence in the UK is estimated at a minimum of between 1-2% (3). Heart failure is responsible for the growing demand on healthcare systems, clinicians, patients and support networks. Heart failure, as the primary reason for hospital admission, is estimated at 5% of all acute hospital admissions and responsible for 2% (~£2 billion annually) of the National Health Service (NHS) budget (4). In addition to financial costs, heart failure is associated with poor outcomes, namely poor quality of life, and high mortality rates (3, 5).

1.1.1 Types of heart failure

Heart failure type is determined by measurement of left ventricular ejection fraction (LVEF), using echocardiography or other imaging techniques to phenotype the syndrome (3). LVEF is the measurement (expressed as a percentage) of the amount of blood pumped out to the body by the left ventricle in each heartbeat. Lower percentages equate to worse heart contractions (6).

The national audit of heart failure in the UK reports that 64% of heart failure cases have a reduced left ventricular ejection fraction (HFrEF) (5). The most common aetiology, in Western-type countries, for this type of heart failure is coronary artery disease. Other causes include previous viral infections, alcohol abuse, chemotherapy, and idiopathic dilated cardiomyopathy (including genetic derivations). There is good understanding of the pathologies and treatments for HFrEF (1, 3, 5).

Patients with heart failure may also have preserved or mildly reduced left ventricular ejection fraction (HFpEF/HFmrEF). Individuals with HFpEF/HFmrEF tend to be older, female, and obese compared to those with HFrEF. They are less likely to have coronary artery disease, instead, common aetiology tends to be hypertension and atrial fibrillation (1, 3, 5). Until the recent EMPEROR trial (7), which demonstrated the effectiveness of empagliflozin in this population, there was no strong evidence around the treatment of this type of heart failure, aside from the use of diuretics to alleviate symptoms of congestion (3).

1.1.2 Diagnosis of heart failure

The diagnosis of heart failure is difficult, with patients often presenting with vague symptoms (3, 8). Careful consideration of the signs and symptoms of heart failure and a careful medical history provide key clues that the person is more likely to have heart failure (i.e., previous history of myocardial infarction) and indicate referral to specialist secondary healthcare services. Under specialist care tests such as chest x-ray, echocardiogram, electrocardiogram, cardiac magnetic resonance imaging (MRI), and blood tests can illuminate treatable causes for heart failure and identify heart failure type (1, 3). In 2010 the National Institute for Health and Care Excellence (NICE) guidelines recommended the use of biomarkers (4), identified through blood samples, (B-type natriuretic peptide (BNP) and N-terminal pro-B-type natriuretic peptide (NT-proBNP) to provide an objective tool with diagnostic and prognostic value (3).

1.1.3 Treatment strategies in heart failure

Once diagnosed, treatment of heart failure is a combination of pharmaceutical agents, implantable cardiac devices, and self-care regimens dependent on the aetiology of heart failure, function and structure of a person’s heart, and their co-morbidities (1, 3).

Pharmaceutical treatments, for HFrEF, until 2021 were a combination of diuretics to relieve signs and symptoms of congestion, accompanied by beta-blockers, mineralocorticoid receptor agonist (MRA) and angiotensin receptor neprilysin inhibitors (ARNI) or angiotensin-converting enzyme inhibitors (ACE-I) or angiotensin receptor blockers (ARB) (1). From 2021 the four pillars of pharmaceutical treatments recommended in guidelines have included a) ACE-I/ARNI, b) beta-blockers, c) MRA, and d) sodium glucose co-transporter 2 inhibitor (SGLT2i) (3). Additionally, ivabradine can also be considered dependent on heart rate and persistence of symptoms. If patients still have signs and symptoms then they may also be considered for an implantable cardiac device (1, 3).

While HFmrEF treatment recommendations are the same as HFrEF, HFpEF treatments included the use of diuretics to reduce oedema and reduce breathlessness together with treatments for the underlying cardiac aetiologies (1). Treatment recommendations have been recently updated to include the use of SGLT2i's as it reduces both cardiovascular deaths and heart failure admissions (7).

Implantable cardiac devices typically considered for heart failure include implantable cardioverter-defibrillator (ICD) or cardiac resynchronization therapy (CRT). ICDs are implanted to reduce the risk of sudden cardiac death (common in heart failure). CRTs restore the timing of contraction of the left ventricle. In selected patients, CRTs reduce the risk of death and hospital admissions and improve symptoms and quality of life (1, 3).

Medical treatment pathways cover heart failure care across primary and secondary care services in the UK. Following diagnosis patients with HFrEF receive combinations of pharmaceutical treatments and may be considered for an implantable cardiac device. Those who have less stable or complex heart failure are seen by medical specialists, but as treatment options are exhausted or illness stabilises these individuals are progressively referred to heart failure specialists (doctors and nurses) in both secondary and primary care), and onward to general practitioners (GP's). In an email, the transformation officer from NHS Hampshire, AM Millard (Jan 24, 2022, unreferenced) confirmed that in the area where this study was undertaken there are limited commissioned specialist secondary care pathways for the care of patients with HFpEF. Care is delegated to GPs. Importantly, people with heart failure are also assigned self-care regimens and receive varying levels of support and education.

The phrase chronic heart failure (CHF), in this thesis, is defined as individuals with any type of heart failure for at least six months. The treatment of CHF includes both the acute management of CHF exacerbations as well as the long-term management of the syndrome.

1.1.4 Symptoms in heart failure

The symptoms of heart failure are often non-specific, so while they may encourage a person to seek medical attention, they may not help a clinician differentiate heart failure from other conditions. Typical symptoms include breathlessness, orthopnoea, paroxysmal nocturnal dyspnoea, reduced exercise tolerance, fatigue, and lower limb oedema. Other less common symptoms include cough, weight fluctuations, bloating, loss of appetite, confusion, depression, palpations, and syncope. Similarly, typical clinical signs (peripheral oedema, pulmonary crepitation's, tachycardia, reduced air entry to bases of lungs, and tachypnoea) of heart failure are also non-specific, disguised by pharmaceutical treatment for co-morbidities, or are difficult to identify in the presence of co-morbidities (obesity, old age, and chronic lung conditions). More specific clinical signs, like elevated jugular pressure and displacement of apical impulse, are harder to detect and frequently result in disagreement between healthcare professionals. The same signs and symptoms are used to monitor response to treatments, illness stability and progression by both clinicians and patients. Persistence of symptoms despite treatments usually indicates the need for additional therapies and the worsening of symptoms typically indicates a need for hospitalisation (1, 3).

1.1.4.1 Heart failure classification based on symptoms

For the past 100 years a simple subjective system of classification for heart failure, based on symptoms, has been used as a tool for risk stratification, clinical decision making, and eligibility for clinical trials (9). The New York Heart Association (NYHA) classification divides patients with CHF into four groups:

1) NYHA I: ordinary physical activity does not cause undue typical CHF symptoms (fatigue, breathlessness, etc.). There are no limitations to physical activity and usual activity.
2) NYHA II: ordinary physical activity causes some CHF symptoms (fatigue, breathlessness). There are slight limitations to physical activity and usual activity.
3) NYHA III: Less than ordinary activity causes typical CHF symptoms (fatigue, breathlessness). Physical activity is limited and only resting relieves symptoms. Usual activity is greatly reduced.
4) NYHA IV: All physical activity causes symptoms of CHF (fatigue, breathlessness), including resting. Physical activity increases symptom severity and any activity causes distress (10).

While biomarkers are helpful in the diagnosis of CHF, research does not currently support the routine use of biomarkers (BNP or NT-proBNP) as a tool to guide medical treatment adjustments (3). Thus, patients and clinicians still rely primarily on subjective signs and symptoms to guide their decision-making around treatment regimens. Recognizing symptoms, alongside monitoring and interpretation, remains challenging (11).

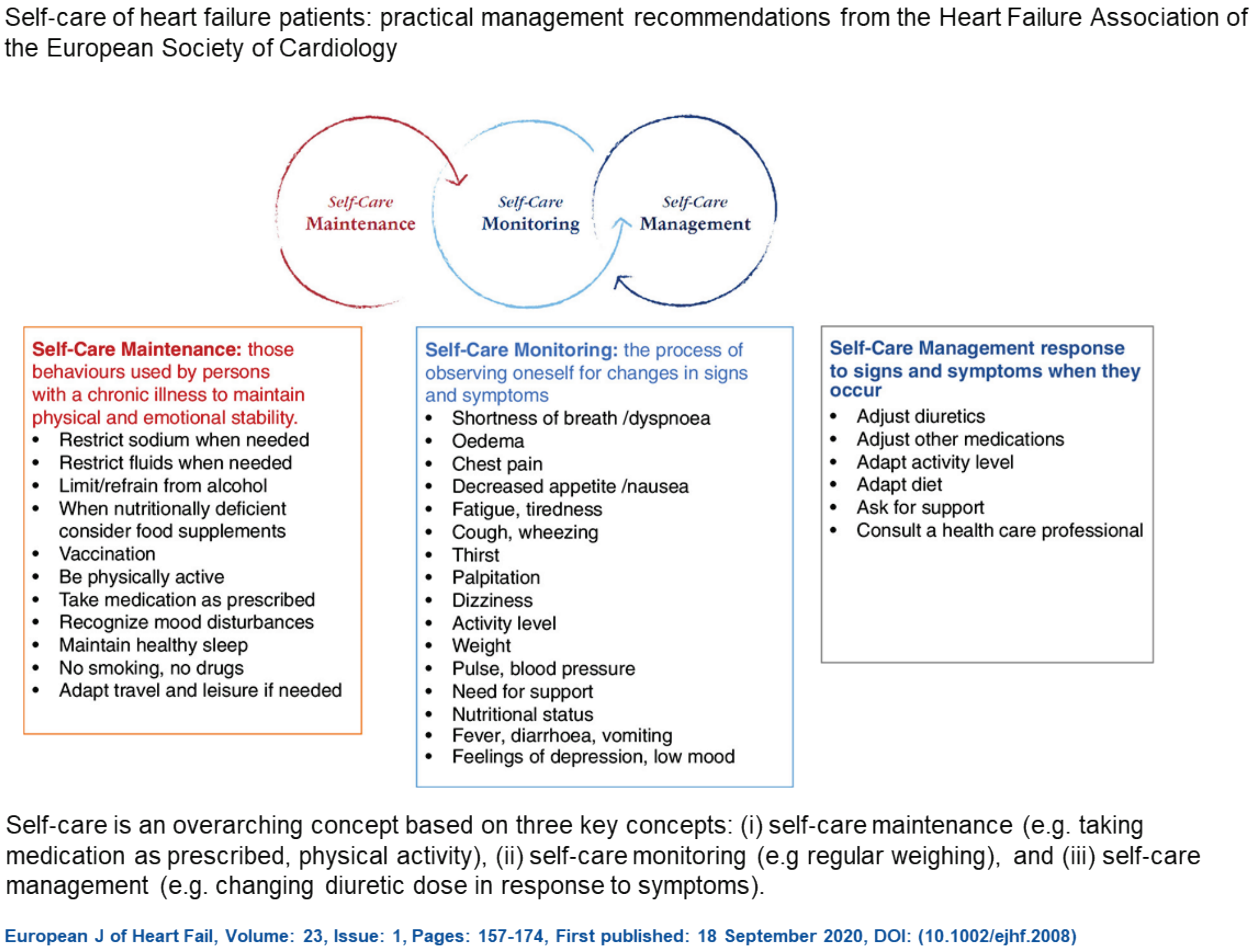
1.1.4.2 Burden of symptoms

Despite major advances in treating CHF in the past 5 years, with the addition of ARNIs and SGL2Ti mortality and morbidity remain high (12). Survival in those with CHF has improved due to pharmaceutical treatments but does not always alleviate symptoms. Symptoms of CHF are typically viewed by clinicians as a sign of disease progression or an indication for increasing treatments. CHF symptoms other than dyspnoea and oedema are often overlooked in clinical evaluations. Symptoms have been associated with poor quality of life (QoL), poor clinical outcomes, increased healthcare utilization, and decreased motivation to live (13). Symptoms create considerable burdens for both patients and healthcare systems (14). The impact on patients' QoL is so great that patients have said that they would rather trade survival for improvements in their quality of life (15, 16).

1.1.5 Self-care regimens in CHF

Self-care is an important part of CHF management and failures in self-care are thought to be contributors to rehospitalisation's and exacerbations of CHF. Engagement with self-care regimens has been associated with better quality of life and lower symptom burden (17). In the heart failure literature, self-care is most commonly linked to a definition which combines self-care maintenance, monitoring, and management (18, 19).

Jaarsma, Hill, Bayes-Genis (20) created a practical guideline for healthcare professionals and patients outlining what is involved in CHF self-care (Figure 1). Typical self-care tasks assigned by healthcare professionals include: taking medications, attending and coordinating healthcare appointments, learning about health conditions, symptom monitoring, symptom evaluation, adjusting treatments or seeking urgent healthcare support in response to changes in symptoms, and enacting lifestyle behaviours (smoking cessation, reduction in alcohol consumption, dietary alterations, weight control, and exercise) (20).



Self-care of heart failure patients: practical management recommendations from the Heart Failure Association of the European Society of Cardiology

Self-Care Maintenance: those behaviours used by persons with a chronic illness to maintain physical and emotional stability.

- Restrict sodium when needed
- Restrict fluids when needed
- Limit/refrain from alcohol
- When nutritionally deficient consider food supplements
- Vaccination
- Be physically active
- Take medication as prescribed
- Recognize mood disturbances
- Maintain healthy sleep
- No smoking, no drugs
- Adapt travel and leisure if needed

Self-Care Monitoring: the process of observing oneself for changes in signs and symptoms

- Shortness of breath /dyspnoea
- Oedema
- Chest pain
- Decreased appetite /nausea
- Fatigue, tiredness
- Cough, wheezing
- Thirst
- Palpitation
- Dizziness
- Activity level
- Weight
- Pulse, blood pressure
- Need for support
- Nutritional status
- Fever, diarrhoea, vomiting
- Feelings of depression, low mood

Self-Care Management response to signs and symptoms when they occur

- Adjust diuretics
- Adjust other medications
- Adapt activity level
- Adapt diet
- Ask for support
- Consult a health care professional

Self-care is an overarching concept based on three key concepts: (i) self-care maintenance (e.g. taking medication as prescribed, physical activity), (ii) self-care monitoring (e.g regular weighing), and (iii) self-care management (e.g. changing diuretic dose in response to symptoms).

European J of Heart Fail, Volume: 23, Issue: 1, Pages: 157-174, First published: 18 September 2020, DOI: (10.1002/ejhf.2008)

Figure 1: Overview of self-care concepts and associated tasks. From Jaarsma et al (20), and reproduced with permission (license number 5250700040223).

People with CHF are commonly reported to fail to adhere to self-care regimens which are thought to contribute to worsening outcomes and poor quality of life (17, 21-23). Yet, there is limited evidence which clearly outlines the positive effect of these regimens on patient or clinical outcomes (24, 25). Self-care abilities may vary between patients, where main contributing factors are thought to be cognitive status, health literacy, depression, and self-confidence or self-efficacy (26).

Self-care in this thesis will be defined as tasks both assigned to, and assumed by patients, including tasks typically included in self-care maintenance, monitoring, and management, as defined in the theory of self-care in chronic illness.

1.2 Background: work of illness and treatment

The primary focus of the NHS, since its inception, has been on preventative and curative health services (27); which has led to improved survival from acute health crises and an increasing prevalence of non-communicable diseases (NCD) requiring chronic illness management strategies (28). Cardiovascular diseases, including CHF, are the dominant contributors to both global burden and NCD deaths (~17.9 million people annually) (29). When assessing the effectiveness of global healthcare provision and prevention for NCD, Alwan, MacLean, Riley (30) argued the management of NCDs was insufficient.

The overwhelming demand on healthcare systems created by ageing and the rising prevalence of chronic illnesses or NCD (31), led to a shifting of responsibility for health outcomes. While healthcare providers retained their expertise, they were required to both educate and acknowledge patients had personal expertise arising from their illness experience. Patients' expertise and their newly gained knowledge imparted by doctors were argued to give patients the knowledge they needed to engage in the required work of illness management (32). Ever increasingly, including the resultant effect of the Covid-19 pandemic, patients are expected to assume greater responsibility for work associated with managing illness, with follow-up appointments to be patient initiated (33).

The current healthcare system in the UK assigns the bulk of chronic illness management to patients through self-care regimens. A better understanding of the work involved in self-care regimens in CHF understanding illness work is essential.

1.2.1 Work of illness

Strauss, Fagerhaugh, Suczek (34) were the first to detail the social demands inherent in the experience of chronic illness as work. Participation in healthcare, related to illness or its treatment, was viewed as work. Initially describing the work of patients in a hospital, but in the following years Anselm Strauss and Juliet Corbin went on to describe the work of chronic illness at home (35). They outlined patient work as three types: illness work, everyday life work, and biographical work. Illness work was defined as tasks that resulted in illness crisis prevention and management, symptom management, and diagnostic related work. Which has similarities to the components of the self-care theory of chronic illness (Figure 1). Everyday life work was defined as all of the tasks normally performed at home (e.g., housekeeping, leisure activities, employment, etc.). Finally, biographical work was described as the consequential alteration to a personal biography or life story resultant from alterations due to illness. Pathophysiological alterations or symptoms from chronic illness result in alterations to abilities, forming the impetus for the reframing of a personal biography (35). For example, if breathless when walking from the kitchen to the lounge, it follows that a person disengages from the rambling group. If that person saw being a rambler as part of their identity, this would now need to be reframed; I used to be a rambler, but not anymore.

Kathy Charmaz (36) described how the suffering associated with chronic illness alters an individual's identity. She describes how suffering is more than the common clinical view of suffering (physical, mental, and emotional symptoms together with iatrogenic treatment side-effects) and includes the loss of a person's self-image causing further suffering characterised by living limited lives, social isolation, stigmatisation, and becoming a burdensome dependent (36). The alteration in personal biography due to alterations in one's capabilities requires that the chronically ill negotiate additional support to complete the work of illness and everyday life.

Corbin and Strauss (35) outlined the concept that patients would need to access resources, external to themselves, to match the demands of this work. Resources could be material (e.g., physical environment, finances, healthcare systems, etc.) or affective (e.g., social support structures, emotional support of family and friends, etc.) (35). The work of these authors provided a foundation for the formulation of the burden of treatment theory.

The concept of *living with chronic illness* emerged in Strauss's work around addressing the psychosocial aspects of illness (34) and further was linked to identity by Charmaz (37). More recently a concept analysis, which examined 36 qualitative articles exploring the experience of living with chronic illness (38), defined the concept of living with chronic illness. Ambrosio, Senosiain Garcia (38) defined it as a complex and dynamic process with multiple attributes (acceptance, coping, self-management, integration, and adjustment) which results in four different ways of living; a) disavowal, b) false normality, c) the new normal, and d) disruption where the desired outcome is the achievement of positive living. They described a process where personal antecedents (personal networks, awareness, attitudes, knowledge and education) informed the attributes of how a patient embodies one of four ways of living with chronic illness. The desired outcome of positive living has the consequences of the patient experiencing a degree of control, mastery, balance and normality which impacts on quality of life and well-being. The characterisation of this concept led to a body of research leading to the creation and refinement of a patient reported outcome measure evaluating the specific way of living a patient with chronic illness has embodied (39, 40). This tool has been tested and refined in multiple conditions including heart failure (41-44). The focus of this thesis is on exploring the interaction of symptoms of CHF on a patient's BoT and the intensity of treatment burden associated with performing self-care work, rather than the psychosocial experience of illness. Therefore, this concept was not included as a foundational theory, but it is acknowledged that this concept is a key component of patients' illness experience.

1.2.2 Work of treatment

Apportioning the responsibility and work associated with illness management to the patient (or members of the public) is argued to be related to the inadequacy of health care systems to meet the overwhelming demand for chronic NCD, including cardiovascular disease (31, 32). The shift of this responsibility to patients led to a rise in the ideas around self-management. From the late 1990's NHS England embraced the ideas behind self-management as they were cheaper and believed to lead to a population engaged in the management of their health (32). It was postulated that activated patients are flexible, empowered with self-efficacy and readily engaged in self-care. Activated patients result in people with improved health experiences and health status who also do not utilize healthcare services (32).

In 2001 the expert patients programme was established by the Department of Health in England. It was designed to tackle the overwhelming demand of chronic illness by increasing self-care and self-management strategies through the activation of expert patients (31, 32). Thus, responsibility for effective self-care would be delegated to patients while only very complex cases would be managed by healthcare professionals. The success of this model is debated widely (31, 32), but the principles are infused in the policy and practice relating to long-term conditions.

Although there have been alterations to the frameworks around self-management, the underlying assumption remains the same. Patients (expert or novice) require the right motivation, approach and education to become self-efficacious (31, 32). Albert Bandura stated that gaining self-efficacy was related to an individual’s perception of their capabilities. He defined self-efficacy as:

> “people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives. Self-efficacy beliefs determine how people feel, think, motivate themselves and behave. (…) A strong sense of efficacy enhances human accomplishment and personal well-being in many ways. People with high assurance in their capabilities approach difficult tasks as challenges to be mastered rather than as threats to be avoided. (…) They quickly recover their sense of efficacy after failures or setbacks. They attribute failure to insufficient effort or deficient knowledge and skills which are acquirable. They approach threatening situations with assurance that they can exercise control over them. (…)
>
> In contrast, people who doubt their capabilities shy away from difficult tasks which they view as personal threats. They have low aspirations and weak commitment to the goals they choose to pursue. When faced with difficult tasks, they dwell on their personal deficiencies, the obstacles they will encounter, and all kinds of adverse outcomes rather than concentrate on how to perform successfully. They slacken their efforts and give up quickly in the face of difficulties. They are slow to recover their sense of efficacy following failure or setbacks. Because they view insufficient performance as deficient aptitude it does not require much failure for them to lose faith in their capabilities. They fall easy victim to stress and depression.” (45 p. 2)

In Bandura’s definition of self-efficacy, illness effects are not explicitly considered. Stressors are discussed in terms of challenges in personal development, lifestyle or behaviour choices, and/or creative and intellectual outputs. When faced with a stressor or challenge Bandura proposes that results in perseverance if self-efficacy is strong. Failures are attributed to a lack of motivation or knowledge, by those with strong self-efficacy. Alternatively, those with a self-perceived low self-efficacy view stressors and challenges as threats, focusing on personal deficiencies and adverse events rather than the steps required to complete the difficult task. He describes how the decrease in physical capabilities, due to ageing, can be offset or balanced through a strong sense of self-efficacy through a compensatory action of one’s knowledge, skills, and expertise (45). Underpinning self-care frameworks and theories is the concept that self-efficacious individuals can obtain positive outcomes when faced with a stressor, providing they have a positive outlook, are motivated, and have sufficient knowledge. But there is little acknowledgement as to how illness acts on self-efficacy and thus influences self-care work.

Rogers, Bury (32) have argued that self-care (or management) was adopted in the UK in response to rising costs and demand on healthcare from an ageing population. Through the normative expectations that patients are experts in living with their illness, the principles of self-efficacy and naturalistic decision-making processes facilitated a shift of responsibility for the work of illness management onto patients. Healthcare professionals via health education programmes could empower patients to successfully manage their condition through health promotion practices. This idea is reliant on the belief that if a patient engages in their self-care work, they will experience a positive benefit; thus, reinforcing the practice. However, there was wide variability in both patient expertise and healthcare professionals' willingness to accept patient expertise (32). To date, effective self-care interventions based on these ideas remain popular, yet the evidence of their effectiveness in obtaining the goals of improved outcomes for patients with heart failure is not clear (21, 24, 46). Clinicians in CHF care and the literature around CHF commonly report people with CHF fail to adhere to self-care regimens – often citing poor patient motivation and health literacy (32) – which is linked to hospital readmissions and poor outcomes (21, 47, 48). Interventions to improve self-care are thus often focused on resolving patient motivation, increasing self-monitoring and improving health literacy. Those interventions have had mixed results (21, 24, 26, 47, 49). The role of self-care work and the burden self-care places on patients receives limited attention within self-care literature.

The underpinning concepts (self-efficacy and patients as experts) informing the delegation of self-care work neglects to acknowledge the difficult work of both being ill together with the difficulty of performing the work assigned by healthcare professionals (50). The idea of treatment burden proposed by May, Montori, and Mair, in 2009, argues chronic illness creates unavoidable burden compounded by the burden associated with treatments related to the illness (51). They propose reasons for non-adherence are complex, and not limited to the typical apportioning of blame on patients' poor motivation and health literacy. Instead, they argue patients may not be alone in the culpability of self-care failures. Healthcare services may also contribute to structurally induced non-adherence for some patients with chronic illness. Their resultant call is for "minimally disruptive medicine", which proposes a more collaborative approach to healthcare where together patient priorities and abilities are matched with proposed treatment regimens. Minimally disruptive medicine takes into account the delegated workload and its burden and thinks about how that workload can be reduced by accounting for patient priorities, clinical care coordination and comorbidities (51, 52).

The definition of treatment burden has been expanded through further research. It includes the impact associated with the work of being a patient together with the actions and resources which patients devote to their healthcare (53). Illness work associated with treatment has inherent financial, time and travel, medication, and healthcare access burden (54). Treatment burden is compounded by multi-morbidity (55). Failing to consider treatment burden leads to multiple adverse outcomes; increased hospitalisations, increased mortality rates and poor quality of life (51, 56-63), which are concurrently prevalent in heart failure (22). Healthcare services and care pathways have been noted to influence treatment burden (64-66).

The concepts of self-care and treatment burden may seem opposed to each other. While both have a similar goal – to increase patient engagement and improve clinical outcomes – their viewpoints on a patient's role in achieving this goal are divergent. Apart from the acknowledgement that limitations resulting from illness may contribute to the work of illness in biographical work, neither of these concepts appear to fully consider how the pathophysiological effects of either illness or its treatment might influence the goal of improved health outcomes.

1.3 Theories that informed the foundation of my thesis

1.3.1 Theory of self-care in heart failure

While multiple self-care theories, definitions and frameworks exist around NCDs and chronic illness (67) as the focus of this thesis is CHF, I will focus on those aimed specifically around heart failure or underpinned by research in heart failure. There are two major self-care theories which inform each other as well as the majority of the research and clinical guidelines around self-care in heart failure.

1.3.1.1 Situation-specific theory of heart failure self-care

In 2008 Riegel and Dickson (18), described a situation-specific theory based on research in heart failure populations. Together with other self-care research in palliative, cancer, and health promotion; they built a conceptual model that provides a more concrete description of clinical phenomena in heart failure. Initially, they defined self-care as:

> A naturalistic decision-making process involving the choice of behaviours that maintain physiologic stability (maintenance) and the response to symptoms when they occur (management) (18).

Important to note, naturalistic decision-making is a description of how people make high-stakes decisions. Originally based on research from professionals in high-stakes careers (e.g., military commanders, medics, nurses, pilots, etc.), it is a real-world knowledge based decision-making approach, where the individual making the decision has substantial experience, the ability to perceive and recognise prior situations to generate an appropriate response from more than just a list of choices (68). This ties in with the expert patient programme in the UK (32) and reinforced the placement of responsibility for chronic illness management on ill people.

Riegel and Dickson (18) proposed that self-care maintenance, which involves symptom monitoring and treatment adherence, is interconnected with self-care management, a process initiated by symptom evaluation leading to treatment implementation and evaluation. A third concept, self-care confidence, was proposed to both mediate and/or moderate various outcomes as an effect of self-care (18). The theory was built around the development of a tool (self-care of heart failure index) which measures self-care in heart failure (69) and data from studies which utilise this tool was then used to test and refine the theory (18). The theory was tested and refined through psychometric testing (70) and individual theory propositions that influence self-care ability, tested with empirical research techniques:

- symptom recognition – randomised control trial (RCT) (71)
- knowledge and skill – mixed methods study (72)
- experience/expertise – mixed methods and RCT (72-74)
- personal values – mixed methods study (72)
- confidence as a moderator – RCT (74) and longitudinal retrospective analysis (75)
- Confidence as a mediator – cross-sectional data (18)

The situation-specific theory of heart failure self-care was updated in 2016 (76). There were three major changes to this theory. The revisions were based on multiple research studies that further explored and refined the following concepts:

- symptom perception – mixed methods (77, 78), pilot study (79), secondary analysis of registry data (80), survey or observational study (81, 82)
- naturalistic decision-making process and influencing factors (experience, knowledge, skill, compatibility with values, ethnicity, health literacy, cultural identity, socioeconomic status, self-efficacy, multimorbidity, physical functioning, emotional support and other support structures) – descriptive study (83-97), mixed methods (72, 98-100), editorial (101), literature review (102-105), RCT (106), pilot study (107), secondary meta-analysis (108-110), qualitative study (111-113), qualitative meta-analysis (114), secondary analysis (115, 116).

Firstly, Riegel, Dickson (76) added a third major concept of symptom perception, defined as a combination of tasks including monitoring, recognition, interpretation, and labelling of symptoms alongside body listening. Symptom perception is proposed as a building block between self-care maintenance and management, which build on each other as part of the self-care process. Second, they added the distinction that self-care behaviour can be a combination of individual (autonomous) decisions (e.g., I am breathless walking upstairs, so I limit the number of times I climb the stairs) and decisions made after discussion (consultative) with family members, carers, or healthcare professionals. Their theory states all concepts of self-care will have elements of autonomous or consultative decision-making.

Secondly, their revised theory is stated to be more closely integrated with naturalistic decision-making in all of the concepts of self-care. They suggested that while typically the decision-making process should flow from the situation (i.e., the person with CHF, their problem and their environment) which is then integrated with the process (i.e., their experience, knowledge, skills, and values) to enable a decision on the individual action required (i.e., self-care maintenance, symptom perception, and self-care management). In heart failure, they propose the decision-making process can be non-linear and/or multi-directional, meaning that positive outcomes from effective treatment and regular healthcare appointments may alter the person making it more likely that they will continue to act in accordance with healthcare professionals' guidance.

The theory of heart failure self-care suggests that patients who engage with self-care tasks will experience improvement in their lived experience, motivating patients to continue and expand these behaviours as their health knowledge and illness experiences progress. But in a systematic literature review of articles that mentioned the situation-specific theory of heart failure (n=85) it was illustrated that while many people are referencing the theory it is not being tested (in its entirety) nor is it used in consistently clinical practice (76).

1.3.1.2 Middle-range theory of self-care in chronic illness

The middle-range theory of self-care in chronic illness, first described in 2012, is the process of maintaining and managing chronic illness, developed from observations in clinical heart failure practice (19). The definition of self-care does not differ from the situation-specific theory of heart failure self-care. The theory aims to better describe self-care practices used by those with chronic illness to identify areas where patients struggle to inform intervention development with the purpose of improving outcomes and engagement with self-care. The three main concepts of self-care theory in chronic illness are self-care maintenance, monitoring, and management. Self-care maintenance are behaviours used by patients to maintain stability in physical and emotional health, including behaviours initiated by the individual or recommended/assigned by healthcare providers. Self-care maintenance is typically viewed as behaviours that promote health through lifestyle choices and adherence to treatment regimens. Self-care monitoring was described as the process of self-observation for indications of changes in illness (signs and symptoms). Humans often engage in this behaviour automatically regardless of illness, e.g., 'I weigh more after Christmas'. In the context of illness, they propose that three criteria must be true for effective monitoring: a) there must be clinically relevant changes over time for the health condition, b) a reliable method of measuring change must exist, and c) a reasonable response must be possible. Symptom recognition and perception are key in self-care monitoring. Self-care management is the action that an individual takes in response to observed changes in signs and symptoms (19). Riegel, Jaarsma (19) state that using a combination of naturalist decision-making, as defined above (page 10), and a reflection by those who are chronically ill results in four individual types. These are, a) low knowledge poor self-care engagement, i.e., they do not understand the rationale of self-care therefore they perform very few self-care tasks, b) low knowledge good self-care engagement, i.e., despite not understanding self-care they still perform the task but do so in an unobservant manner leaving them aware of changes but unable to respond to those changes, c) good knowledge poor self-care engagement, i.e., they know what to do but choose not to perform self-care tasks, or d) good knowledge good self-care engagement, i.e., they understand the rationale of self-care and the tasks required of them and the actively engage in these tasks resulting in better health and less burden on healthcare systems. The fourth individual type is considered to be the ideal (19).

The theory of self-care in chronic illness acknowledges multiple factors may influence self-care including personal internal factors (e.g., experience, motivation, confidence, etc.) and external factors (e.g., support from others and access to healthcare). Internal factors include the functional and cognitive abilities of the person, but the theory focuses on the lack of knowledge and motivation to justify poor self-care in heart failure (20).

In 2019, Riegel, Jaarsma, Lee (117), updated their theory by describing how symptoms of CHF might interact with self-care. They concluded that symptoms experienced in CHF will build skills in self-care. Symptoms as either antecedents (encouraging engagement with self-care) or consequences (improved patient and/or clinical outcomes). While they mention that symptoms like depression or cognitive dysfunction may blunt a patient's motivation to engage in self-care, there is scant consideration to the effect of illness on the individual or treatment burden resulting from self-care engagement (117).

The self-care theories described have provided the foundation of many qualitative and quantitative research projects aimed at improving self-care in patients with CHF. There remains little conclusive evidence that interventions utilising this theory result in improvements in self-care in CHF. Self-care theories also appear to assume that engagement in these tasks will result in an improved experience for CHF patients. However, in my clinical experience, I observed how adherence to CHF self-care regimens can cause harm (e.g., kidney damage, hypotensive falls) as well as encourage self-isolation due to low self-value and side effects of treatments. Inferring a gap between that the processes described in self-care theories and the CHF patient experience. The introduction of the ideas around the work of illness and treatment offered an alternative way to explore the CHF patient experience. Burden of treatment theory offered a patient focused framework to view the work associated with illness.

1.3.2 Burden of treatment theory

In clinical heart failure literature, burden associated with CHF traditionally describes the burden of CHF on the healthcare system, with some acknowledgement of morbidity and poor QoL that patients experience (14). However, this is not the burden that will be discussed in this thesis. Instead, burden will be considered from the sociological notions of patient work developed by Strauss, Fagerhaugh (34) and developed into the burden of treatment theory by May, Eton, Boehmer (118)

The work of treatment as introduced in section 1.2 and was the beginning of the concept that treatment is burdensome from a sociological viewpoint. Research has now highlighted that in CHF treatment burden includes the work outlined in the theories of self-care, being that of knowledge acquisition about treatments, taking medications, altering lifestyle behaviours and appraising treatments (59, 63, 119). Different from the theory of self-care, treatment burden highlighted there was additional patient work required around negotiating and coordinating help from others to engage with self-care regimens (59). Treatment burden research, in CHF, illuminated that multiple treatments/medications, poor communication from healthcare professionals together with the lack of accessible care services, and complex siloed healthcare organizations increased patients' treatment burdens (59, 63, 119).

Research on treatment burden in CHF as well as other chronic illnesses has helped to inform Burden of Treatment (BoT) theory. BoT theory was developed from analyses of organisational changes and delivery of care and has since been applied to various chronic illnesses. It recognises there is a difference between the treatment burden described by Strauss (34, 35) which focused on the interactions, identities, and social meaning of symptoms. As compared to the definition of treatment burden associated with the continual expansion of delegated chronic illness treatment and medical work into domestic life, together with the erosion of the patient relationship with healthcare professionals (120-122).

BoT theory describes the delicate balance between *workload* associated with managing illness and its treatments together with the resources or *capacity*, both internal or external to the individual, to perform the work of treatment (118). The *impact* of performing that work together with the impact of illness on one's identity. Theories undergo a continual refinement process. Thus, the domains of BoT theory will be discussed both in relation to the original definition, as well as how other researchers both informed and refined these ideas to formulate the definitions used in this thesis.

1.3.2.1 Workload

In 2012 Eton, Ramalho de Oliveira (58), defined workload as "the demands made on a patient's time and energy due to treatment for a condition(s) as well as other aspects of self-care" (58 p. 40). In BoT theory, workload is categorised as both the work associated with mobilization around delegated tasks and the enactment of those tasks, incorporating both the individual and collective work that self-care in chronic illness necessitates. The specifics of what this work entails, listed below, are supported by research on treatment burden, where treatment burden is considered the workload of healthcare (55, 63-66, 123-129):

- learning about illness(es) and its progression together with treatment(s) and their consequences
- treatment and medication adherence (self-care maintenance: Figure 1)
- enactment of lifestyle behaviour changes (self-care maintenance: Figure 1)
- monitoring of symptoms and evaluation of treatments and self-care regimens (self-care monitoring and management: Figure 1)
- accessing and attending healthcare services (self-care management: Figure 1)
- acquisition and coordination of support from social support networks
- biographical work due to the impact of illness and its treatments

Some of this work is also included in self-care theories, but not all. BoT theory mentions that symptoms will impact on an individual's functional performance, altering their personal capacity, but it does not expand on the nature of the interaction between symptoms and workload. In this thesis, workload is defined as the self-care, and illness workloads combined with the work of recruiting and negotiating extra support.

1.3.2.2 Capacity

Contrary to clinical environments where capacity is typically viewed as an individual's mental capacity to comprehend and consent to treatment, BoT theory defines capacity as a complex and dynamic concept. Shippee, Shah (62), in their cumulative complexity model, defined capacity as abilities (physical/mental functioning, literacy and attitudes/beliefs), resources (socioeconomic and social support) and readiness to manage the work associated with treatments. BoT theory describes capacity as comprised of resources, both internal and external to the patient. Patient agency (things that are done to engage in illness management and with people within their support structures) is influenced by the pathophysiological, psychological, and social illness process. Those processes limit a person's internal capability meaning they need to rely on those within their support structure to aid in the performance of illness management, requiring them to build and negotiate relationships which will increase their capacity through the delegation of illness work. Those social support structures include family, friends, illness support groups, and importantly healthcare professionals. When help is required, patients rely on a combination of informal support or caregiving from family and friends, in addition to the support provided by healthcare services in advising, managing, or treating illness (118). Boehmer, Gionfriddo (126) in describing capacity in chronic illness, described similar concepts but added a description of how the reframing of personal biography, in terms of diagnosis and treatments, impacted on the individual enabling greater utilization of more components of capacity. While capacity remains a complex idea, in general, it is typically described as a combination of (62, 64-66, 118, 127, 130, 131):

- personal physical, mental, emotional, and spiritual abilities/capabilities
- resources: socioeconomic status, literacy, social support network, informal caregivers, healthcare systems and practitioners, finances, life workload, environment, society perception of illness
- personal resilience and adaptability to reframe personal biographies and relationships

To date, the influence of symptoms on capacity has been limited to describing a decrease in an individual's capabilities to do the work of treatment (65, 66, 118). In this thesis, capacity was defined as the combination of internal capabilities together with accessible and available external resources. Where internal capabilities were defined as physical, mental, emotional and spiritual abilities and external resources as social, financial, environmental, and accessible healthcare services.

1.3.2.3 Impact

First described as “reciprocal impact” in 1985, where the work of managing illness and living with illness has consequences on the individual’s biographical work or vice versa (35). For example, diuretic pills increase urinary frequency but also decrease breathlessness, when taken patients tend to self-isolate out of fear of having accidental incontinence. Alternatively, a patient might happily take heart medications which may cause iatrogenic harm to their kidneys. As that same medication is thought to be a wonder drug, adding more days to his life. The patient wishes to see a grandchild grow and develop so he is willing to risk kidney damage to improve the chances of being present in the grandchild’s life. In 2012, Eton, Ramalho de Oliveira (58) defined further impact as “the effect that the workload has on the patients behavioural, cognitive, physical and psychosocial wellbeing” (58 p. 40). May, Eton (118) paper introducing BoT theory, proposes when workload exceeds capacity patients then engage in relational work making adaptations to their personal biographies, regaining the balance between workload and capacity. Thus, workload may affect patients’ sense of self as well as requiring increases to the workload of negotiating and organizing assistance. Demain, Goncalves (127) described how treatment and its negative side effects were experienced as a disruption by patients with chronic illness. The disruptions impacted both personal biographies and how they related to friends and family. If those disruptions were considered unacceptable then patients would make rational decisions to adapt treatment regimens or justify non-adherence (127).

For this thesis impact was defined as the alteration of oneself or their role due to the capacity to engage in workload.

1.4 Thesis outline and methods

1.4.1 Thesis research question

How do the symptoms experienced in heart failure interact with burden of treatment?

1.4.2 Thesis aim

The aim is to identify, characterise, and explain any observed interaction or influence symptoms of heart failure have on any of the domains of burden of treatment.

1.4.3 Thesis objectives

1. To examine if symptoms of chronic heart failure interact with any of the domains of burden of treatment
2. To identify, characterise, and explain the nature of any observed interactions between symptoms and burden of treatment
3. To refine the concept of burden of treatment and its associated theory considering specific associations with symptoms and/or chronic heart failure
4. To build an empirically informed conceptual model to explain observed interactions between symptoms, chronic heart failure, and burden of treatment
5. To identify modifiable factors which may be used for the creation of future patient focused interventions in chronic heart failure which aim to alleviate burden of treatment.

1.4.4 Thesis overview and paper descriptions

A Doctor of Philosophy (PhD) by publication requires the author to present a minimum of 3 publishable or published papers which together tell a singular story. The six papers included here are integrated to produce a cohesive story leading to a singular conclusion which would not be possible without the multiple publications. The papers include:

1. An editorial, introducing the main theories included in this thesis, together with the proposed interactions of symptoms in CHF with the components included in both self-care and BoT theories (132).
2. A research protocol paper outlining the research design for the body of empirical research work (133).
3. A qualitative evidence synthesis paper which demonstrated that symptoms in heart failure do interact with various domains of burden of treatment and described the nature of those interactions (134).
4. A results paper from a multi-centre survey of patients with chronic heart failure. Describing the population surveyed, this paper also explores the interaction between symptoms and burden of treatment measured by validated questionnaires (135).
5. A results paper from a series of semi-structured interviews from a sub-sample of the survey population. Participants’ opinions and beliefs about the interaction between symptoms and BoT were identified, described, and explained with particular reference to unexpected findings of the survey (136).

6. A model building paper integrating the results from the above papers together with other research results that offers a CHF specific BoT theory (Chapter 7: *unpublished, but in publishable format*).

The doctoral work presented within this thesis will demonstrate how, like a jigsaw, the individual papers fit together. Each paper builds on the previous paper where the ideas, results or findings help increase understanding of how symptoms of CHF interact with BoT, which would not have been possible if only a single piece of work was examined (Figure 2).

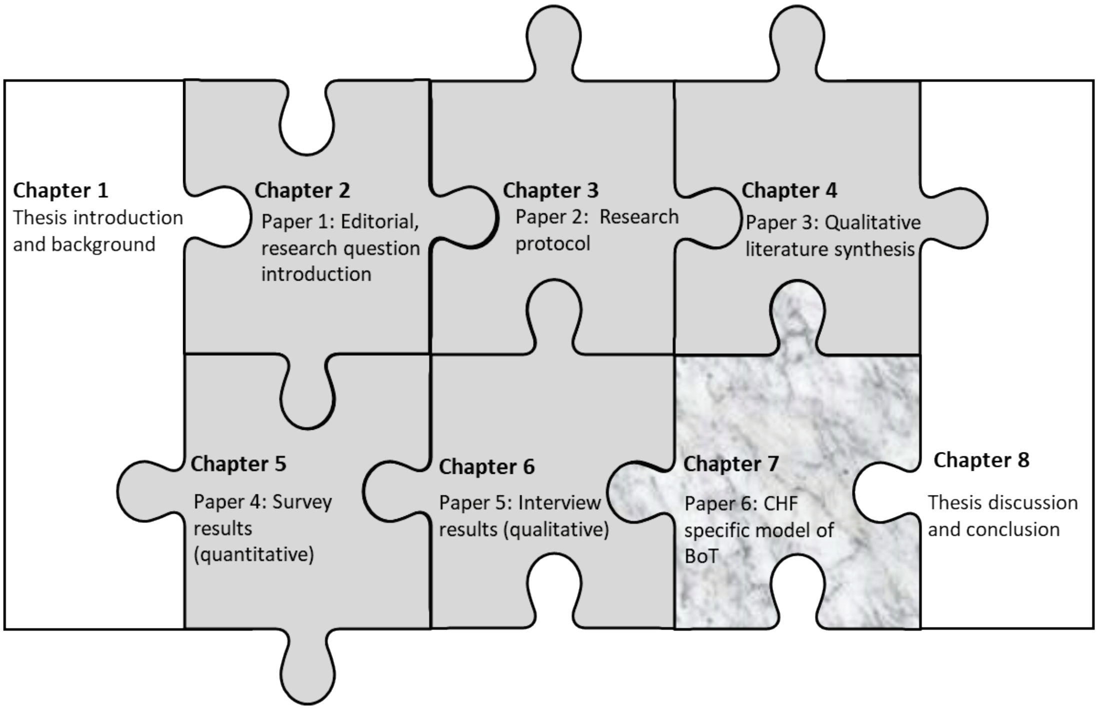


Figure 2: Thesis structure overview. White puzzle pieces represent chapters specifically written for the thesis, grey puzzle pieces represent work published or submitted to a journal, and the textured grey puzzle piece represents work in a publishable format, but not submitted for publication consideration.

1.4.5 Thesis methodology

1.4.5.1 My personal position

I am a Caucasian, Canadian, female nurse in my early forties. I have worked as a nurse in three countries (Canada, Australia, and England) with varying degrees of socialised healthcare systems. I have nursing experience ranging from emergency departments and intensive care units at varying levels of seniority. As a research nurse, I have worked within the English NHS in dermatology, renal transplant, and cardiology. I have extensive experience in research delivery. My clinical expertise is both as a research nurse and in cardiology, with a special interest in heart failure. These experiences and levels of expertise have influenced my approach to research design, data collection and analysis. Undoubtedly, the way I was trained as a nurse together with my personal characteristics, have shaped what I believe truth is and how knowledge is formulated. Throughout this thesis, I iteratively and reflexively, considered how these thoughts were influencing my decisions; from research design and data collection to my interpretations of data and dissemination. Throughout my doctoral work, my thoughts on the importance of epistemology and ontology shifted as well as my beliefs about the role of patients in failures to engage in self-care.

1.4.5.2 My foundational ontology and epistemology

The majority of my beliefs about what constituted knowledge centred on deductive approaches. My foundations of how I believed knowledge to be formed were positivist. Positivism argues that knowledge is formed by working deductively from observation through to formulation and testing of a hypothesis reality will be discovered (137). A positivist would argue that the researcher and environment being studied are separate and that knowledge or truth is an external reality independent of the researcher. Suggesting that observations in research, reflect the observable reality (137). However, positivism did not reflect my experience as a nurse.

I had seen multiple times how the experience of people with various medical conditions had defied current knowledge based on positivist research. Instead, I believed that while knowledge based on positivist research held a degree of truth; as it focuses heavily on the “normal” or average response there might be other truths not represented in positivist research (138). I believe at this stage my ideas were more closely related to those around critical realism. Critical realism proposes that knowledge is a combination of multiple realities. Knowledge is a combination of what is known but may not always be observable; what is observable and the necessary preconditions for the observable. Another key component of critical realism is it seeks to go beyond measuring and tries to understand why that phenomenon was observed (139). Merging these two philosophies, positivism and critical realism, helped me to rationalise my observation of CHF patients not engaging in self-care. My clinical observation that CHF symptoms were interfering with a patient’s engagement with self-care despite providing health education, was their lived experience and what I believed was their truth. The common theories of self-care were the established knowledge or evidenced-based truth. This truth informed me that if I educated the patient, they would then engage in their self-care. Contrary to the observed patient truth where despite education self-care engagement remained poor. Thus, I had two truths which did not appear to relate to each other. The only way I could justify this was that perhaps both phenomena were true, but there was a missing piece of the puzzle which would elucidate how both could be true.

The positivist way of knowing is through deductive knowledge built by starting with an established theory or relationships, which are broken up into smaller components (variables) to be tested in a reproducible manner. The focus is the formulation of a testable hypothesis through observations of measurable variables, and analysis of data to formulate conclusions. But the critical realism way of knowing encourages acknowledging other ways of knowing are possible. Inductive knowledge formation starts with an observation and discovers recurrent relationships within that phenomenon. The focus is on exploring and understanding through iterative refinement of the phenomena of interest until a theory is formulated (140).

The philosophical positions of these two types of knowledge formation are argued to be diametrically opposed and yet mixed methodology research encompasses utilising methods from both these philosophies. I believed my research question (section 1.4.1), would require a combination of both deductive methods and inductive methods, thus falling into a mixed methodology level of reasoning.

In 2010 Feilzer (141) wrote a paper which became my guide when thinking about mixed methods. She proposed a pragmatic approach which aligned with my belief that truth might be found through different ways of knowing. A pragmatist views the measurable world as closer to the version of reality described by Dewey (142), who saw reality as a world based on experiences that could be objective, subjective, or both. Justifying the use of both inductive and deductive ways of obtaining knowledge and aligning with my critical realism belief. Pragmatism does not require a specific method or methods mixture, instead, it uses what the researcher determines is the more appropriate method to examine or explore that research question (141).

While there is much debate around pragmatism and the implications on a researcher's philosophy (143) I related my ontological viewpoint to the below definition of pragmatism,

> "sidesteps the contentious issues of truth and reality, accepts philosophically, that there are singular and multiple realities that are open to empirical inquiry and orientates itself to solving practical problems in the real world" (141 p. 8).

The overarching belief that pragmatism centres on finding practical solutions for real problems, rang true with my own personal and professional experiences around both what I believed about truth and knowledge. Already, in my brief exploration into the philosophy, I had grown tired of authors arguing over the differences between philosophical standings. I did not understand its importance or relevance to the practical issues I faced in a clinical environment. Instead, I sided with the arguments presented by Feilzer (141), who raised previous thoughts by Rorty (144) who argued that knowledge should have practical utility. A pragmatic formulation of knowledge meant that knowledge may not be absolute. Instead, knowledge may alter with time and individual interpretation, and while there may be a solid framework of how different phenomena interact, knowledge may shift and change (141).

It was in the Feilzer (141) paper I was first introduced to the idea of abductive reasoning, encouraging the researcher to flow between the different ways of knowing to logically connect between data, theories, observations and anomalies. My understanding at this point of abductive reasoning was limited. I grasped the above definition together with the notion that abduction was also argued to be a way of using the different methods to aid in a better understanding of a phenomenon. By combining the different data types and knowledge you could gain the specific experience of generalisable findings (145). Again, this chimed with my critical realist viewpoint, you can take a photograph of a windsurfer or paint a picture of a windsurfer. The photo and the painting may have different qualities, but both will capture the image of a windsurfer (Figure 3).

Figure 3: Photograph and painting of the same windsurfer. Photo from personal collection and painting by author of thesis.

As a nurse, I had found that reality lay somewhere between a patient's expert experience of living with their illness(es) and the cumulative knowledge and expertise of a clinician. I had experienced success many times in blending the two truths to help a patient feel heard and valued while at the same time aiming to have the patient comply with what I as a clinician thought was best for them. I had been inspired by Dr Oliver Sacks who took a whole person approach blending evidence based treatments with patient specific tweaks to treatments which facilitated better quality of life even if treatment regimens were not adherent to guideline recommendations (146).

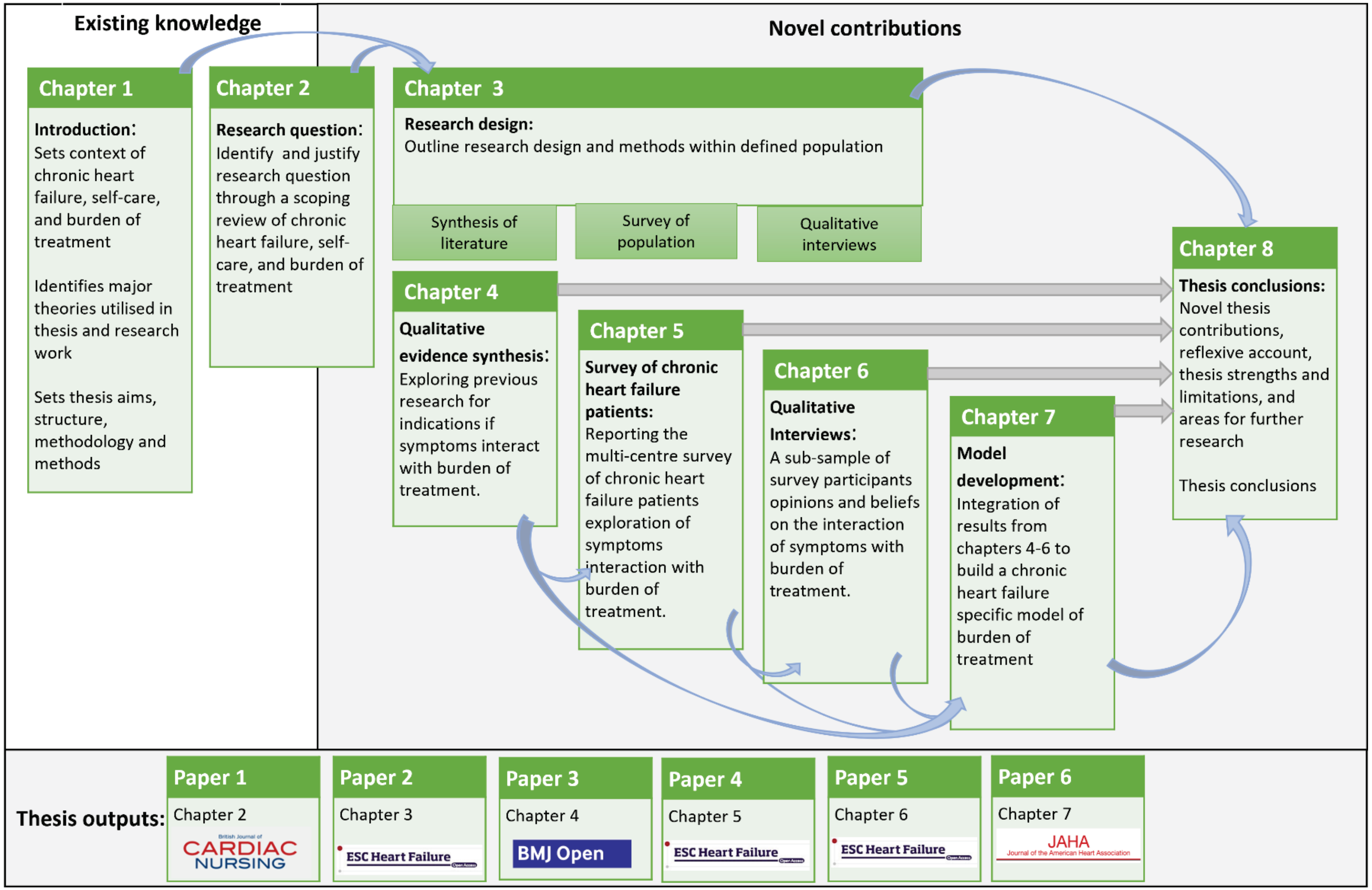
> "He would take Haldol 'dutifully' throughout the working week, but would take himself off it, and 'let fly' at the weekends."(146 p. 101)

A person-centred approach guided is by an expert clinician and enables the person living with illness to be a contributing member of society, even though as seen in the above example, it may encourage a degree of non-compliance. It also provides an example of how multiple truths can be blended.

Together my epistemology and ontological beliefs formed a research paradigm, embracing abductive reasoning and leading me towards mixed methods research. I believed these methods would help me elucidate the difference between the different truths that I had observed. Mixed methods would facilitate an examination of the phenomena using tools accepted by clinicians and enabling description of a large population's experience. Together with an exploration of the same phenomena which would encourage patients to expand on their experiences without the imposed limitations of validated tools.

1.4.6 Thesis methods

In addition to the individual papers reporting the methods undertaken, a brief overview of how the separate chapters inform each other alongside a more detailed justification of the methods are included in this section. The process followed is outlined in Figure 4:



Chapter 1

Introduction: Sets context of chronic heart failure, self-care, and burden of treatment

Identifies major theories utilised in thesis and research work

Sets thesis aims, structure, methodology and methods

Chapter 2

Research question: Identify and justify research question through a scoping review of chronic heart failure, self-care, and burden of treatment

Chapter 3

Research design: Outline research design and methods within defined population

Chapter 4

Qualitative evidence synthesis: Exploring previous research for indications if symptoms interact with burden of treatment.

Chapter 5

Survey of chronic heart failure patients: Reporting the multi-centre survey of chronic heart failure patients exploration of symptoms interaction with burden of treatment.

Chapter 6

Qualitative Interviews: A sub-sample of survey participants opinions and beliefs on the interaction of symptoms with burden of treatment.

Chapter 7

Model development: Integration of results from chapters 4-6 to build a chronic heart failure specific model of burden of treatment

Chapter 8

Thesis conclusions: Novel thesis contributions, reflexive account, thesis strengths and limitations, and areas for further research

Thesis conclusions

Figure 4: Detailed thesis map *Paper 6 will be submitted to JAHA after paper 5 is accepted

1.4.6.1 Editorial

Aim: An introduction of the major concepts – CHF, self-care, and BoT – and how they informed the research question.

Justification of methods: A scoping review was undertaken in the process of refining the thesis research question by exploring existing literature. Important concepts were identified and cross-over between concepts characterised formulating a robust research question. I thought that as the work I was planning to do was novel and addressed an important issue in CHF care, non-adherence to self-care regimens, it was important to introduce these ideas to the clinical audience. As this work was a scoping review and presented an alternative view to non-adherence in CHF rather than being original research it was more of an opinion piece or editorial, which is how it was eventually published.

How this work informed the following research: The knowledge I gained in this work informed and shaped the BoT framework (Appendix F). The research papers that I read in this work also began to inform my thoughts on the research design I would use to explore my research question.

1.4.6.2 Protocol for mixed methods research

Aim: Describe the research design for the mixed method research aimed at answering the research question: how symptoms of CHF interact with BoT.

Justification of methods: The research protocol paper was written after the study had been designed, refined, and ethically approved. At this juncture, existing research had primarily focused on the area of CHF and burden of treatment utilising qualitative research methods (59, 63, 119). The creation and publication of two questionnaires used in multi-morbid populations appealed to my positivist side. By using valid and reliable tools that captured BoT together with tools that captured CHF symptoms, I would be able to test my hypothesis.

I decided that my mixed method study would have a substantial focus on quantitative work, as no such study had been performed, thereby filling an identified gap in the literature. This focus aligned with my positivist beliefs and pragmatic clinician self. I thought the statistical analysis would help to identify culprit symptoms causing poor self-care and form the foundation for intervention. The qualitative phase of the research would facilitate exploration of any unexpected results and sense check the CHF patient experience of symptoms and managing illness utilising BoT theory. Mixed methods research designs are potent strategies for the investigation of complex health care systems, illness conditions, and processes. They draw on individual strengths of both quantitative and qualitative methods promoting the consideration of the patient perspective (147, 148). In chronic illness, describing patient preferences in balance with their needs is important and can be achieved through mixed methodologies (149) and help promote the establishment of minimally disruptive medicine (51).

I chose a sequential explanatory mixed methods design where quantitative methods are followed by qualitative methods (150). Exploration of quantitative results can be useful in understanding how well a quantitative tool captures what it intends to measure (150, 151). As the phenomenon of interest was the interaction between the two concepts the tools were measuring, the method was adapted (133). Rather than exploring how well the questionnaires captured what they aimed to capture, instead, I focused on using this technique to explore if the correlation, created in comparing the scores, captured the experience of the participants. Sequential explanatory mixed methods aim to explain and elaborate on quantitative results, in such a way that the qualitative results build on the quantitative results (151). This was what I proposed to accomplish.

The main criticism of this type of mixed method research is how long it takes to complete (151). Being pragmatic and with a limited time frame to complete the research as a doctoral student, I further adapted the method. In addition to deciding to take a broad cross-sectional sample of people with CHF across three NHS trusts and community support groups optimising the speed of recruitment and capturing a broad overview of the population. I purposely chose to perform an interim analysis at the halfway point of the quantitative study, instead of waiting for the final results. I set the goal of performing an interim analysis that would inform the qualitative research at 9 months into recruitment to the survey or when I reached 150 participants (whichever came first). A sample of this size was calculated to be powered with the desired confidence interval (CI) width of 0.3 with a CI of 95%. A sample of this size should indicate the existence of an association, but may not indicate the strength (152). I believed this target was feasible based on my experience as a specialist research nurse on heart failure studies. The interim analysis results, rather than the final results, would inform adaptations to the interview schedule and purposive sampling for the qualitative interviews. The analysis of the qualitative data would be informed by the results from the full survey data set.

To inform the choice of quantitative instruments used to capture symptoms of CHF and BoT I looked at evaluations of those tools, how they were formulated, what they claimed to measure, and their financial costs. To capture CHF symptoms, I chose Minnesota living with heart failure questionnaire (MLHFQ), (Appendix A). It is a valid and reliable instrument that captures key physical, emotional, social and mental dimensions of health related-QoL (HR-QoL) in a brief questionnaire. Participants complete a 6-point Likert scale on 21 questions, where the maximum score is 105 and lower scores relate to better HR-QoL (153). Garin, Ferrer, Pont (154), report that the MLHFQ is the most frequently used tool for assessing QoL in heart failure (n= 91 studies). It has physical and emotional sub-scores shown to be valid and suitable for both clinical and research use (155). The owners of this tool provided a free licence for educational purposes. As it measured both HR-QoL and symptoms, was valid, reliable and well respected in both clinical and research circles I decided to include it. I also knew from personal research delivery experience that participants did not struggle to answer the questions, but the physical sub-score did not comprehensively capture all symptoms of CHF.

The heart failure symptom survey (HFSS) is a valid and reliable instrument for quantifying heart failure signs and symptoms (156, 157) (Appendix B). It measures the frequency and severity of 14 symptoms. Symptoms are measured on a Likert scale, where higher scores equate to more severe experience. The HFSS also captures the impact of symptoms on an individual’s physical activity and enjoyment of life on a similar scale; scored 0-10 where the higher score equates to greater interference. The tool was designed for use for those with heart failure who are not inpatients at a healthcare facility (i.e., they are managing the illness at home) (156). This tool captured both typical and atypical CHF symptoms and it captures the burden of those symptoms. The authors agreed to provide it free of charge for educational purposes. I believed it would complement the MLHFQ well and looked relatively easy for participants to complete.

According to Sav, Salehi, Mair (158), there were two tools thought to be effective at measuring BoT; the patient experience of treatment and self-management (PETS) (124) and treatment burden questionnaire (TBQ) (159). One of the differences between them important to consider as I was already using two questionnaires was the length of these tools. The TBQ was brief (15 items) and the PETS was long (48 items). The brevity of TBQ, while less burdensome, would be less comprehensive as it did not capture as many domains of BoT. PETS was built on a framework developed through qualitative interviews of multi-morbid patients describing the work, facilitating tools, and exacerbating factors involved in self-care of chronic illness (58). It quantifies the patient experience of those with multiple morbidities across nine domains and is valid and reliable (158). A higher total score indicates greater BoT and has been correlated to more distress, less adherence to medications, lower self-efficacy, worse physical and mental health, and lower convenience of healthcare (124). Sav, Salehi (158) examined existing tools which purport to measure BoT. While no gold standard tool yet exists, the PETS was recommended as a good starting point as a comprehensive tool to measure BoT (Appendix C). Thus, it was chosen as the measure to capture BoT.

For the qualitative phase of my planned research, decision-making focused on sampling and creating the interview schedule. The qualitative interview sample aimed to be as representative as possible. In the published protocol I described this process as maximum variation sampling. The sampling process that I developed took key characteristics thought to be relevant to either symptoms or BoT (age, gender, and LVEF) together with survey population characteristics (location, and ethnicity). These characteristics were cross-referenced with a wide range of questionnaire responses, creating a purposive sampling grid (Appendix I). This process increased my confidence the data in the qualitative phase of the research would encapsulate both the mean experience and the extreme experience of CHF patients.

In creating the interview schedule, I took five different interview schedules (58, 59, 160-162) created around exploring the ideas associated with burden of treatment in multiple chronic illnesses (Appendix D.1). By comparing pre-existing interview schedules and considering the role of symptoms, I created an adapted interview schedule (Appendix D.2). Thus, creating an evidence based, theoretically informed interview schedule.

How this work informed the following research: The design of each stage of the empirical research provided the framework for the conducting of the research studies in NHS trusts. The publication also served as a framework ensuring the results, we published matched the protocol published, promoting transparency.

1.4.6.3 Qualitative evidence synthesis

Aim: Describe the results from the systematic qualitative evidence synthesis which aimed to explore if symptoms of CHF could be observed interacting with elements of BoT, within existing qualitative research publications.

Justification of methods

To test the observation that symptoms of CHF interacted with BoT, the first step was to examine existing literature. My knowledge of BoT the scoping review (132) informed the framework (Appendix F) used in this research. Within the existing literature around the lived experience of CHF, I planned to test two main ideas, a) were symptoms of CHF present in this literature, and b) if present, did symptoms interact with elements of BoT?

I developed a systematic literature review protocol and registered it on PROSPERO, an international database of prospectively registered systematic reviews. The protocol can be accessed at https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=77487. The protocol followed the framework for a systematic review of qualitative literature to synthesise the results of the included articles. There was also an element of secondary analysis, where the published data was explored for phenomena outside of the original purpose of that research. While there is much debate around secondary analysis (163) I believed I needed more evidence to form a foundation that went beyond a clinical observation. A qualitative evidence synthesis that aimed to explore existing data for new observations would achieve three major goals: a) it would teach me more about qualitative research through the process of critically assessing published papers, b) it would help me begin to test my hypothesis, and c) it would increase my knowledge around burden of treatment.

My knowledge of qualitative research was very basic. One of the elements of qualitative research that I struggled with was the idea that a mean or average experience is not the goal, instead, individual experiences are combined to inform a framework, model, or theory. While I was beginning to see the value in this philosophy of creating knowledge, the positivist, pragmatic clinical side wanted to demonstrate that my observations were more than just a single person with this experience. The observations in data extracted from these articles were from different countries, different time periods, and different populations, strengthening the observations. Not because it was the mean experience but because these experiences transcended borders, times, and personal characteristics. The desire to communicate the depth of these observations led me to present my data visually in novel ways (section 8.2). Qualitative analysis requires the researcher to perform a deep dive into the data creating themes which describe the data and explain how those themes fit within existing knowledge and build frameworks, models and theories about a phenomenon. In doing this I was able to see how strong the observed connections between concepts were, but I struggled to communicate the strength and depth of those observations without numbers. The discovery of a Sankey diagram offered the opportunity to visually demonstrate the observations I had made. A Sankey diagram was first created by Captain Matthew Sankey who used this diagram to illustrate the energy efficiency of a steam engine (164). Sankey diagrams visualise flow, where the width of the arrows are proportional to the flow rate, they are typically used in physics, and cost breakdowns (165). However, I thought that I could use them to demonstrate the proportional flow of the coding to demonstrate the depth of findings from the analysis I had performed; thus, demonstrating how I had come to the conclusions drawn. The numbers that I used to inform the Sankey diagram were based on the counts of coding performed in NVivo. I did not rest on the visualisation alone. I still presented the data in the standard way of reporting qualitative data, but together I believed the work presented a stronger argument for the novel findings observed.

How this work informed the following research: The results presented in this paper began the process of answering the research question by confirming that symptoms of CHF did interact with

BoT. The qualitative analysis skills I learned were transferred to the analysis of the series of interviews. The results influenced my thinking about how symptoms interacted with BoT and were integrated with other research results to build the CHF specific BoT theory.

1.4.6.4 Survey results

Aim: To report the description of the population that participated in the survey, along with the results of the questionnaire scores and the inferential statistics performed.

Justification of analysis methods: The process of collecting and cleaning quantitative data, was one I was very familiar with as a specialist research nurse. I knew that having a secure, accessible electronic platform was key to ensuring high quality data input with an auditable trail. Electronic case report forms (eCRF) are used in clinical trials to perform this task. I was granted access by Wessex clinical research network (CRN) to utilize the REDCap Cloud system (166). Allowing me to have unique, secure logins for all delegated research staff and to create a customized platform for the data I wished to collect in this phase. While I decided on which data I would collect and the format of that data, for the actual creation of the web-based platform I was supported by Milan Chauhan[1] who converted the paper data collection forms into eCRF (Appendix H). Data monitoring is expected in research trials, I adopted a risk-based strategy; verifying the 10% of the data where the error rate determined the extent of verification.

I had decided to use validated and reliable tools independently rated as valuable and useful tools to capture either symptoms or BoT, I anticipated a calculated score would be used to perform planned statistical analysis. This was true with MLHFQ and HFSS, but I discovered that the PETS only had sub-scores and not a single summary score. The description of the interaction of symptoms on multiple domains of BoT was possible, but not with the generalised experience of BoT. Eton, Yost (124) in the dimensions of medical information, monitoring health, medical expenses, and difficulty with healthcare services decided to take valid responses of patients (i.e., “does not apply to me”) and convert that response into missing data. I believed that this discounted the patient’s responses. For example, a patient with CHF may believe their illness knowledge is complete as a clinician had told them that they were a model patient. Selecting “does not apply to me” as they felt there is nothing new to learn about their illness and this belief was reinforced by a clinical expert. To me, I could think of multiple scenarios where a participant would report that an item might not apply to them. I did not agree with the author’s decision to

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[1] Milan Chauhan is a (Research data coordinator) who works at Portsmouth Hospitals University Trust in the Portsmouth Technologies Trials Unit. He provided technical support in programming the online database for the survey data collection in this thesis.

convert valid patient answers into missing data. In the domains of diet, exercise or physical therapy, and medical equipment there was a similar situation, where participant responses were converted into missing data. As the purpose of this thesis is not to appraise or refine the tools, I accepted the scoring decisions by the authors, as this would allow data comparison with others using PETS.

The brief PETS (167), created and published during the doctoral studies, included the creation of a workload and impact index, combining some of the domains to create index scores. I believed that this helped my analysis as it would now permit me to capture a correlation between symptoms and the workload index, which I believed would be a comprehensive examination of how symptoms of CHF interacted with the burden associated with completing many self-care tasks. Similarly, I felt that using the impact index in PETS would give some indication around the interaction of symptoms with patients' internal capacity as affected through engagement in self-care activities.

How this work informed the following research: The results of the survey were key to informing the qualitative research work. The interim results were used to adapt the interview schedule (Appendix D.3) and challenged the conclusions I had formed after the qualitative evidence synthesis. The final results informed the interview analysis and were integrated to develop the CHF specific BoT theory.

1.4.6.5 Semi-structured interview results

Aim: Explore the experiences of a sub-sample of survey participants on the interaction of symptoms with BoT to clarify survey results and characterise that interaction.

Justification of analysis methods: In the research design stage I described the analysis plan for the semi-structured interview data as very similar to the plan I had for my qualitative evidence thesis (133). Research is an iterative process; the results from my previous research (134, 135), had altered the study specific research question from "do symptoms interact with BoT?" to:

1) Was the moderate to strong statistical association between symptoms and BoT observed in the survey research reflected in the participants' experience?
2) If symptoms and BoT interact, then what are possible explanations for the results that did not match this association?

The analysis plan needed to change and an abductive approach using a recursive and iterative process to examine and observe the phenomena multiple times, where adaptions are made to explore surprising results or findings was utilised (168). This matched with the sequential explanatory mixed method approach, where the qualitative portion of the research can be used to explore surprising quantitative findings (141, 148, 151). As my interim results had already highlighted unexpected results that was confirmed in the final results, I adapted the interview schedule to reflect those new observations (Appendix D.3). The interview data were specifically examined line by line for any extracts which illustrated a relationship between symptoms and elements of BoT. The interview data that arose from direct questioning of participants around their beliefs of that proposed relationship, were also examined line by line for their beliefs, the nature, and influencing factors of that relationship. Together these new lines of inquiry informed this results paper.

Extracts of data from the interviews were identified according to the research aims as described in section 6.4.6. They were then organised within these sections to describe and explain the nature of the interaction observed and the impact of symptoms on engagement with illness or treatment work. In so doing an explanation of how symptoms interact with BoT alongside intervening factors was outlined and a model of that interaction is offered. My critical realistic and pragmatic viewpoint helped me to see how those intervening factors might explain the unexpected results from the survey. While my clinical background helped me to identify how these patients had communicated a good understanding and compliance with self-care tasks reinforcing my hypothesis that symptoms might influence patient abilities to engage with self-care rather than motivation or knowledge.

How this work informed the following research: The results of this paper help to frame the results from the survey and offered explanations for unexpected results. These findings corroborated the findings in the qualitative evidence synthesis and together with the survey results were integrated into the CHF specific BoT theory.

1.4.6.6 Theory development

Aim: To integrate findings from the three empirical research studies proposed in the research design (Chapter 3) to describe how symptoms of CHF interact with BoT by building a model which explains that interaction.

Justification of methods: An established framework of model and theory building was used (118, 169) to shape the outline of this paper. The detailed justification for the integration of the different research styles and underpinning theories is presented in the concluding chapter of this thesis (Chapter 8). A brief description of the multiple integration methods used is included in the theory building paper (Chapter 7). Methods that were used to integrate the different data sources were chosen as they aligned with the sequential explanatory design and abductive analysis approach. The theory that is offered both integrates the research work presented here and provides a testable framework for future research as well as providing a new framework to inform clinical interactions.

1.5 Clinical context of the thesis research question

In 2016 I was working as a Cardiology Specialist Research Nurse and was new to working with individuals with CHF. My nursing experience, in the past 8 years, spanned multiple chronic illnesses from chronic kidney disease to multiple neurologic conditions. One of the nursing skills I had been commended on was my ability to take complex concepts and make them easy to understand, a skill I often used with patients. An early interaction with a person with chronic heart failure (CHF), who despite a long history of multiple heart failure specialist interactions, provided me with the opportunity to use that nursing skill. He told me that he didn't understand why I was asking him to take part in a heart failure research study, "There is nothing wrong with my heart, it is my lungs that are the problem!" While a part of me struggled to understand how he had come to this conclusion. I jumped at the opportunity to use my skills to hopefully clear this confusion up for him. By the end of our conversation, he seemed more informed and thanked me for being the person to finally explain to him why he kept seeing a heart doctor. I went home proud and fulfilled as I felt I had made a difference. Two weeks later when he returned for his research follow-up visit, he again told me, "There is nothing wrong with my heart, it is my breathing that is the issue!" How could he go from completely understanding his illness, to in a short time, reverting to his original misunderstanding? I felt I had provided targeted person-centred health education. My nurse training had instilled the belief in me that person-centred care would increase someone's understanding and engagement in the management of their health conditions. Here I was faced with the exact opposite. I wasn't alone in this observation, nationally research nurses were reporting the same issue, resulting in senior research investigators changing the wording on patient facing documents from describing 'heart failure' as the condition of interest, instead being described as a 'heart condition'.

I was inspired to research the idea that symptoms of CHF might be a factor in this population's lack of engagement in their healthcare. I believed that the theories informing how we delivered care to patients were well established and evidence based; therefore, I concluded the gap was in the lack of support and treatments around symptoms of CHF (e.g., cognitive impairment, breathlessness, fatigue). Guided by my supervisors Professors Carl May and Paul R Kalra, I started on a journey to become a Nurse Researcher. By exploring the knowledge behind symptoms of CHF and self-care together with a concept that I had not heard of before, treatment burden. Later in my doctoral journey, my supervisory group grew to include Professors Lisette Schoonhoven and Alison Richardson.

The foundation of my knowledge grew around CHF, symptoms, self-care and BoT (132). I believed I had observed gaps in both the theories of self-care and the BoT theory important to consider for those with CHF. The symptoms of CHF are invasive, persistent, progressive, and subjective making them difficult to monitor, evaluate and take corrective treatment adjustments. This is true for both clinicians and patients. Symptoms of CHF also negatively impacts QoL forcing people with this syndrome to accept ever increasing limitations on their abilities. I did not believe that the foundational belief that self-care always leads to an improvement in patient experience. Nor did I believe that BoT theory had fully considered the full impact of symptoms on workload, but I believed that its framework offered a more patient focused framework to examine the issue of CHF patient adherence to self-care regimens. What I wanted was to find a practical solution that would help CHF patients better engage with their self-care. In embracing critical realism and pragmatism I believed I would have the required flexibility and freedom to explore my research question with the variety of theories and ontological underpinnings that those theories required.

Chapter 2 Editorial introducing the research question: Paper 1

2.1 Burden of treatment in chronic heart failure: does symptom burden play a role?

Austin, RC, Schoonhoven, L, Kalra, PR, and May, CR. Burden of treatment in chronic heart failure: does symptom burden play a role? 2019; British Journal of Cardiac Nursing, 14(2), 91-93. *(132)*

2.2 Introduction

In the past twelve years, Chronic Heart Failure (CHF) prevalence has increased by 23%, responsible for the growing demand on health systems, hospitals, patients and their support networks (2). A fundamental component of CHF care provision is empowering patients to self-manage their CHF with regular input from health care providers (47), including Heart Failure Specialist Nurses (HFSN).

2.3 Self-care and management

Self-management is an important adjunct strategy to CHF management (1) and a powerful treatment strategy that may delay progression of illness (17, 170). It is widely known that CHF patients struggle to successfully complete self-management regimens guided by HFSN. The resultant effect on mortality and morbidity is thought to be substantial (17, 47). The Burden of Treatment Theory (BoT) helps us to identify, characterise, and understand the work of self-care. BoT proposes that adherence to self-care regimens is shaped by interactions between the workload of self-care and patient capacity to meet the demands of that workload (118). Consequently, if BoT can be modified in the patient’s favour, then adherence to self-care regimens should improve along with clinical outcomes. BoT might provide HFSN with information that could be used to help patients engage more successfully with their self-care regimens.

2.4 BoT theory

BoT is an emerging theory, thought to be comprised of dynamic states of workload (time and energy required to manage a condition), impact (effect of the workload on the patient), and individual capacity (factors altering ability to handle the work) (58, 62, 118, 171) (Table 1). Sav, King (56) suggest that BoT attributes are a dynamic multidimensional process that is comprised of; objective elements (total workload and complexity) and patient specific subjective elements (feelings of guilt, hopelessness and fear). They state BoT will be influenced by predisposing factors: age, gender, relational networks, comorbidities, polypharmacy, treatment requirements, and healthcare relationships. Despite the acknowledgement of these antecedents, they agree with May, Eton (118) in the belief that BoT is a theoretically distinct concept from symptom burden. Sav, King (56), propose a cyclic interaction between disease progression and increased symptom burden resulting in more treatments with a concurrent rise in BoT. However, for the patient, the relationship between symptom burden and BoT may be more entangled in their lived experience of managing CHF.

Table 1: What burden of treatment means to patients and clinicians

BoT	Patient Implications	Clinical considerations
Workload	Work of managing illness (e.g., take medications, attend appointments, learn about illness and treatments, enact lifestyle changes, monitor illness, etc.) Recruit others to assist with care, use tools and strategies to help with care Manage factors that intensify burden (e.g., navigating healthcare systems, side-effects of treatment, etc.)	How much work am I asking the patient to do?
Impact	Changes to self Changes to relationships Changes to activity (work and recreation)	Will this treatment suggestion negatively disrupt the patient's life, decreasing their motivation to adhere to the treatment?
Individual Capacity	Physical ability Cognitive function Emotional status Socioeconomic resources	Does this patient have the capacity and resources to successfully engage with the treatment plan?

2.5 Influence of BoT

Evidence is mounting that BoT likely influences patient engagement. Eton, Elraiyah, Yost (172), in examining disease specific measures of burden, state burden appears to influence self-care, clinical outcomes, number of hospitalizations, and health related quality of life (HR-QoL). Shippee, Shah (62), argue that if the components of BoT become unbalanced then the patient is less likely to adhere, resulting in higher burden of illness and poorer outcomes. May, Eton (118) argue that overwhelming burden leads to non-compliance and under-utilization of health services likely leading to worsening illness and more treatments. Sav, King (56), in a systematic literature review, determined that the consequences of BoT included poor health and well-being, lack of compliance to treatment strategies, ineffective resource use, and increased reliance on others. Understanding modifiable factors of BoT is crucial. It appears that BoT negatively influences patients' engagement with self-care strategies resulting in poor outcomes, and increasing treatments.

2.6 Symptom burden

Patients experience symptoms due to illness or treatments. Symptoms can be associated with objective clinical measurements, but also exist without a concurrent clinical observation. Symptom burden is thought to be the lived experience of these cumulative symptoms (173) and goes beyond scoring symptom severity or prevalence, as it encompasses the impact of the experience that the symptoms bring to the individual (174). CHF symptom burden appears to influence quality of life (QoL). Zambroski, Moser, Bhat (175) and Blinderman, Homel, Billings (176) examined symptom burden in CHF patients. They both found that CHF patients had a high level of symptom burden that negatively affected QoL. Their findings suggest that improvements in symptoms will have a positive impact on QoL. While the complete elimination of symptoms is unlikely, there are treatment options that may help to reduce the symptom burden of the most prevalent symptoms. Further lower symptom burden is associated with improved functional ability, and better self-care engagement (17). Implicit in this is that with more adequate self-care patients' BoT would be lower, but this has yet to be explored.

2.7 Proposed interaction between symptom burden and BoT

Clinical observation of CHF patients suggests that symptoms may be central to a patient's experience. Their perceived BoT could be intrinsically linked with their symptom burden. Symptoms may interact with individual capacity but may also alter workload and its impact; thus, changing their overall BoT. If this relationship exists, then it may be possible to increase CHF patients' engagement with their self-management through altering their overall symptom burden.

2.8 Implications for practice

Understanding the interaction between symptom burden and BoT that CHF patients experience, could be important in helping increase their engagement with self-management (177). The authors are conducting a mixed methods study with the intention of understanding any interaction that may exist as well as identifying modifiable factors. The study, “SYMPACT: How do symptoms and management tasks in chronic heart failure impact on a person’s life?” will measure and explore symptom burden and BoT in CHF patients (http://generic.wordpress.soton.ac.uk/sympact/). Until more is known, it could be worth considering what work as health care professionals we are asking CHF patients to do.

2.9 Acknowledgements and declarations

At the time this work was completed, CM and LS were staff at the University of Southampton. The research is supported by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care Wessex and the Wessex Clinical Academic Scheme. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care. In this month’s BANCC piece for the journal, BANCC would like to thank member Rosalynn Austin and her collaborators for contributing this excellent piece on the burden of treatment theory and how we can apply this in our work as cardiac nurses. BANCC welcomes all members to contact us if they have a piece of work to share.

Conflict of interest: None.

Ethics approval and consent to participate, not applicable; consent for publication, not applicable; availability of data and material, not applicable.

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2.11 Author Contributions

All authors read and approved the final manuscript. RA drafted the article. CM and LS are the academic supervisors for RA’s PhD project and contributed to the intellectual review. PRK is the clinical supervisor for RA’s PhD project and contributed to the clinical review.

Chapter 3 Research study design: Paper 2

3.1 How do SYMptoms and management tasks in chronic heart failure imPACT a person’s life (SYMPACT)? Protocol for mixed methods study

Austin, RC, Schoonhoven, L, Richardson, A, Kalra, PR, and May, CR. How **SYM**ptoms and management tasks in chronic heart failure im**PACT** on a person’s life (SYMPACT)? Protocol for a Mixed Methods Study. ESC Heart Failure. 2020 Sep 17; 7(6), pp. 4472– 4477. https://doi.org/10.1002/ehf2.13010. (133)

3.2 Abstract

3.2.1 Aims

Patients with chronic heart failure (CHF) struggle to follow self-care plans, which may lead to worsening illness and poor quality of life. Burden of treatment (BoT) describes this workload and its impact on patients' lives. Suggesting the balance between a patient's treatment workload and their capability to manage it is crucial. If BoT is reduced, self-care engagement and quality of life may improve. This article describes the SYMPACT study design and methods used to explore how symptoms and management tasks impact CHF patients' lives.

3.2.2 Methods and results

We used a sequential exploratory mixed-methods design to investigate the interaction between symptoms and BoT in CHF patients.

3.2.3 Conclusions

If symptoms and BoT are intrinsically linked, then the high level of symptoms experienced by CHF patients may lead to increased treatment burden, which likely decreases patients' engagement with self-care plans. SYMPACT may identify modifiable factors to improve CHF patients' experience.

3.3 Introduction

Patients with chronic heart failure (CHF) often struggle to adhere to self-care expectations (21). Non-compliance with self-care is suggested as a contributor to poor outcomes in CHF and is attributed to self-care that is neither sufficient nor effective (47). Burden of Treatment (BoT) is comprised of dynamic states of workload (time and energy required to treat and manage a condition) and individual capacity (factors which alter ability to do work) (58, 62, 118, 127, 171). Overwhelming treatment burden may be associated with adverse clinical outcomes (62, 118). Patient responsibility and engagement with self-care adding to BoT is not unique to CHF (127). Clinical pathways and personal capacity appear to influence BoT in lung cancer and COPD (65). BoT appears to be exacerbated by the level of support provided by healthcare systems and socioeconomic disadvantages in end-stage kidney disease (66). How symptoms interact with burden of treatment has yet to be investigated.

CHF is a life-limiting syndrome and patients experience persistent, progressive, and debilitating symptoms such as breathlessness, fatigue, and oedema compromising their quality of life (QoL) despite optimized clinical treatment plans (175). Complete elimination of symptoms is unlikely, yet there are likely treatment options that could help reduce symptoms. Lower symptom burden is associated with improved functional ability, and better self-care engagement (17). While the theory of BoT acknowledges symptom burden it argues that symptoms are theoretically distinct. Examination of the literature, clinical observations, and patient and public involvement (PPI) suggests the symptoms in CHF may directly interact with BoT (132). In this study, possible interactions between BoT and symptom burden will be measured quantitatively and explored qualitatively through interviews facilitating a deeper understanding of how patients with CHF experience burden of treatment. This paper outlines the design of the study: “How SYMptoms and management tasks in chronic heart failure imPACT on a patient’s life (SYMPACT)?” SYMPACT will examine and explore the interaction of symptoms experienced by patients with CHF with BoT. Authors will test and explore the hypothesis (aims) that symptoms are intrinsically linked with BoT, i.e., patients with lower reported symptoms will report lower BoT and patients with higher reported symptoms will report higher BoT. This will be confirmed in how patients describe their experience. The research questions are: (Phase I) Is there a relationship between quantitatively measured symptoms and BoT?; (Phase II) What is the perspective of patients with CHF on their experienced symptom burden and BoT?; and (Phase III) How do symptoms interact with BoT in CHF?

3.4 Study design

SYMPACT is a sequential explanatory mixed method study (Figure 5); this methodology promotes the exploration of results in a quantitative study (150, 178). Qualitative results expand on insights derived from quantitative results (178) facilitating deeper explanations of observed statistical relationships. Combining the SYMPACT study results with a qualitative literature synthesis (177) enables the adductive analysis approach (168) to form a conceptual model of the interaction between BoT and symptom burden in CHF.

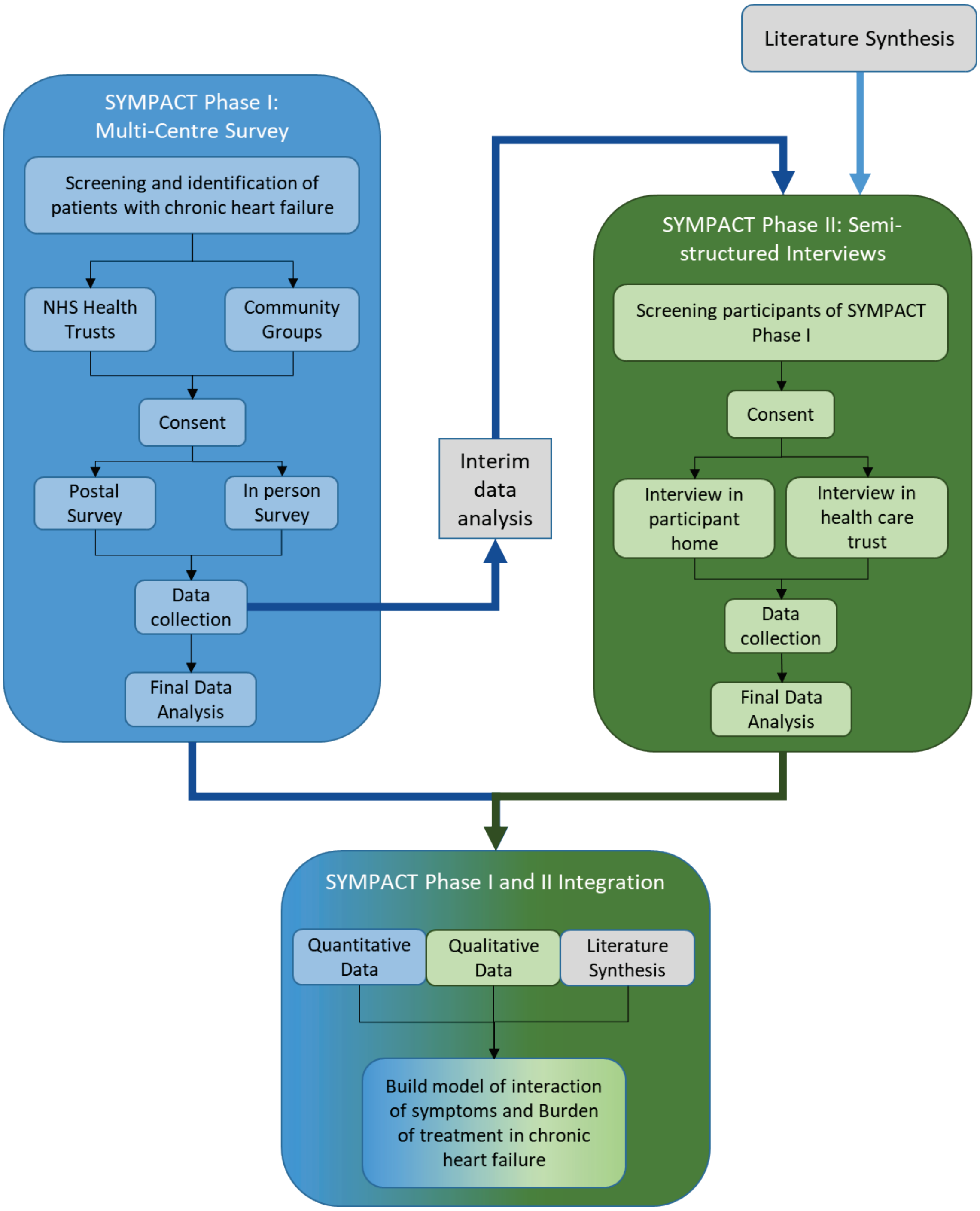

Figure 5: SYMPACT study design overview: flowchart illustrating the phases of SYMPACT and how they inform each other.

SYMPACT adheres to the Declaration of Helsinki and has been reviewed and approved by the University of Southampton Ethics Committee (ERGO: 41287) and the Nottingham HRA1 Research Ethic Committee, Health Research Authority (MREC: 18/EM/0339, IRAS: 247773).

3.4.1 Phase I: multi-centre survey of symptoms and burden of treatment in chronic heart failure

Phase I of SYMPACT will test the following hypothesis: Symptom burden reported by CHF patients will be correlated with reported domains of BoT.

3.4.1.1 Design

A single time point survey using three validated questionnaires is used.

3.4.1.2 Participants

This is a multi-centre study across primary and secondary care National Health Service (NHS) health trusts in the UK. English-speaking adults with CHF (minimum of 6 months), and in the investigators' opinion are not cognitively impaired, will be invited to complete the questionnaires. Patients with heart transplants or who are receiving palliative care will be excluded.

3.4.1.3 Methods

Following informed consent, health information will be collected: 1) demographics (age, gender, ethnicity, marital status, living situation), 2) CHF characteristics (diagnosis date, aetiology, New York Heart Association [NYHA] class, ejection fraction, clinical evaluations), and 3) personal health information (health issues, medications, hospitalisations).

Patients will be invited to complete 3 validated questionnaires: Heart Failure Symptom Survey (HFSS) (156), Minnesota Living with Heart Failure Questionnaire (MLHFQ) (179), and the Patient Experience of Treatment and Self-Care (PETS) (124).

1. HFSS is a reliable disease specific evaluation of heart failure signs and symptoms (156). It measures the frequency, severity and impact of 14 symptoms, where a higher score equates to a more severe experience.
2. MLHFQ captures key physical, emotional, social and mental dimensions of QoL in a brief questionnaire (153). Lower scores on the MLHFQ relate to better health related QoL.
3. PETS describes the work of illness, facilitating tools, and exacerbating factors involved in self-care of generic chronic illness. It is a 48-item questionnaire quantifying the patient experience of BoT across nine domains (124).

3.4.1.4 Sample size

Sample size calculation is based on estimating the correlation between the above measures, within a pre-specified precision (as defined by the 95% confidence interval [CI]). A width of 0.2 was chosen as a balance between the practical considerations and the ability to draw useful conclusions from the observed correlations. Pearson's correlations power calculation formula (152), suggests a sample of size 350 will achieve this for any value of correlation.

3.4.1.5 Data analysis

Descriptive statistics will be used to summarize the study participants' personal, CHF and health characteristics. Patients' questionnaire responses will be described across gender, age, number of health issues and medications, NYHA class, and according to left ventricular ejection fraction.

A scatter plot will be used to visually assess the relationship between reported symptom burden (measured by HFSS and MLHFQ) and BoT (measured by PETS); this will guide the choice of a suitable correlation tool (e.g., Pearson's or Spearman's) to summarize the relationship between the variables. Correlations will be presented with 95% confidence intervals.

An interim analysis will occur at about the halfway point. The results will be used to adapt the interview schedule, with specific probes to be used in Phase II.

3.4.1.6 Limitations

Limiting the sample to only three hospitals in a single county in the UK and patients who only speak English may reduce the generalizability of the results. Further, limiting the sample to CHF patients without heart transplants will ensure a focus on the generic lived experience of CHF. These limitations were thought to be reasonable due to the limited availability of translated versions of the validated questionnaires and the aim of the project.

3.4.2 Phase II: semi-structured interviews

CHF patients who complete Phase I will be invited to take part in a semi-structured interview. The aim of this phase is to explore their experiences of living with CHF and elaborate on their questionnaire responses.

3.4.2.1 Design

Semi-structured interviews will be conducted either at a healthcare facility or the participant's home, according to patient choice. Using the interim results of the questionnaires as probes in the interview should encourage in-depth description of their experience of BoT, thereby substantiating the results from Phase I or providing explanations for differences observed.

3.4.2.2 Participants

Phase I patients are eligible to participate in Phase II. Phase II will begin after the completion of the interim analysis.

3.4.2.3 Sampling

Sample size will be defined by data saturation when three consecutive interviews do not generate any new information (180). A maximum variation sampling technique will be used ensuring Phase II sample is representative of Phase I sample population.

3.4.2.4 Methods

Interviews will be audio recorded and the interviewer may take field notes.

SYMPACT Phase II interview schedule is based on previous interview questions developed by other researchers interested in BoT (58, 59, 160-162) and covers domains measured by PETS (Appendix D.2). Further probing questions developed from Phase I interim results will be added to the interview schedule. Following the interview, the researcher's reflections on the interview will be audio recorded, to promote transparency and reflexivity.

3.4.2.5 Data analysis

All interviews and researcher reflections will be transcribed. Fieldnotes, where appropriate, were converted into word documents. All participant identifiers in the interview data will be coded using the participant's unique study number, assigned in Phase I.

Analysis of the interviews will follow an adapted form of Thomas and Harden's methods for thematic synthesis (181). Using NVivo (QRS Internationals), the interview transcripts and researcher notes will be examined line by line for symptom terminology. These will form the initial nodes. Coding credibility will be achieved through member checking (PPI, clinical expert, and co-authors) (182). Each symptom node will be read in its context and a descriptive theme created. Finally, descriptive themes will be examined for similarities to the 'a priori' BoT framework. Constant comparison, reflexivity and discussion with co-researchers will increase rigour and trustworthiness (183).

The ‘a priori’ BoT framework incorporates the following: (1) *Workload*: involving the effort required to: enact tasks (technical and logistic); alter relationships (activate support and seek assistance); and evaluate outcomes of treatments (understanding and evaluation) (58, 59). (2) *Individual capacity*: encompassing an individual’s abilities, resources and readiness to address the workload. Including consideration of a patient’s physical function, cognitive function, emotional status, socioeconomic resources, social support networks, literacy, culture, and beliefs (62). (3) *Impact*: alterations to the patient’s perception of self and their role. Including factors which make adhering to treatment plans more difficult (58, 127).

3.4.3 Phase III: data integration

Data integration for SYMPACT was planned in the study design. The validated questionnaires used were chosen according to theoretical similarities to BoT theory (detailed in Table 2). The data from Phase I and Phase II will be integrated to inform the understanding of how symptoms interact with BoT in CHF. Symptom nodes and descriptive themes (Phase II) will be transformed through content analysis (184) and compared to the symptom burden scores (HFSS and MLHFQ) and BoT scores (PETS) from Phase I providing greater depth and insight into the patient experience. Through constantly comparing codes to the data (150) the descriptive themes will be refined and explored for points of interaction with the a priori BoT framework. This process should provide qualitative narratives to build on the statistical results from Phase I.

Table 2: Data integration overview for SYMPACT

A priori BoT Framework	**Phase I (Quantitative)** Variable measured	**Phase II (Qualitative)** Question theme
Workload:		
Enact tasks	Clinical demands * PETS domain **	What tasks are performed in managing chronic heart failure? Does anyone help with this?
Alter relationships		
Evaluate outcomes		
Individual Capacity:		
Individual's ability	Clinical characteristics*** Personal characteristics^ HFSS total score	What makes managing chronic heart failure more difficult or easy?
Resources and readiness		
Impact:		
Alterations to self and role	MLHFQ total score HFSS interference scores^^ PETS domains**	How does the work of managing chronic heart failure impact their life?
Factors influencing adherence		

*Clinical demands: number of health issues and medications, hospitalisations within a year.

**PETS domains: sub-scores in PETS by work tasks (e.g., medication management, attending appointments, etc.), facilitating tools, and exacerbating factors involved in self-care.

***Clinical characteristics: NYHA classification, aetiology, ejection fraction, CHF type, and years since diagnosis.

^Personal Characteristics: age, gender, marital status, and living situation.

^^HFSS interference scores: sub-scale in HFSS that captures reported interference with physical activity and enjoyment of life.

3.4.4 Patient and public involvement

The PPI group (members of the Patient Research Ambassadors from the Queen Alexandra Hospital) are members of the public with a variety of chronic conditions, including carers of people with CHF. They stated SYMPACT asks a valuable question which they identified as being important to their experience as patients and carers. They approved of the study design as enabling would encourage participants to provide more in-depth information not covered by the questionnaires in this emerging field which was of great importance to them, as they felt that often patient questionnaires don't ask the questions that are important to them. They provided input on study design elements which helped to decrease the study burden for participants. They assisted in the production of the participant and public-facing documents as well as refining and rephrasing interview questions for Phase II. They agreed to help promote SYMPACT, perform credibility checks (part of the data analysis plan for Phase II) and assist in results dissemination. This group is and continues to be an integral part of this project and the primary author's PhD with regular meetings held to keep them appraised of progress and to encourage their input.

3.5 Discussion

Patients with CHF have high symptom burden and are expected to self-manage an illness with poor quality of life and high rates of morbidity and mortality. Despite marked progress with medical and device treatments readmission rates due to perceived non-adherence remain high and quality of life poor. CHF prevalence is expected to rise and the current demands on healthcare systems are already high. BoT provides a different perspective for examining the patient experience. It is thought that overwhelming treatment burden can lead to poor engagement with self-care which may contribute to poor outcomes. SYMPACT proposes a detailed measurement and exploration of treatment burden in patients with CHF. By exploring if symptoms interact with BoT, modifiable factors may be highlighted, providing the starting point for a patient focused intervention. Further, as there are similarities in self-care expectations between CHF and other chronic illnesses this study may also offer transferable knowledge to the understanding of BoT across multiple chronic illnesses.

3.6 Acknowledgements and declarations

We thank Dr Sean Ewing for his statistical advice. Public and Patient Involvement provided by members of the Patient Research Ambassadors (Bill Ware, Carole King, Noreen Cole, Tim Coney, Anna Ganville-Hearson, Graham Edwards, and Chris Staples) from Portsmouth Hospitals NHS Trust.

Declarations: Ethics approval was received from the UK Health Research Authority (MREC: 18/EM/0339) and the University of Southampton (ERGO: 41287). ISRCTN11011943.

Professor Alison Richardson is a National Institute for Health Research (NIHR) Senior Investigator. The views expressed in this article are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

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3.8 Author contributions

All authors read and approved the final manuscript. CRM, AR, and LS are the academic supervisors and PRK is the clinical supervisor for RA’s PhD project. RA, AR, LS, PRK, and CM contributed to the conception and design of the study. RA drafted the article, with LS, PRK, AR and CM revising and editing for intellectual and clinical content.

Chapter 4 Qualitative Evidence Synthesis: Paper 3

4.1 Do chronic heart failure symptoms interact with burden of treatment? Qualitative systematic review

Austin, RC, Schoonhoven, L, Clancy, M, Richardson, AR, Kalra, PR, May, CR. Do chronic heart failure symptoms interact with burden of treatment? Qualitative literature systematic review. BMJ Open. 2021; 11:e047060. doi: 10.1136/bmjopen-2020-047060. (134)

4.2 Abstract

4.2.1 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.

4.2.2 Design

Review of qualitative research studies

4.2.3 Data sources

CINAHL, EMBASE, MEDLINE, PsychINFO, Scopus, and Web of Science were searched between January 2007 - 2020.

4.2.4 Eligibility criteria

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

4.2.5 Results

35 articles were 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: a) Symptoms appear to infrequently drive patients to engage in self-care (9.2% of codes), b) symptoms appear to impede (70.5% of codes) and, c) symptoms form barriers to self-

care engagement (20.3% of codes). Symptoms increase illness workload, making completing tasks more difficult; simultaneously, symptoms alter a patient's capacity, through a reduction in their individual capabilities and willingness to access external resources (i.e., hospitals) often with devastating impact on patient's lives.

4.2.6 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

4.2.7 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.
- This is a review of previously published qualitative studies; observations are restricted by the choice of published quotes from the included articles, and our conclusions were formed by using data to develop explanatory ideas different from those of the original researchers.
- Difference in articles; like various healthcare settings, and broad patient characteristics strengthens the confidence that our observations are common in the chronic heart failure patient population.
- The innovative methods to visually illustrate the qualitative data, allows the reader to observe the depth and breadth of the themes 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.

4.3 Introduction

Chronic heart failure (CHF) is increasing in prevalence, it is now estimated there are just under 1 million patients living with CHF in the UK (2). Despite major advances in its treatment, many people with CHF experience substantial symptom burden and life-limiting prognosis (176, 185, 186). The focus of CHF management is increasingly centred on self-care (1). 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, increased treatments and costs, and poor patient outcomes (21). It should be noted, however, that experiences of illness and adherence to self-care regimens may be influenced by CHF symptoms or co-morbidities, such as cognitive impairment (95), anaemia (187) and fatigue (188). Understanding interactions between symptoms and treatment burden in CHF is an important question, which has yet to be explored. It has been proposed that as symptom burden increases, there is a reduction in the affective, cognitive, relational, informational, material, and physical capacity of people with long-term conditions. This reduction in capacity is reflected in increases in experienced burden of treatment, the dynamic modifiable workload delegated to patients (65, 118, 127). Burden of treatment (BoT) theory (118) 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 (58, 62, 118, 127, 171, 189). BoT theory was chosen as it provides a patient focused framework to explore CHF patient experience, focusing on patients' individual capacity, illness workload and their effects. We have previously argued (132) 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.

4.3.1 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.

4.3.2 Research question

Do symptoms in CHF interact with BoT?

4.4 Methods

4.4.1 Identification of studies

Using a refined search strategy (adapted from May, Cummings (189)), we searched CINAHL, EMBASE, MEDLINE, PsychINFO, Scopus, and Web of Science. Search strategies are provided (Appendix E). 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 a 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 3).

Table 3: Eligibility criteria for included articles

Inclusion criteria	Exclusion criteria
Participants: Aged >18 years old with a diagnosis of CHF	Experience of patients with a 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 a 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., papers 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, 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	

4.4.2 Study selection

RA screened titles and abstracts, using Covidence(190), 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 was made. The comprehensiveness of the search was confirmed through hand searching articles bibliography.

4.4.3 Article quality assessment

RA, CRM and LS assessed articles using the Critical Appraisal Skills Program (CASP) (191). Papers were scored on the presence of additional participant and CHF characteristics. Articles were grouped into high or medium quality categories. NVivo (192) analysis demonstrated no theme was preferentially represented in either high or medium quality articles; therefore, all articles were considered equally.

4.4.4 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 (193).

4.4.4.1 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 (Appendix F). Counts of symptom nodes were used to rank the symptoms according to the frequency and consistency of coding in included articles. Sankey diagrams were built using an open-source coding program, SankeyMATIC (194). A Sankey diagram is a flow diagram, where the width of the arrows represents the depth of that interaction or flow rate.

4.4.4.2 Qualitative analysis

A refinement of Thomas and Harden (181) methodology for thematic synthesis was used. *Stage one, identification:* Extracted data were examined by RA for text referring to symptoms of CHF, forming symptom nodes. A Patient and Public Involvement (PPI) group reviewed the symptom nodes, reorganizing and refining the nodes, whilst simultaneously checking for errors and bias. This process was repeated by a Heart Failure Specialist Nurse (MG). *Stage two, characterization:* codes in each symptom node were read in context and a descriptive theme created capturing the context associated with that symptom. The constant comparison method (195) facilitated an in-depth exploration of the nature of any observed interactions. *Stage three, explain:* Descriptive themes were systematically examined, and compared to the BoT a priori framework coding. Simultaneously, how each symptom acted on the framework was also coded.

4.4.5 Role of public and patient involvement

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

4.5 Results

4.5.1 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 6).

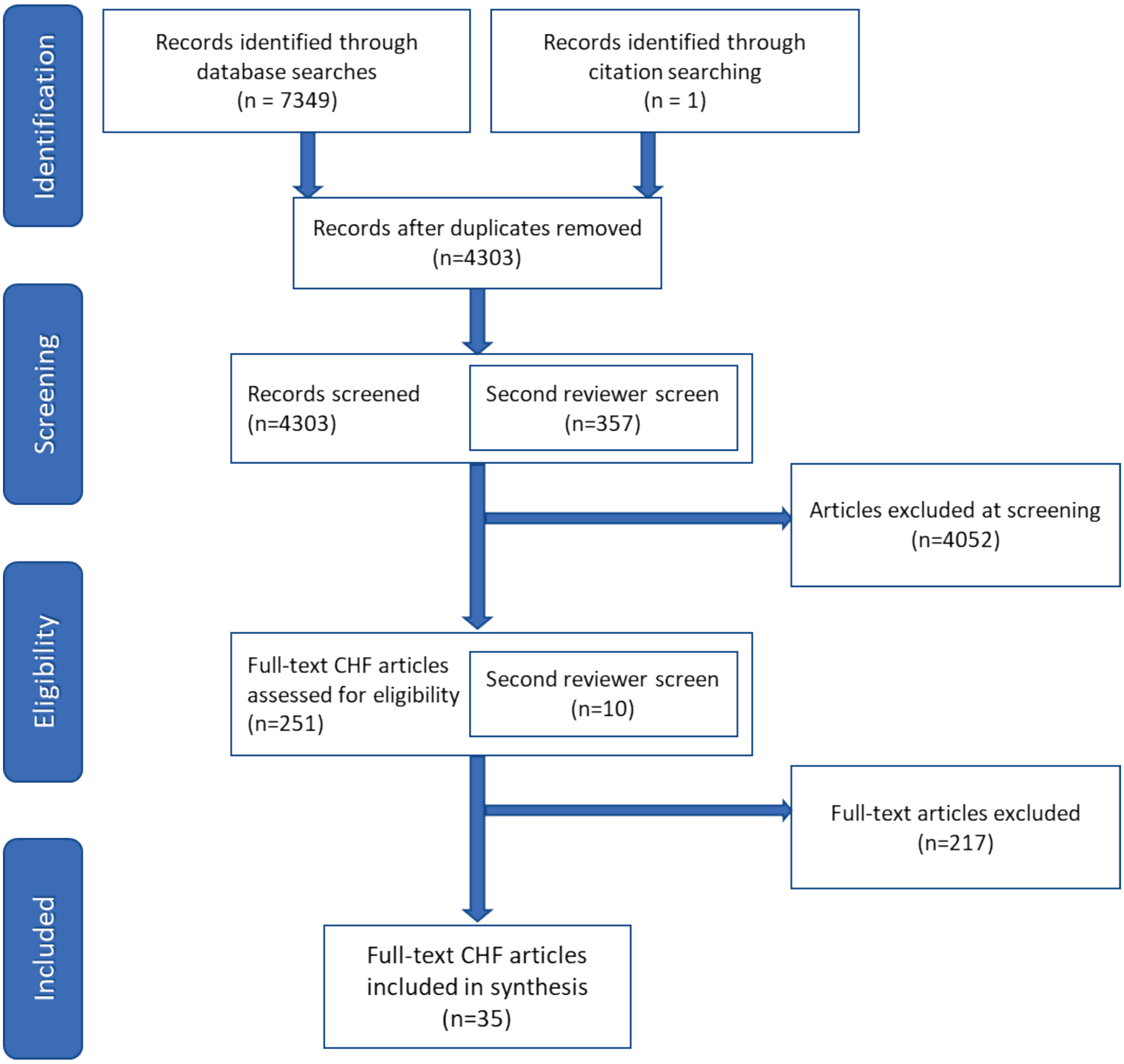


Figure 6: PRISMA Flowchart for CHF articles on patient experience. CHF, chronic heart failure; PRISMA, preferred reporting items for systematic reviews and meta-analysis.

A full list of included articles is provided (Appendix G). Table 4 presents a summative description of included articles.

Table 4: Characteristics of included articles and participants

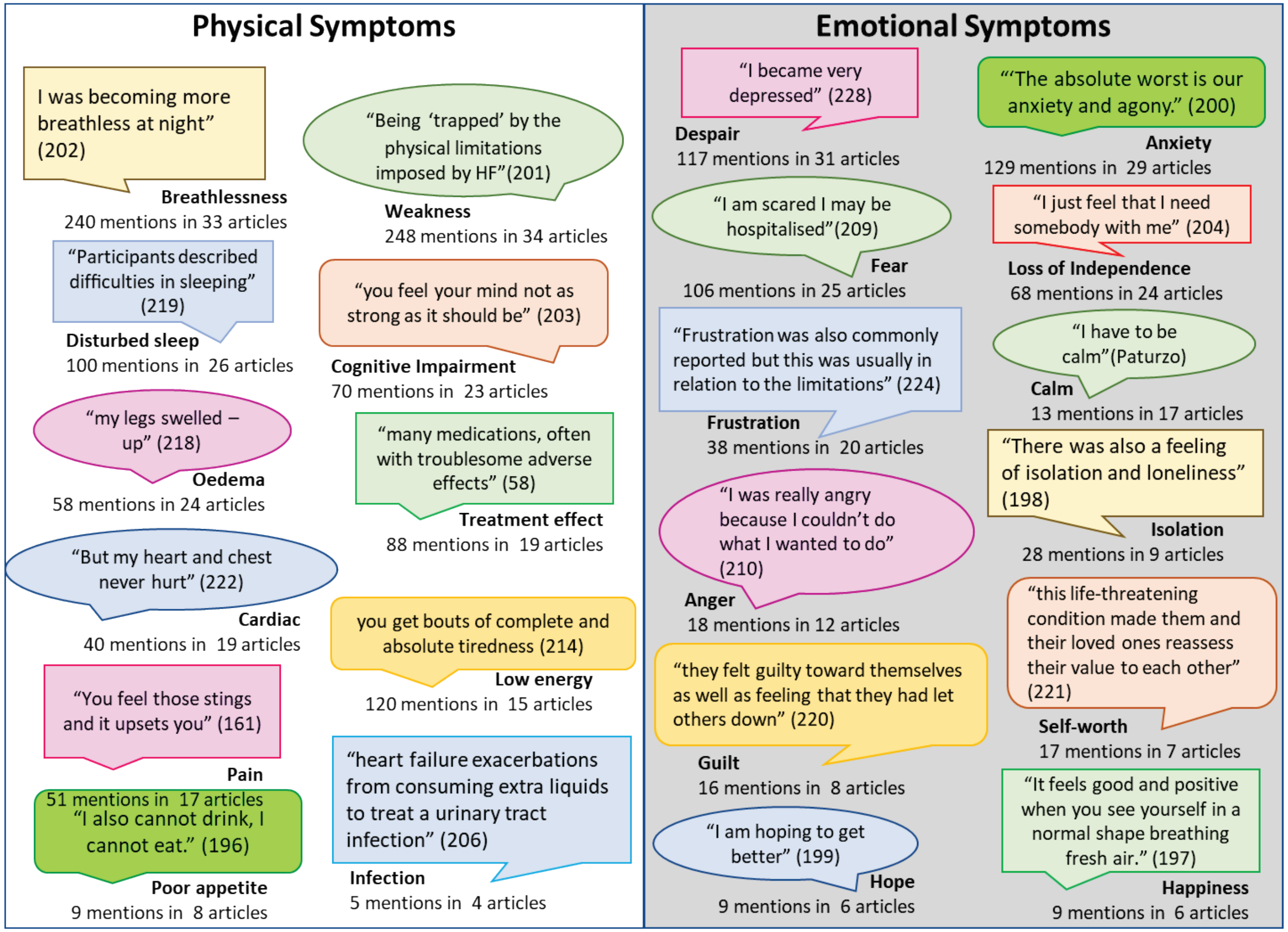
	Total
Location	
North America	11
Asia	9
Europe	14
Africa	1
Methodological Approach	
Qualitative Approach	16
Phenomenology	6
Secondary Analysis	3
Hermeneutic	2
Mixed Methods	1
Constructivist	2
Anthropologic	1
Grounded Theory	2
Patient Narrative	2
Methods	
Interview	30
Focus group	3
Patient Narrative	2
Published participant characteristics	
NYHA Class	21
Ejection Fraction	9
Aetiology of CHF	8
Co-morbidities	12
Duration of illness	18
Employment	17
Education	10
Marital status	21
Ethnicity	18

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

		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*

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.

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 7).



I was becoming more breathless at night" (202)

Breathlessness
240 mentions in 33 articles

"Being 'trapped' by the physical limitations imposed by HF"(201)

Weakness
248 mentions in 34 articles

"Participants described difficulties in sleeping" (219)

Disturbed sleep
100 mentions in 26 articles

"you feel your mind not as strong as it should be" (203)

Cognitive Impairment
70 mentions in 23 articles

"my legs swelled – up" (218)

Oedema
58 mentions in 24 articles

"many medications, often with troublesome adverse effects" (58)

Treatment effect
88 mentions in 19 articles

"But my heart and chest never hurt" (222)

Cardiac
40 mentions in 19 articles

you get bouts of complete and absolute tiredness (214)

Low energy
120 mentions in 15 articles

"You feel those stings and it upsets you" (161)

Pain
51 mentions in 17 articles

"I also cannot drink, I cannot eat." (196)

Poor appetite
9 mentions in 8 articles

"heart failure exacerbations from consuming extra liquids to treat a urinary tract infection" (206)

Infection
5 mentions in 4 articles

"I became very depressed" (228)

Despair
117 mentions in 31 articles

"'The absolute worst is our anxiety and agony." (200)

Anxiety
129 mentions in 29 articles

"I am scared I may be hospitalised"(209)

Fear
106 mentions in 25 articles

"I just feel that I need somebody with me" (204)

Loss of Independence
68 mentions in 24 articles

"Frustration was also commonly reported but this was usually in relation to the limitations" (224)

Frustration
38 mentions in 20 articles

"I have to be calm"(Paturzo)

Calm
13 mentions in 17 articles

"There was also a feeling of isolation and loneliness" (198)

Isolation
28 mentions in 9 articles

"I was really angry because I couldn't do what I wanted to do" (210)

Anger
18 mentions in 12 articles

"this life-threatening condition made them and their loved ones reassess their value to each other" (221)

Self-worth
17 mentions in 7 articles

"they felt guilty toward themselves as well as feeling that they had let others down" (220)

Guilt
16 mentions in 8 articles

"I am hoping to get better" (199)

Hope
9 mentions in 6 articles

"It feels good and positive when you see yourself in a normal shape breathing fresh air." (197)

Happiness
9 mentions in 6 articles

Figure 7: Symptom terms found in included articles: name of symptom node in bold font with example quote in a speech bubble. Counts of frequency and consistency of coding are provided. HF, heart failure.

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 were the most prevalent emotional symptoms.

Figure 8 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.

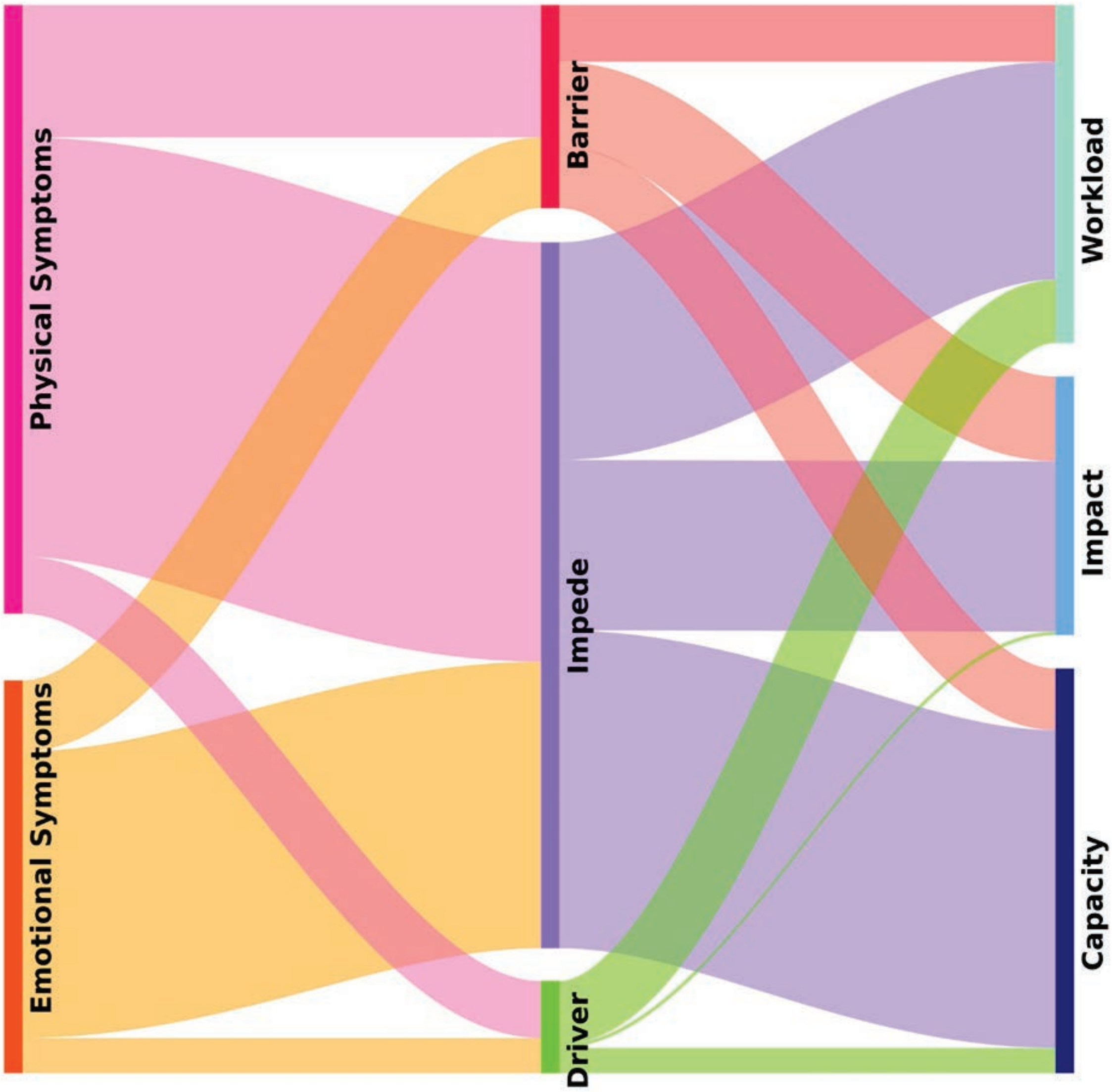


Figure 8: Sankey diagram of symptoms and interaction with burden of treatment. Thickness of the flow bars represents the frequency of that interaction being coded in the analysis.

4.5.2 Results: qualitative content analysis

Here interaction is defined as how a CHF symptom impacted on the patient, influencing their self-care engagement and concurrently altering BoT. Constant comparative analysis (196) revealed positive (drive) and negative (impede and barrier) interactions between symptoms and BoT. Each of these interactions is 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.

4.5.2.1 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: (a) workload in asking for help, and (b) workload in performing tasks of CHF self-care. Symptoms also encouraged patients to utilize their capacity to access external resources. Table 5 provides exemplar quotes and Figure 8 illustrates the interactions.

Table 5: 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 the number of articles coded to this them 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.’’ (197) 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).” (59) pg. 2 online supplementary data*
	Performing 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.” (198) 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.” (199) 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.”(200) 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.” (201) 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 exacerbation (59, 162, 197-219). Symptoms urged patients to access healthcare systems for treatment adjustments or hospital admissions (59, 198, 200, 203, 205, 206, 208, 213, 216-220), receive support from social networks (59, 197, 199-202, 204, 205, 207, 209-213, 215, 217, 219, 221), engage with self-care tasks (59, 162, 197-199, 202, 206, 210, 215-217, 219) and make physical environments alterations (197, 199, 201, 219). 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.

4.5.2.2 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: (a) workload in performing the tasks of CHF self-care, (b) workload in gaining knowledge of CHF, (c) capacity to utilize physical, emotional, mental, and spiritual abilities, (d) capacity to access external resources, and (e) impact of changes to patient self and role. Table 6 provides exemplar quotes and Figure 8 illustrates the interactions.

Table 6: Symptoms 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 the 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	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.” (206) 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)” (222) 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.” (216) 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.” (208) pg. 3602
	In asking for help from social support networks or a 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.” (221) pg. 7

Construct	Themes with exemplar quotes
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)” (204) pg. 266* Emotional (n=25): *“some very dark days over the years’’ and that much of the depression was caused by physical limitations.” (202) 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).” (210) 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)” (215) 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)” (162) pg. 1787* Healthcare system (n=9): *“To see a doctor, you have to wait for an hour. This is very tiring.” (198) 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.’” (212) pg. 266* Physical environment (n=9): *“As she spoke, she pointed to her environment – a three–levelled townhouse. She described 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.” (211) pg. 10*

Construct	Themes with exemplar quotes
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.’’ (202) 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.’” (223) 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).” (207) pg. 142*

Symptoms made monitoring and management of CHF harder (162, 198-201, 205-208, 210, 211, 214, 216, 218, 220, 222, 224). Completing specific tasks such as taking medications, attending appointments, and other self-care activities became more difficult in the presence of symptoms (59, 162, 198, 200, 204-210, 214, 216, 218-220, 222). Further multiple co-morbidities (common in CHF) can create confusion around which illness was responsible for what symptom and which treatment takes priority (198, 203, 205, 207, 210, 211, 216, 217, 222).

Symptoms made daily activities like housework, leisure activities, sexual intimacy, and personal hygiene more difficult restricting patients' holistic participation in life (162, 197-199, 201, 202, 204-213, 216, 219, 220, 222, 225, 226). Within this context of impaired capability, engagement with lifestyle changes was limited (201, 206, 209, 210, 213, 216, 220, 222). When CHF patients were unsuccessful in completing work assigned by health care practitioners: stress, guilt, and anxiety were exacerbated (162, 198, 207, 210, 214, 218). Some reported purposely choosing not to make lifestyle behaviour changes as the effort of these changes outweighed perceived benefits (162, 216).

Symptoms can restrict patients' ability to acquire knowledge around CHF. The sometimes progressive and vague nature of CHF symptoms together with the presence of co-morbidities created confusion hindering baseline understanding of CHF (162, 197, 199, 200, 205-207, 216-219, 224). Treatments for CHF can have iatrogenic effects leading to confusion between disease progression or treatment side effects deterring the evaluation of treatment outcomes (162, 198, 200, 205-208, 210). 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 (162, 198, 200).

Symptoms have a pervasive interaction on patients' physical, mental, emotional and spiritual capabilities, reducing capacity. The interaction between CHF symptoms and patients' physical capability makes activities from talking to exercising more difficult (59, 162, 197-202, 204-208, 210, 211, 215-217, 220-222, 224-228). 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 (59, 162, 197-202, 204, 206-208, 210, 212, 213, 215, 217, 220-226, 229). The coordination and recruitment of this assistance also increases demand on mental capabilities, with negative effects. We observed reported difficulties in comprehending information, decision making, forgetfulness and psychological distress (162, 198, 200, 201, 206-208, 210, 211, 215, 217, 220, 221). Emotional capability appears affected by symptoms in four main ways: a) physical symptoms directly causing emotional distress (162, 198-200, 202, 204, 208, 210, 215, 217, 220-222, 225, 226, 229), b) emotional distress due to being reliant on others to do their work (197, 199, 204, 208, 211, 212, 215, 225), c) a grief process around loss of abilities (162, 198-201, 204, 206, 207, 210, 212, 215, 220-225), and d) accepting a life-limiting diagnosis (59, 198, 200-202, 204, 206, 207, 210, 220, 221, 223, 225). Symptoms mean patients lose what was and begrudgingly accept a new normal.

Symptoms appear to impede patients' 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 (162, 197, 201, 210, 215, 216, 220, 221, 223); yet, symptoms require reliance on family or friends due to decreased physical capability (162, 199, 202, 204, 205, 211, 215, 219, 222, 225, 229). There was also a sense that physical limitations meant adapting or giving up recreational and social activities leading to isolation and loneliness (162, 198, 200, 210, 220, 222, 223). Interactions with healthcare systems, around symptoms, were reported to cause fatigue, fear, confusion, and depression (162, 198, 200, 206, 222). The ambiguous nature of CHF symptoms saw healthcare professionals sometimes misdiagnose patients', providing patients with wrong information, adding further confusion and harming relationships with healthcare professionals (203, 206, 217). Healthcare systems were described as costly in terms of energy (162, 198, 200).

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 Thailand (197, 198, 200, 206, 210, 212, 216, 221, 222). Symptoms also alter a patient's employability decreasing family incomes and changing family roles (197, 198, 200, 206, 210, 212, 216, 221, 222). Unaffordable healthcare and treatments meant that symptoms were ignored by patients until the symptoms were unbearable or that their lives were threatened (197, 198, 200, 210).

Symptoms impact on individual 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, and anxiety at these changes (162, 197-199, 201-206, 208-212, 215, 216, 219-226). 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 their family, care for children, and/or accepting the possibility of an early death (162, 197-201, 205-208, 210, 212-217, 219-222, 225, 226, 229). 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 (162, 197-201, 205-207, 210, 211, 214, 222, 228). Disruptive side-effects of medication meant medications were not taken and/or social activities were restricted (162, 198, 205-207, 210).

4.5.2.3 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: (a) workload in performing tasks of CHF management, (b) workload in gaining knowledge of CHF syndrome, (c) capacity to utilize physical, emotional, mental, and spiritual abilities, (d) individual capacity to access external resources, and (e) impact of changes to self and role. Table 7 provides exemplar quotes and Figure 8 illustrates the interactions.

Table 7: Symptoms as a barrier to patients 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 the number of articles coded to this theme in the BoT framework and had an interaction with a symptom of BoT.

Construct	Themes with exemplar quotes
Workload	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…." (224) 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)" (162) pg. 1787* Gaining knowledge around CHF; understanding 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" (207)pg. 138* In asking for help from social support networks or healthcare professionals (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)" (220) pg. 77*

Construct	Themes with exemplar quotes
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.” (225) 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)” (229) 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.” (210) 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.” (222) 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.” (212) 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” (205) pg.5*

Construct	Themes with exemplar quotes
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.” (223) 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 (202)*

*S*ymptoms 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 (59, 162, 197-200, 203-208, 210-212, 214-216, 218, 220-224, 226, 229). Assigned complex CHF self-care regimens likely become insurmountable in the face of such symptoms (59, 162, 208, 212, 220, 223). The subjective nature of CHF symptoms can form a barrier to both patients and healthcare providers acting in a timely matter to those symptoms (200, 203, 205, 207, 208, 211, 218, 223, 224). Resulting in delayed treatment seeking and poor illness management (200, 203, 205, 208, 215, 218, 220).

Symptoms of CHF appear to form a barrier to patients' physical, mental, emotional and spiritual abilities (59, 162, 199, 201, 202, 206, 207, 210-212, 215, 221-225, 227, 229). The limitation in abilities creates a substantial deficit in their individual capacity, appearing to erode agency immobilizing patients, who then suffer with CHF rather than living with it (162, 199, 202, 207, 210-212, 215, 225, 229).

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 (200, 205, 208, 215, 217). Symptoms stop patients accessing their social support networks; they retreat from their social support networks fearing embarrassment and becoming burdensome (162, 197, 198, 200, 210, 212, 215, 221, 222, 225, 229).

Symptoms inhibit patients from performing desired activities, creating a sense of personal worthlessness (162, 197, 199, 200, 202, 206, 207, 210-212, 215, 216, 220, 221, 223-225, 228, 229). The lack of individual capability alters their role in social support networks, forming a barrier to patients' relationships and future lives (162, 197-200, 202, 203, 206, 207, 210, 212, 215, 216, 219-223, 225, 226). The loss of perceived roles in social support networks has a high cost. The power of the metaphors (Figure 9) used in patients' description of this interaction demonstrates the high degree of impact of symptoms on patient identity.

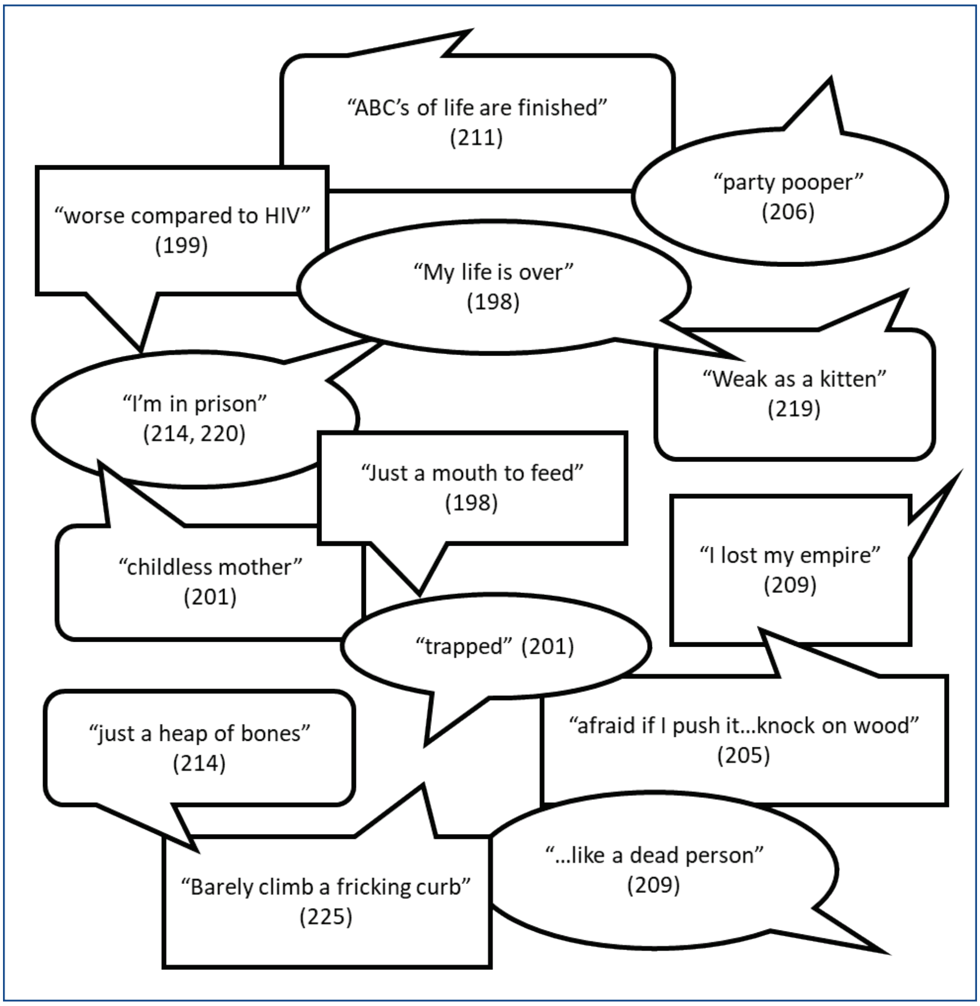


Figure 9: Exemplar metaphors: describing how symptoms form barriers to engagement in desired activities and their perceived role

4.6 Discussion

4.6.1 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 to patients' description of CHF experience, altering BoT; adding to the understanding of factors which influence BoT in chronic illness (189). The work on treatment burden by Jani, Blane (63) 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 align (230-233).

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' delay in seeking healthcare support due to multiple influencing factors (e.g. previous negative experiences, perceived barriers to care, misattribution of symptoms, etc.) (234) rather than symptoms alone (235). Failures in self-care were previously blamed on patients' denial of illness or poor health literacy (231, 236) rather than as this work suggests symptoms having a more complex interaction with patient engagement with healthcare services.

Symptoms impede engagement with self-care were coded in 70.5% of 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, Richardson (65) described how different patient clinical pathways influenced BoT in COPD and lung cancer, where lung cancer patients are expected to follow a structured 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 difficult (60, 233). 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, Jacome, Demain (237), 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 were 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, Lee (232), 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, Cummings (66) noted in chronic kidney disease. From the patient's 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 inhibits patients from engaging in self-care. Previous reviews on living with heart failure appear to neglect to highlight the importance of symptoms on capacity, instead focusing on patients' poor adaptation to their illness and its impact on their lives(236) and their health literacy (238, 239); as well as inadequate healthcare encounters (233, 238, 239).

A preliminary model describing how symptoms interact with BoT has been developed (Figure 10). 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 patient's ability to engage with self-care regimens due to perceived overwhelming BoT.

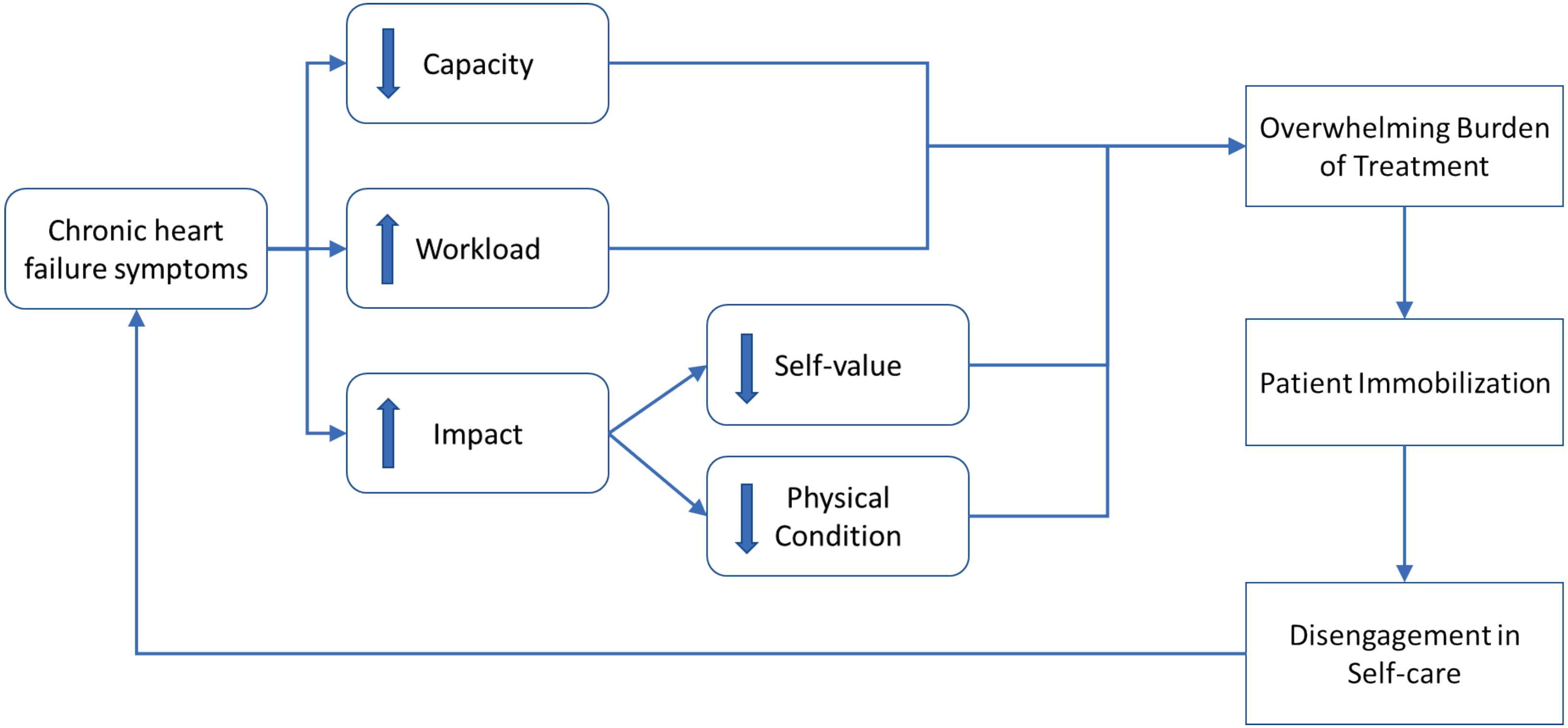


Figure 10: Initial model: CHF symptoms interaction with BoT theory primary constructs. CHF, chronic heart failure

Current research on self-care in CHF focuses on the assumption of patient self-efficacy, which assumes that 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 (117). 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.

4.6.2 Strengths and weaknesses of the study

Our review is the first to explore qualitative literature on patients' experiences of CHF with respect to the interactions of symptoms with BoT. It builds on the foundation of BoT theory (189) 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 stances 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 were 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 a textual comparison (184), 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 (181) methodology for thematic synthesis, which used a three-stage coding process. We adapted their third stage to follow Gallacher, Jani (171) work which takes second stage codes (characterise) and compares them against an a priori framework helping to explain the observations.

4.6.3 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 (133).

4.7 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 symptoms 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 and are a major contributor. Our findings call for more research underpinned by BoT in CHF; exploring changes in CHF service delivery and interventions to enhance patient self-care by focusing on their experiences.

4.8 Acknowledgements and declarations

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Competing interest statement. Professor Alison Richardson is a National Institute for Health Research (NIHR) Senior Investigator. The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health Research, NHS or the Department of Health and Social Care.

Patient consent: Not required

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

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4.10 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.

Chapter 5 Cross-sectional survey of patients with CHF: Paper 4

5.1 SYMptoms in chronic heart failure imPACT on burden of treatment (SYMPACT): a cross-sectional survey

Austin, RC, Schoonhoven, L, Koutra, V, Richardson, AR, Kalra, PR, May, CR. SYMptoms in chronic heart failure imPACT on burden of treatment (SYMPACT): a cross-sectional survey. ESC Heart Failure; https://doi.org/10.1002/ehf2.13904 (135).

5.2 Abstract

5.2.1 Aim

This study aimed to describe patient reported symptoms and burden of treatment (BoT) experienced by patients with chronic heart failure (CHF). BoT describes the illness workload, individual capacity to perform that work and resultant impact on the individual. Overwhelming BoT is related to poor quality of life and worse clinical outcomes. This research is the first to explore symptoms and BoT in people with CHF, in the United Kingdom.

5.2.2 Methods

A cross-sectional questionnaire survey of CHF patients. Participants completed the heart failure symptom survey (HFSS; max score 10) and the Minnesota living with heart failure questionnaire (MLHFQ; max scores: physical 40, emotional 25, and total 105) which measured symptoms. BoT was measured with the patient experience of treatment and self-management (PETS; max score 100) questionnaires. Participant characteristics and questionnaire results were summarised using descriptive statistics. Relationships between symptoms and BoT, summarised by the workload and impact indices, were explored using Spearman's and Pearson's correlation coefficients together with scatterplots.

5.2.3 Results

The survey was completed by 333 participants, mean age of 71 (± 13) years old. The majority (89%) were recruited from secondary care NHS trusts and 25% were female. All types of heart failure were represented. Mean symptom scores were: HFSS burden score: 2.4 (±2.1) and MLHFQ scores physical score 20 (± 12.4), emotional score 9.9 (± 8.1), total score 41.3 (± 26.3). The highest mean PETS domain scores were *exercise* (51.3 (± 24.7)), *diet* (40.3 (± 22.7)), *difficulty with healthcare services* (39.9 (± 21.3)), and *physical and mental fatigue* (36.0 (± 25.7)). Pairwise correlations were observed between HFSS scores and MLHFQ physical and emotional sub-scores with PETS workload and impact indices. Positive correlations were weak to moderate (0.326 - 0.487) between workload index and symptoms and moderate to strong between impact index and symptoms (0.553 -0 .725). The p value was 0.006, adjusted by Bonferroni's correction.

5.2.4 Conclusions

Symptoms are associated with BoT in CHF patients. Although symptom burden was low, CHF patients reported higher levels of burden around self-care activities of exercise, diet, healthcare interaction, as well as physical and mental fatigue due to engagement with self-care regimens. Observed higher levels of burden were in key self-care areas for CHF and suggest areas where service delivery and support of CHF patients may be improved to reduce BoT. Clinicians could individualise their consultations by focusing on troublesome symptoms, as well as alleviating illness workload, which may better enable patients to live well with CHF.

Keywords: Chronic heart failure, burden of treatment, symptoms, cross-sectional survey, self-care

5.3 Introduction

While advances in treatment for chronic heart failure (CHF) have improved patient survival, symptoms of CHF can be progressively debilitating (13). More severe symptoms have been linked to an increased risk of adverse clinical events like hospitalizations (185). Symptoms of CHF have a negative impact on health-related quality of life (HR-QoL) and contribute to psychological distress (13, 185). According to Riegel, Jaarsma (117) theory of self-care, monitoring and managing symptoms are now considered part of the work patients are expected to engage with whilst living with a chronic illness. Self-care refers to the self-monitoring of illness processes, treatment and healthcare management tasks, as well as behaviour changes aimed at improving patient HR-QoL and clinical outcomes. Self-care is a central component of CHF care (1, 20) and a key component of a patient's burden of treatment (BoT). The theory of BoT describes the dynamic interaction between an individual's capacity (capability and resources), workload assigned by healthcare professionals (treatments, self-care regimens), together with the resultant impact on that individual's life (56, 58, 118, 127). Similar to the theory of self-care, the theory of BoT acknowledges symptoms as part of the work but does not specify the influence that CHF symptoms like breathlessness or fatigue might have on self-care engagement or experienced BoT.

In chronic illnesses, including CHF, overwhelming BoT is thought to contribute to poor adherence to self-care regimens (56, 189). Failures of CHF patients to engage with self-care activities are not well understood but are considered a common reason for recurring admissions and poor outcomes (21). BoT specific to CHF has been linked to multiple medications and disjointed healthcare services (59, 119). Emotional burden and an individual's capacity have been highlighted as factors which increase BoT in CHF (131). Physical symptoms are thought to contribute to emotional burden (240). Heart failure symptoms (e.g., fatigue, breathlessness) could understandably make tasks like attending hospital appointments much harder and increase BoT. The relationship between symptoms of CHF and BoT has not been explored.

5.3.1 Objectives

The aim of this study was to explore the interaction between symptoms and BoT in CHF, with the hypothesis that higher reported symptoms will relate to higher scores of BoT.

5.4 Methods

5.4.1 Design

The SYMPACT study design was previously published (133). This paper reports on Phase I, an observational cross-sectional survey of CHF patients' symptoms and BoT measured by validated questionnaires. Adults with CHF in three NHS trusts in Hampshire, United Kingdom (secondary and primary care services) in receipt of inpatient and outpatient care or a member of a community support group were invited to participate. Individuals were given the choice to complete the three questionnaires with the support of research staff or to complete them independently, returning questionnaires and consent by post. Written full informed consent was received from all participants.

Inclusion criteria were English speaking adults over the age of 18. Participants with a clinical diagnosis of heart failure (for at least six months), with a broad range of New York Heart Association (NYHA) classification and left ventricular ejection fractions, who were prescribed a minimum of one treatment for heart failure were considered. The exclusion criteria were patients with or waiting for heart transplants, receiving palliative care, or with substantial cognitive impairment (in the investigators' opinion).

5.4.2 Data collection

Personal characteristics of participants (age, gender, height, weight, ethnicity, marital status, and living situation), clinical information (co-morbidities, medications, CHF diagnosis date), and CHF details (CHF type, aetiology, NYHA classification, left ventricular ejection fraction, and oedema level) were collected from participants and their medical records. Participants completed three validated and reliable questionnaires.

5.4.3 Heart failure symptom survey

The heart failure symptoms survey (HFSS) is a disease specific tool that measures 14 CHF symptoms (e.g., breathlessness, fatigue, oedema, etc.). Each symptom is measured on a Likert scale (from 0-10) where a higher score represents a more severe experience. Each symptom is captured in four dimensions: symptom frequency and severity, as well as interference with physical activity and enjoyment of life (156). HFSS includes both typical and atypical symptoms of CHF (157). HFSS burden score (max score 10) was calculated. This is a standardized summation of two dimensions (frequency and severity) of all 14 symptoms, quantifying the reported burden of symptoms. Individual symptom scores (max score 10) were also calculated as a standardised summation of all four dimensions for each symptom. A score of <1 was chosen to indicate that the participant denied experiencing that symptom, as it meant that the participant did not report individual items as high enough to result in a summed total score of >1. Participants were asked to report on their symptoms from the last week.

5.4.4 Minnesota living with heart failure questionnaire

The Minnesota living with heart failure questionnaire (MLHFQ) is a tool that measures key physical, emotional, social and mental dimensions of HR-QoL (179). The MLHFQ physical and emotional sub-scores were calculated (155) and used to describe participants' symptoms. Additionally, the MLHRQ total score was calculated. Maximum MLHFQ total score is 105, the sub-scores have maximum scores of 40 (physical) and 25 (emotional). Higher scores are related to worse HR-QoL or symptom experience. Participants were asked to report on their experience over the last month.

5.4.5 Patient experience with treatment and self-management

The patient experience with treatment and self-management (PETS) questionnaire is a tool that quantifies the patient's experience of BoT. It was designed for use in multi-morbid chronic illness (124). While the 48-item tool was used, we report results using the more recently revised brief

PETS (167). The brief PETS is a 34-item tool that has reduced the original nine domains into 2 indices and 4 individual domains. The workload index summarises the domains of medical information, medications, medical appointments, and monitoring health. The impact index summarises the domains of role and social activity limitations together with physical/mental fatigue. The 4 individual domains are: diet, exercise/physical therapy, medical expenses, and difficulty with healthcare services (167). Maximum score of the indices or domains is 100, with higher scores relating to greater burden. In the domains of medical information, monitoring health, medical expenses, and difficulty with healthcare services the PETS scoring system requires that the participant response “did not apply” be converted into missing data. In the domains of diet and exercise/physical therapy, participants are asked a yes/no question where ‘no’ means they do not continue with the items in this domain. Both data processing techniques increase the amount of missing data. It also provides the opportunity to describe how many participants reported not having diet or exercise/physical therapy discussed with them by a healthcare provider. As PETS does not have a single summary score, indices (workload and impact indices) were used as summative measures for BoT and used in the correlation analysis. Participants were asked to report on their experience over the last month.

5.4.6 Data analysis

Statistical analyses were performed using the Statistical Package for Social Sciences (SPSS) Version 26 (241). Descriptive statistics were performed on participants’ clinical data and questionnaire responses. Data were summarised as mean (± standard deviation) and median [with range and interquartile range]. Correlations and scatter plots were obtained to assess the hypothesised pairwise relationships between symptoms (HFSS burden score, MLHFQ physical and emotional sub-scores) and BoT (PETS workload and impact indices). The assumption of normality was assessed using the Kolmogorov-Smirnov and Shapiro-Wilk normality tests and visually examined using histograms and normal Q-Q plots. Results with a p value less than 0.05 were considered statistically significant and Bonferroni method was used when required to adjust for multiple testing. Correlation coefficient above 0.5 was considered at least moderate (242).

5.4.7 Ethics

Ethical approval was granted by the University of Southampton Ethics Committee (ERGO: 41287) and the Nottingham HRA1 Research Ethic Committee, Health Research Authority (MREC: 18/EM/0339, IRAS: 247773). SYMPACT conforms with the Declaration of Helsinki principles (243). SYMPACT was registered with the ISRCTN registry: ISRCTN11011943.

5.4.8 Procedures

Screening of participants occurred between November 2018 and March 2020. They were approached by a research team member whilst attending NHS trusts (inpatients and outpatients) or community support groups. After providing time for participants to consider participation, fully informed written consent was received either in person or through the post. Method of consent was chosen by the participants.

Participants who completed the study activity in an NHS trust were offered the support of a research nurse, to answer specific queries regarding the questionnaires. Participants who chose to self-consent were asked to return the completed questionnaires and consent form by post in provided self-addressed stamped envelopes. If the study packs were not returned participants were called and if interest in participation was confirmed, then participants were reminded to complete and return the study packs to the appropriate study centre. Clinical data from medical records were collected by research staff. These data along with the completed questionnaires: HFSS (156), MLHFQ (179), and PETS (124) were entered into an electronic database. All data were managed by REDCap Cloud software (166). All data entered in the database by research staff at local centres were verified by a second researcher. Identified errors, mainly typographical, were corrected.

5.5 Results

Adults with CHF (n=633) were screened across 3 NHS trusts and community support groups in Hampshire, UK: 387 were eligible and approached to participate, 338 consented and 333 completed study activities. Those found not to be eligible included individuals with a new diagnosis of CHF, receiving end-of-life care, or with cognitive concerns. Those who chose not to participate mainly cited inconvenience of the study for non-participation.

5.5.1 Survey characteristics

Most participants (89%) were recruited from secondary NHS trusts with the remainder of participants from primary care trusts (9%) or community support groups (2%). A minority of participants (26%, n=88) reported receiving help from carer/family member to complete the questionnaires. Only four questionnaires (3 HFSS and 1 MLHFQ) were not completed or were missing in study packs returned by post.

5.5.2 Study population

Participants had an average age of 71 (± 13 years) with an age range of 22-96 years old. The majority of participants were male (72%) and identified as white British (79%). Over half of the patients reported living with a spouse or partner (58%). Detailed study population characteristics are presented in Table 8.

Table 8: Participant characteristics

Age (years)		**Ethnicity**	**n (%)**
Mean (SD)	71 (13)	*White British*	263 (79)
Missing (n)	1	*White other*	6 (1.8)
BMI		*Asian*	3 (0.9)
Mean (SD)	30.6 (6.5)	*White & Asian*	1 (0.3)
Missing (n)	62	*Missing*	60 (18)
Number of medications		**Marital Status**	**n (%)**
Mean (SD)	9 (3.3)	*Married*	186 (55.9)
Number of health issues		*Civil partnership*	11 (3.3)
Mean (SD)	7 (3.4)	*Divorced*	36 (10.8)
Co-morbidities	**n (%)**	*Separated*	5 (1.5)
Atrial fibrillation	147 (44)	*Widow*	54 (16.2)
Myocardial Infarction	67 (20)	*Single*	31 (9.3)
Blood pressure disease	133 (40)	*Missing*	10 (3.0)
Stroke or mini-stroke	33 (10)	**Living situation**	**n (%)**
Peripheral Vascular disease	13 (4)	*With partner/spouse*	194 (58.3)
COPD	51 (15)	*With other family members*	31 (9.3)
Diabetes (type I and II)	100 (30)	*On my own*	93 (27.9)
Chronic Kidney Disease	61 (18)	*Sheltered accommodation*	4 (1.2)
Muscle-skeletal disease	83 (25)	*With lodgers*	2 (0.6)
Mental Health diagnosis	22 (7)	*Missing*	9 (2.7)
Cancer	26 (8)		

Missing values include unreported by participant, not in medical records in the past 4 months, or records not accessed. n number of participants, SD: standard deviation, BMI: body mass index COPD: chronic obstructive pulmonary disorder, SD: standard deviation.

5.5.3 CHF characteristics and treatments

All participants had a diagnosis of CHF for a minimum of 6 months. Sixteen percent of participants were classed as heart failure with preserved ejection fraction (HFpEF) in clinical records. A third had ischaemic heart disease documented as CHF aetiology. Over half of the population (53%) had no documented NYHA classification in their medical records over the preceding 4 months. Participants were prescribed a mean of 9 (± 3.3) medications and had 7 (± 3.4) co-morbidities documented. The majority of participants (66%) were on triple therapy for CHF (at least 3 of the medication types listed in Table 9). Additionally, 72% were on some type of diuretic and 34% had an implantable cardiac device. Further details on participant CHF characteristics and treatments are in Table 9.

Table 9: CHF characteristics and treatments

Type of Heart Failure	**n (%)**	**Left ventricular ejection fraction****	**n (%)**
HFrEF	209 (62.8)	*Normal (≥55%)*	38 (11.4)
HFpEF	53 (15.9)	*Borderline (50-54%)*	18 (5.4)
Missing	71 (21.3)	*Impaired (36-49%)*	94 (28.2)
Aetiology	**n (%)**	*Severely impaired (≤35%)*	161 (48.3)
Ischaemia	111 (33.3)	*Missing*	22 (6.6)
Cardiomyopathy (any type)	76 (22.8)	**Oedema level**	**n (%)**
Hypertension	17 (5.1)	*Nil oedema*	125 (37.5)
Multi-factorial	16 (4.8)	*Minor (feet to mid-shin)*	67 (20.1)
*Other**	15 (4.5)	*Moderate (lower limb)*	24 (7.2)
Missing	98 (29.5)	*Severe (above knee)*	20 (6.0)
Years since diagnosis	**n (%)**	*Missing*	97 (29)
6 months – 1 year	62 (18.6)	**CHF treatments**	**n (%)**
1 -3 years	100 (30.0)	*Betablocker*	295 (89)
3-5 years	49 (14.7)	*ACE inhibitor / Angiotensin receptor blocker*	153 (46)
5-10 years	48 (14.4)	*Mineralocorticoid receptor antagonist*	270 (81)
10+ years	31 (9.3)	*Sacubitril/Valsartan*	136 (41)
Missing (at least 6 months)	43 (12.9)	*Ivabradine*	23 (7)
NYHA classification	**n (%)**	*Diuretics*	239 (72)
I	28 (8.4)	*Implantable cardiac device*	124 (37)
II	71 (21.3)		
III	35 (10.5)		
IV	4 (1.2)		
Missing	195 (58.6)		

*Missing values include unreported by participant, not in medical records in the past 4 months or records not accessed. n: number of participants, SD: CHF: chronic heart failure, HFpEF: heart failure preserved ejection fraction, HFrEF: heart failure reduced ejection fraction, HYNA: New York heart association. *Other: atrial fibrillation, pulmonary hypertension, valve disease, hyperthyroidism, rheumatic fever. **Classified according to the British society of echocardiography standards (244)*

5.5.4 Questionnaire results

5.5.4.1 HFSS

For a quarter of participants (26%) HFSS burden score was less than 1, which was interpreted as CHF symptoms creating no burden (section 5.4). Fatigue and shortness of breath with activity were most often reported to cause a degree of burden (score >1), 85% and 82% respectively. Symptoms such as dizziness, forgetfulness and depression were reported for at least 50% of the sample. Median HFSS burden score was 2.3 [0, 9.8]. Individual symptom scores are reported in Table 10.

5.5.4.2 MLHFQ

A small proportion of participants (13%) reported that CHF did not impact HR-QoL (total score <1). In the symptom sub-score 28% (n=93) denied physical symptoms and 52% (n=175) denied emotional symptoms (scores <1). Symptom sub-scores were also calculated with the mean physical score of 20 (±12.4) and emotional score of 9.9 (±8.1). The mean total MLHFQ score was 41.3 (± 26.3).

5.5.4.3 PETS

In the domains *diet* and *exercise/physical therapy*, respectively 54% and 46.5% of participants reported that no healthcare professional had given them guidance around dietary recommendations or exercise/physical therapy advice. For those who reported receiving advice in these domains, participants reported a mean score of 40.3 (± 22.7) and 51.3 (± 24.7) respectively. The domain of *difficulty with healthcare services* (39.9 (± 21.3)) and *physical and mental fatigue* (36.0 (± 25.7)) were the next most burdensome domains. Workload index had a mean score of 27.3 (± 17.1) and impact index had a mean score of 33.2 (± 25.4). Table 10 reports PETS individual domain scores.

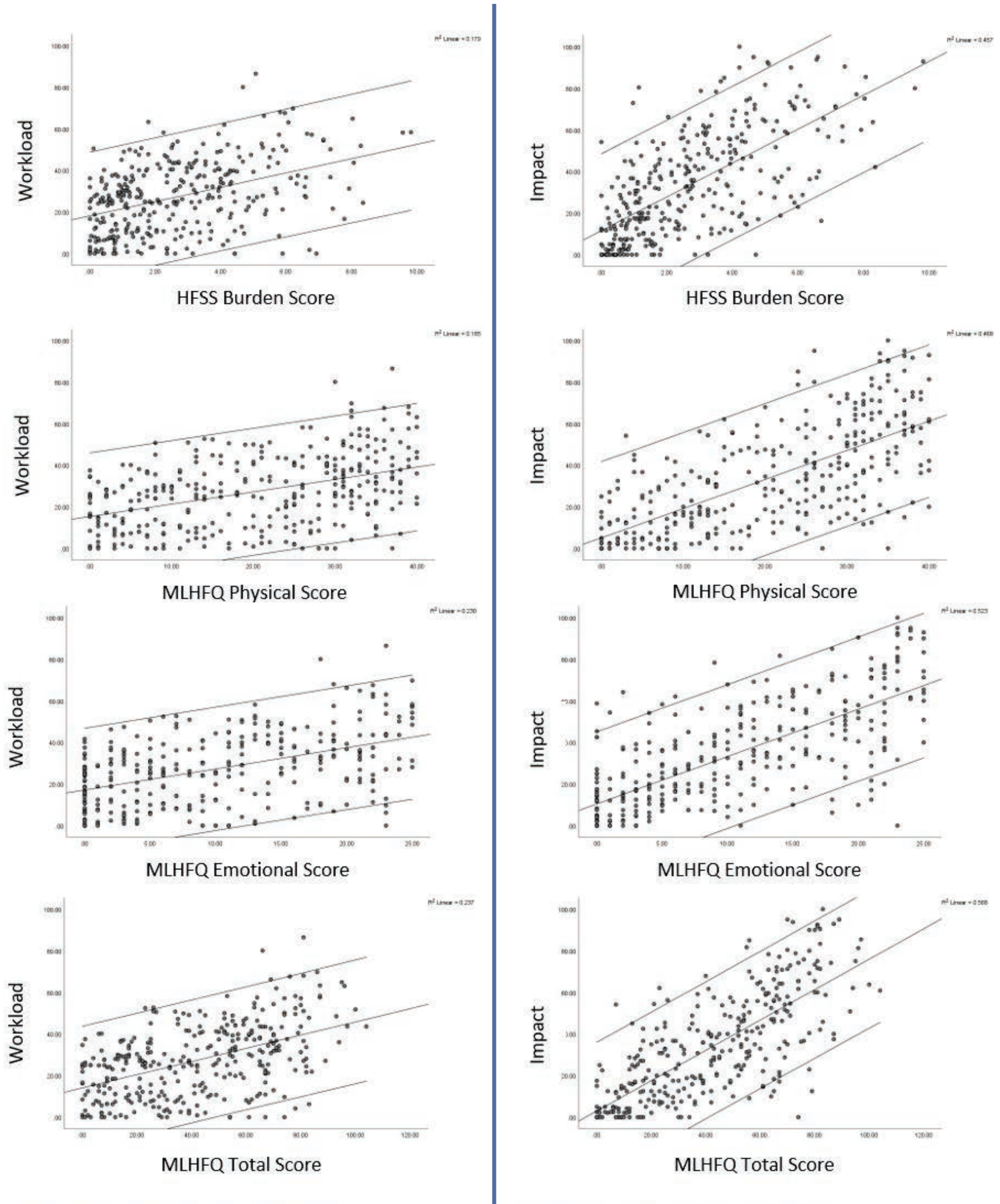
Table 10: Questionnaire results.

	Mean (SD)	Median [min, max]	IQR	Missing (n)	Score <1 (n)
HFSS (n=330)					
Burden Score	2.4 (2.1)	2.3 [0,9.8]	3.1	3	88
Short of breath at rest	2.3 (3.0)	0.4 [0,10]	3.8	5	175
Short of breath with activity	4.7 (3.4)	4.8 [0,10]	6.3	7	63
Short of breath when lying down	1.6 (2.6)	0 [0,10]	2.1	3	212
Short of breath wake up at night	1.4 (2.4)	0 [0,10]	2.0	4	217
Swelling in lower limbs	2.4 (3.3)	0.3 [0,10]	4.5	6	183
Bloated abdomen	2.3 (3.2)	0.3 [0,10]	4.0	3	186
Fatigue	5.1 (3.5)	5 [0,10]	6.3	4	54
Chest pressure	1.7 (2.7)	0 [0,10]	2.5	5	208
Irregular heartbeat	2.0 (2.9)	0.3 [0,10]	3.5	4	186
Worsening cough	1.7 (2.8)	0 [0,10]	2.3	4	209
Dizziness	2.4 (2.9)	1 [0,10]	4.0	3	150
Difficulty sleeping	2.4 (3.2)	0.9 [0,10]	4.5	3	165
Forgetfulness	2.2 (2.9)	1 [0,10]	3.8	8	135
Depressed	2.7 (3.2)	1.3 [0,10]	4.5	9	146
MLHFQ (n=332)					
Total score	41.3 (26.3)	41 [0-104]	47	1	49
Physical symptom score	20 (12.4)	21 [0-40]	22.8	1	93
Emotional score	9.9 (8.1)	9 [0-25]	15	1	175
PETS (n=333)					
Workload index score	27.3 (17.1)	26.9 [0-86]	27.1	6	65
Medical information	28.8 (19.5)	25 [0-93]	28.6	9	61
Medications	20.0 (18.7)	21.4 [0-86]	28.6	1	125
Medical appointments	27.1 (22.1)	25 [0-96]	33.3	0	98
Monitoring health	33.7 (24.4)	25 [0-100]	37.5	45	56
Impact index score	33.2 (25.4)	29.6 [0-100]	40.31	7	71
Role and social activity limitations	30.4 (29.7)	25 [0-100]	45.8	2	117
Physical and mental fatigue	36.0 (25.7)	25 [0-100]	40.0	6	57
Medical expenses	31.2 (24.6)	25 [0-100]	41.25	61	68
Difficulty with healthcare services	39.9 (21.3)	38.9 [0-100]	24.04	19	36
Diet	40.3 (22.7)	33 [0-100]	22.2	195	14
Exercise / Physical Therapy	51.3 (24.7)	50 [0-100]	33.3	166	14

Missing values include unreported by a participant or as a function of that tool's scoring system (n=number of participants). Scores <1 are reported to illustrate the number of participants (n) who reported that factor as; not present (HFSS and MLHFQ) or very easy (PETS). HFSS: Heat failure symptom survey. MLHFQ: Minnesota living with heart failure questionnaire. PETS: patient experience of treatment and self-care. IQR: Interquartile range.

5.5.5 Correlation between symptoms and burden of treatment

Pairwise correlations were obtained to examine the relationship between HFSS scores and MLHFQ physical and emotional sub-scores with PETS workload and impact indices. Scatterplots between symptom scores (HFSS burden score, MLHFQ physical and emotional scores) and burden of treatment scores (PETS workload index, impact index) showed some indication of linear relationship (Figure 11).

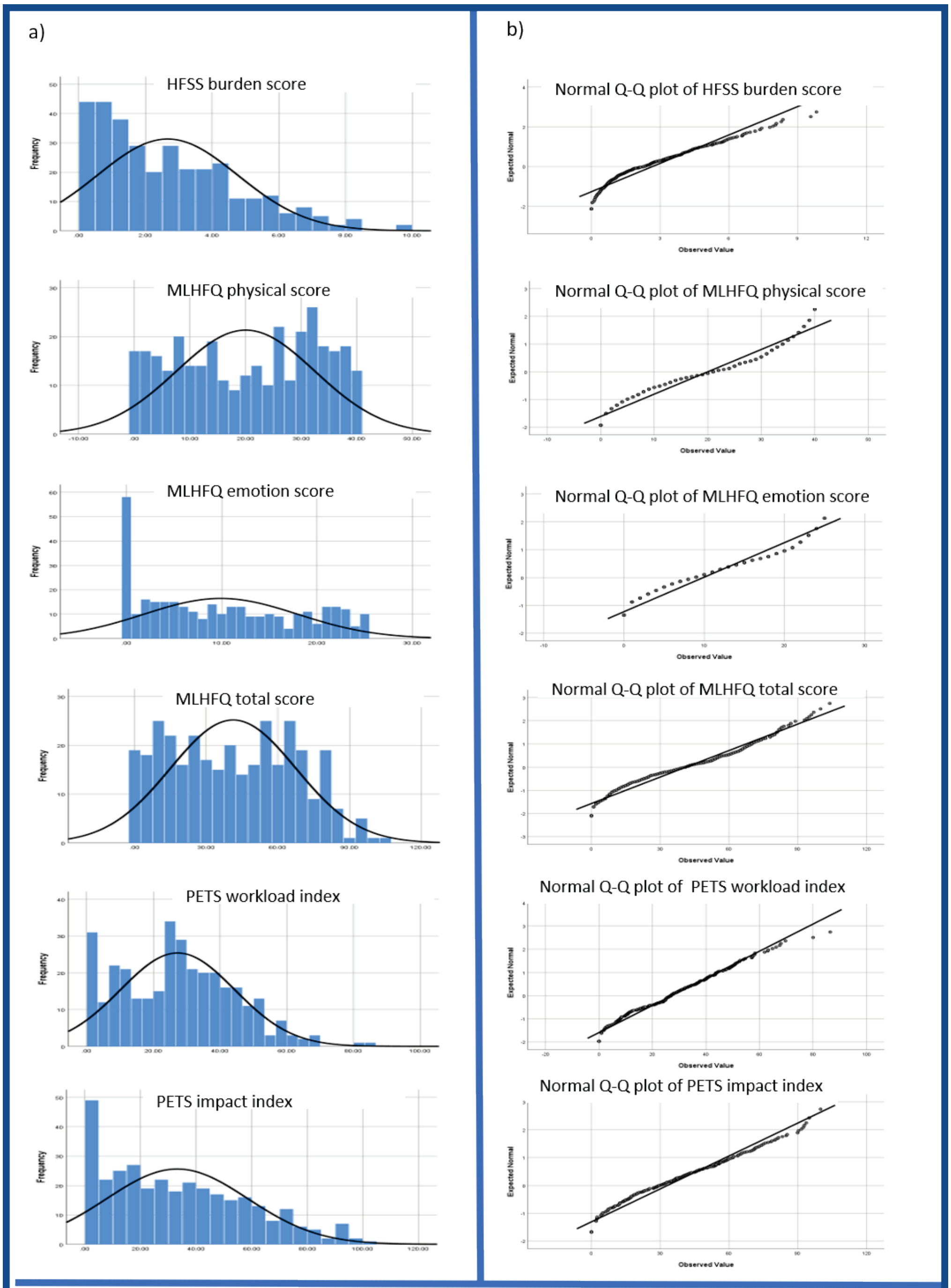


a) Workload index versus symptoms

b) Impact index versus symptoms

Figure 11: Scatterplots of BoT indices (PETS) and symptom scores (HFSS and MLHFQ). Workload is shown in (a) and Impact is shown in (b). Linear lines of best fit and 95% confidence lines are shown. BoT: Burden of treatment. PETS: Patient experience of treatment and self-management, HFSS: Heart failure symptom survey, MLHFQ: Minnesota living with heart failure questionnaire.

From a combination of graphical inspection and formal testing, most scores did not follow a normal distribution except for some of the MLHFW and PETS scores, where there were no strong deviations from normality according to Q-Q plots (Figure 12).



c)

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
HFSS burden score	0.110	330	0.000	0.925	330	0.000
MLHFQ physical score	0.106	332	0.000	0.935	332	0.000
MLHFQ emotion score	0.117	332	0.000	0.913	332	0.000
MLHFQ total score	0.084	332	0.000	0.960	332	0.000
PETS Workload index	0.065	327	0.002	0.975	327	0.000
PETS Impact index	0.095	326	0.000	0.944	326	0.000

[a] Lilliefors Significance Correction. p<0.001 significance level

Figure 12: Normality examinations of HFSS burden, MLHFQ scores, and PETS indices. a) Shows histograms with normal curves for all variables used in correlations. (b) Shows Normal Q-Q curves for those same variables. (c) Shows the normality test results.

PETS: Patient experience of treatment and self-management, HFSS: Heart failure symptom survey, MLHRQ: Minnesota living with heart failure questionnaire.

Both parametric and non-parametric correlation results are presented in Table 11. All correlation coefficients are significantly different from zero using a Bonferroni correction at a 5% family-wise significance level. Differences between the parametric and non-parametric tests are minimal. Correlations between symptoms (HFSS burden or MLHFQ sub-scores) and the PETS impact index score were moderate to strong (.553 - .725). In comparison correlations between symptoms (HFSS burden or MLHFQ sub-scores) and the PETS workload index score were weak (.326 - .467). Similar differences in correlation strengths were observed between HR-QoL (MLFHQ total score) and the workload and impact indices.

Table 11: Correlations between symptoms and BoT.

	HFSS burden score		**MLHFQ physical score**		**MLHFQ emotional score**		**MLHFQ total score**	
	Correlation Coefficient	p	Correlation Coefficient	p	Correlation Coefficient	p	Correlation Coefficient	p
Workload Index								
n	324		326		326		326	
Pearson’s	.344*	.000	.326*	.000	.406*	.000	.487*	.000
Spearman’s	.408*	.000	.424*	.000	.463*	.000	.467*	.000
Impact Index								
n	324		325		325		326	
Pearson’s	.572*	.000	.553*	.000	.621*	.000	.753*	.000
Spearman’s	.693*	.000	.699*	.000	.725*	.000	.762*	.000

*HFSS: heart failure symptom survey, MLHFQ: Minnesota living with heart failure questionnaire, n the numbers of participants. *Adjusted significance (two-tailed) threshold using Bonferroni’s correction is p < 0.006*

5.6 Discussion

Our survey demonstrates a positive association between symptoms (measured by HFSS and MLHFQ) and BoT (measured by PETS) in CHF patients (Figure 13). As symptom burden increases there is a positive stepwise increase in workload and impact and thereby BoT. Our exploration into the association between symptoms and BoT, measured by these questionnaires, revealed that symptoms and workload index appear to have a weak association while symptoms and impact index have a moderate to strong association. This shows that symptoms may have a more direct influence on BoT than previously thought.

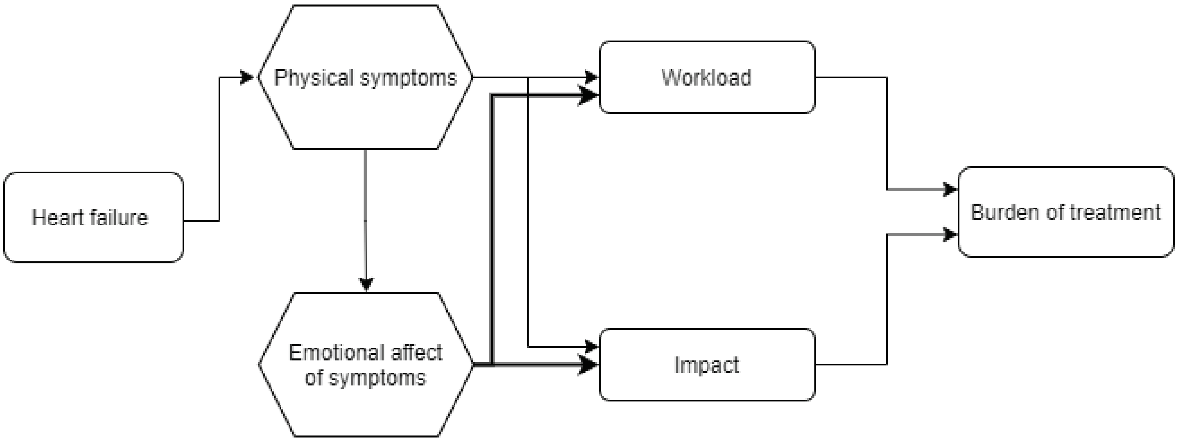


Figure 13: Interaction of CHF symptoms with BoT. Thicker lines represent strong statistical association between these factors as seen in the results. CHF: Chronic heart failure, BoT: Burden of treatment.

With respect to 12 of the 14 symptoms, included in the HFSS, many of our participants denied symptom burden. Symptoms of shortness of breath and fatigue had the highest burden and were more commonly reported. Our population reported lower HFSS burden scores in comparison to others (245-247). However, it was similar to HFFS score reported by Graven, Grant (240), which may be a reflection of differences in sample characteristics, differences in CHF care provision, or due to recent improvements in pharmaceutical CHF treatments. However, MLFHQ sub-scores (physical and emotional) were similar to those reported elsewhere (248-251). The lower symptom score may reflect this population being on optimal treatments for CHF, for example, 41% were receiving sacubitril valsartan. Assessing patient experience of symptoms in CHF is challenging without an agreed gold standard tool (157).

Despite a low median symptom burden score (HFSS), participants reported moderate mean levels of burden in PETS domains of *exercise/physical therapy*, *diet*, *difficulty with healthcare services*, and *physical and mental fatigue*. In our population PETS, individual domain scores were between those reported in a multi-morbid population (167) and those reported in a Norwegian CHF population (252). At least 50% of our participants denied healthcare professionals having advised them about specific diet or exercise recommendations. Both of which are considered important factors in CHF self-care (253) and are often associated with poor self-care practices potentially contributing to readmissions (17). The BoT dimension of *difficulty with healthcare services* had the third highest reported burden, which has parallels with previous work highlighting that the complexity of healthcare service provision can be a barrier to CHF patients engaging with self-care (234).

Symptoms have a moderate to strong correlation with the PETS impact index. The impact index captures how much engagement with self-care regimens interferes with the domains of *role and social activity limitations* (ability to work, family responsibility, daily and social activities) and *physical and mental fatigue* (negative emotional and physical experience from engaging with self-care). In CHF patients in Norway, Nordfonn, Morken (252) observed moderate correlations between HR-QoL scores (MLHFQ total score) and the BoT dimensions (role/social activity limitations and physical/mental fatigue), which are comparable to our findings. In our work we examined this further by looking at the MLHFQ sub-score, which showed a strong association between the emotional sub-score of MLHFQ and the impact of self-care (PETS impact index), further adding to Nordfonn, Morken (131) conclusions that psychological distress adds to BoT and impairs HR-QoL.

The weak to moderate correlation between symptoms and workload index was unexpected. The workload index in PETS captures how easy or difficult patients report their workload around the domains of *medical information* (health literacy), *medications* (medication management), *medical appointments* (arranging and attending medical appointments), and *monitoring health* (illness specific self-care tasks and monitoring lifestyle recommendations). CHF has complex self-care regimens (253) and clinical perception of poor patient compliance (21). We assumed that participants would report, on average, higher workloads with associated high symptom burden. Raising the question, if the work is easy then why are CHF patients thought to be not doing the work? Our results are contrary to others who reported on the heavy self-care burden and impact of symptoms (13). However, key elements of CHF self-care workload (PETS domains: *exercise/physical therapy*, *diet*, and *difficulties with healthcare services*) are not included in PETS workload index. Our population scored these elements as having higher BoT. The reporting of high burden in these domains aligns with previous findings of disjointed healthcare services contributing to patient burden (119, 131) and poor compliance with diet and exercise (254). These results also hint that healthcare interactions might need greater consideration to better understand the CHF patient experience of BoT. In SYMPACT Phase II (qualitative study), we will ask a subset of this population, what is the work involved in managing CHF and do symptoms influence that work; in an effort to better understand these unexpected results.

The project aimed to explore if symptoms of CHF are intrinsically linked to BoT i.e., if a patient has low symptom burden, then the BoT will also be low. The spread of the data (Figure 11) highlights that people with no symptoms reported both low and high burden and it was similar for people with higher symptom scores. This suggests that other factors might also be influencing the observed association between symptoms and BoT. The authors plan to explore this further in a combination of secondary analysis of the quantitative data and qualitative data.

5.6.1 Limitations

CHF experience was captured in a single region in England, with a low percentage of women and ethnic minorities contributing to the data set. Also, while our study includes those with HFpEF, this was a small percentage of the sample due to the delivery of CHF services locally, in that not many individuals with HFpEF currently receive regular clinical follow-ups. This may limit its generalizability. Between 41-65% of the sample denied burden in 12 symptoms in the HFSS, which may indicate the need for a larger sample if you include participants who are stable and with a lower NYHA classification. Filtering out these cases raised the median HFSS burden score to 3.5, which is closer to HFSS scores previously reported. As this study was observational, we were reliant on a combination of patients self-reporting health information and researchers examining participant medical records, leading to some variables having a high amount of missing data.

5.6.2 Clinical implications

This study described how CHF patients reported increased burden in engaging with key elements of their self-care. Healthcare interactions had some of the highest burden scores. Healthcare service providers, clinicians, and researchers need to focus strategies to improve healthcare interactions. Additionally, more needs to be done around communicating and supporting people with CHF in lifestyle behaviours such as dietary changes and exercise.

Our work described how greater emotional affect is associated with greater impact on a patient's role and social activity limitation as well as their physical and mental fatigue associated with engagement with self-care activities. This high personal cost of doing that work together with difficulties in healthcare interactions, likely decreases engagement in self-care regimens, suggesting that perhaps complex healthcare systems may contribute to poor engagement with self-care regimens. Clinicians and researchers need to incorporate the consideration of BoT together with decreasing symptom burden to enable patients to live well with CHF alongside increasing adherence to their self-care treatment plans.

We postulate that if healthcare professionals incorporated BoT into the clinical evaluation of CHF, alongside symptom burden, this will create a more individualised approach. Facilitating a more specific and supportive clinical interaction by focusing on troublesome symptoms (some of which may not be included in a typical heart failure consultation) or in decreasing illness workload.

5.7 Conclusions

Our results add to the evidence that symptoms are associated with BoT in CHF patients. Our exploratory analysis demonstrated a moderate to strong positive association of symptoms with BoT, but more work is required to better understand which interventions may reduce BoT. Symptoms such as fatigue and breathlessness are frequently experienced even though this population's CHF was well treated. Further, the emotional affect from symptoms and engagement with self-care is strongly associated with BoT, suggesting that clinicians should consider symptoms as more than an indication for disease progression or adjustments to pharmaceutical treatments.

5.8 Acknowledgements and declarations

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Declaration of Interest: Professor Alison Richardson is a National Institute for Health Research (NIHR) Senior Investigator. The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health Research, NHS or the Department of Health and Social Care.

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5.10 Author contributions

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

Chapter 6 Semi-structured interview results: Paper 5

6.1 Qualitative interviews with people with heart failure on the interaction between symptoms and self-care work: a sub-sample of SYMPACT survey respondents

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6.2 Abstract

6.2.1 Aim

Following a cross-sectional survey (SYMPACT; n=333) a sub-sample of participants of chronic heart failure (CHF) patients were interviewed. Burden of treatment (BoT) considers both the work associated with illness and treatment (workload), including self-care work, as well as the individuals’ capabilities and resources to engage in that work (capacity). The recent survey, SYMPACT, explored the interaction between symptoms and BoT revealed the existence of a more complex interaction than what was anticipated. To better understand the interaction between symptoms and BoT interviews were conducted. The aim was to explore the interaction between symptoms and BoT in semi-structured interview data.

6.2.2 Methods

Adults with heart failure (any ejection fraction) who participated in the SYMPACT survey were purposely sampled and invited to participate in semi-structured interviews. Location and mode of interview varied by participant choice. The interview schedule was informed by the interim analysis of the survey results to investigate any observed statistical association between symptoms and BoT. Excerpts from the verbatim transcripts were assessed for interactions between symptoms and BoT, and when identified these were characterised and explained.

6.2.3 Results

Participants consistently discussed how symptoms of CHF, comorbidities or treatment side effects altered their capability to engage in the work of self-care. As symptom intensity increased the difficulty of their self-care work also increased. There were a number of intervening factors that appeared to influence the relationship between symptoms and BoT. Intervening factors included illness pathology (CHF, treatment side effects, and co-morbidities), illness identity (how previous experiences inform how illness is adapted into life), the value of the tasks attempted, and available support structures. Since these intervening factors may change how symptoms and BoT are perceived, a model was constructed to try to explain and summarise the complex interactions.

6.2.4 Conclusions

The interaction between symptoms and BoT is complex. Intervening factors - illness identity and pathology, task value and performance, and available support structures - appear to exert a strong influence on the interaction between symptoms and BoT. These intervening factors present clinicians and researchers with opportunities to develop interventions that might reduce BoT and improve symptoms and quality of life.

Key Words: Chronic heart failure, burden of treatment, symptoms, self-care, qualitative research, mixed methods

6.3 Introduction/background

Chronic heart failure (CHF) is accompanied by distressing, uncomfortable and disabling symptoms including dyspnoea, oedema, and fatigue. These symptoms often persist despite optimal treatments (13) which can lead to adverse side effects (255). Whilst patients may be supported by healthcare professionals, the onus for care often lies with the patient who is expected to participate in complex self-care regimens. Jaarsma, Hill (20) identify more than 30 components of these regimens, divided into three main areas of activity: maintenance (behaviours to sustain physical and emotional status), monitoring (tracking symptoms), and management (responding to signs and symptoms). These activities can constitute significant personal work for the patient who may already be suffering from disabling symptoms.

Intuitively disciplined adherence to self-care regimens is essential to symptom control and avoiding exacerbation, with the goal of improved quality of life. Negative interactions between complex symptom burden and self-care work are an important but under-recognised problem and may explain some non-adherence to self-care regimens. The literature acknowledges that patients with CHF frequently appear to *fail* with self-care (21, 22) with responsibility for adherence placed primarily on patients' poor knowledge (1).

Burden of treatment (BoT) theory (118) proposes effective participation in self-care is dependent on the balance between two main concepts: what is the burden of self-care (workload) and what are available resources to do that work (capacity) (58, 118). Research in CHF and treatment burden has demonstrated that patients struggle with self-care work (59, 63) and failures in healthcare service delivery add to BoT (63, 131). Additionally, emotional burden associated with accepting CHF illness and managing self-care regimens was observed (162) and patient's CHF self-care ability was influenced by personal capacity (131). Systematic reviews (65, 66, 126, 127, 134, 189) demonstrated these problems appear common in a range of long-term conditions.

In our previous work (135), a validated tool measuring treatment burden was used in a sample of people with CHF and explored interactions with symptoms. Symptoms were measured with heart failure symptom survey (HFSS) (156) and Minnesota living with heart failure questionnaire (MLHFQ) (155, 179). BoT was measured with the patient's experience of treatment and self-management (PETS) (167). The brief PETS has two indices, workload and impact, which were used to summarise BoT. The impact index captures how engaging in self-care activities effects participants' feelings and interferes with their role and social activity. The workload index captures the ease or difficulty reported with specific self-care tasks (167).

We reported strong associations (correlation co-efficient: .553- .725) between MLHFQ emotional sub-score and PETS impact index. But found weak associations (correlation co-efficient: .326 - .487) between symptoms (HFSS and physical sub-score MLHFQ) and PETS workload index (135). Sub-groups of participants were observed, whose scores on disease severity, symptom measures, and workload were mismatched. For example, some respondents reported low symptom scores with high workload and *vice versa*. These results suggested the interaction between symptoms and BoT for patients with CHF is more complex—and more paradoxical—than is currently captured by these questionnaires.

Exploring complexities and paradoxes in quantitative data is best accomplished by qualitative investigations (141, 168). This gives the opportunity to discover how patients account relevant aspects of their lived experiences of interactions between symptom burden and treatment burden. The following research aims will be explored in this paper: a) is an interaction between symptoms and BoT experienced, b) characterise the nature of any observed interactions between symptoms and BoT, and c) describe the impact of symptoms on engagement with the work of illness and treatment management. The aim of the paper is to develop a model that explains the interaction between symptoms of CHF and BoT.

6.4 Methods

6.4.1 Design

This work is a part of a larger mixed methods research project, SYMPACT (133). Participants with CHF (for at least 6 months, n=333) completed questionnaires. Interim analysis was completed when recruitment to the survey was at the halfway mark. Interim results were used to update the interview schedule for the qualitative phase of the research project, (Appendix D.3). Statistical associations between symptoms and BoT were described to participants to facilitate the exploration of that interaction. Semi-structured interviews explored participants' experience of living with and managing CHF, aligned with the BoT framework (Appendix F) with a focus on exploring interactions between symptoms and the work of care.

6.4.2 Eligibility

Adults (English speaking over the age of 18) with CHF, previous participants of SYMPACT, were invited to participate. Participants were in receipt of inpatient and/or outpatient care or attended a community support group in Hampshire, UK. Exclusion criteria: participants in receipt of palliative care or with a decline in cognitive function (in the investigator's opinion) or had moved out of the region.

6.4.3 Ethics

Ethical approval was granted by the University of Southampton Ethics Committee (ERGO: 41287) and the Nottingham HRA1 Research Ethic Committee, Health Research Authority (MREC: 18/EM/0339, IRAS: 247773). SYMPACT conforms with the Declaration of Helsinki principles (243). SYMPACT was registered with the ISRCTN registry: ISRCTN11011943.

6.4.4 Purposive sampling

Participants were purposively sampled to ensure maximum variation. The purposive sampling grid was developed using theoretical criteria to achieve maximum variation in key variables: personal characteristics (gender and age), illness characteristics (left ventricular ejection fraction (LVEF), and questionnaire scores (HFSS, MLHFQ, and PETS). Identified participants were approached by the local research team and provided with a patient information leaflet. The method of consent and interviews were altered to facilitate remote interviews during COVID-19 pandemic.

6.4.5 Data collection

After receiving written or verbal consent, interviews were organised between January 2020 - Sept 2020: face-to-face, telephone, or online video call according to patient preference and timing in regard to the COVID-19 pandemic (interviews paused between March-July 2020). Interview recordings were transcribed and uploaded into NVivo (192), used to organize the data.

6.4.6 Data analysis

Using the verbatim transcriptions of semi-structured interviews, any observed interactions between symptoms and the *a priori* BoT framework (Appendix F) were identified, characterized and explained. Any excerpts from the interviews which related to the over-arching question, do symptoms interact with BoT were identified and coded under specific research aims outlined in this paper: (a) is an interaction between symptoms and BoT experienced, (b) characterise the nature of any observed interactions between symptoms and BoT, and (c) describe the impact of symptoms on engagement with the work of illness and treatment management. Using abductive analysis (168) these descriptions were integrated to inform a model of how CHF symptoms interact with BoT.

The same interviewer conducted all the interviews. Interviews continued until all researchers felt that maximum variation was achieved, and interviews revealed no new observations.

6.4.7 Study population

Following screening (Figure 14) 54 participants were approached and 32 consented to interview. The maximum sample grid demonstrated the variability in the characteristics of those who participated (Appendix I). All participants chose interviews (in person, by telephone, or video call) to be conducted at their home, except one. Interviews lasted between 32-113 minutes.

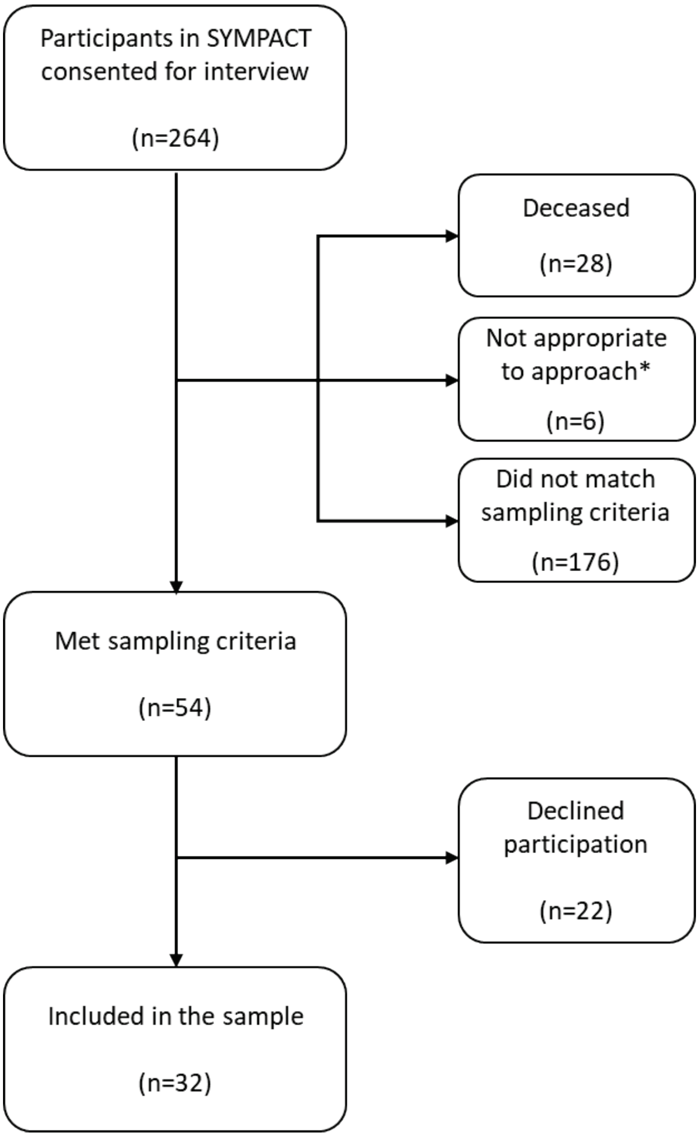


Figure 14: Flowchart showing participant eligibility process

Participants (50% female) had a mean age 68 (± 14) years. LVEF range 8-65% (Table 12).

Table 12: Interview sample characteristics

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

*Triple therapy was defined as a participant who was on at least three medications from the following classifications: Angiotensin-converting enzyme inhibitors, Angiotensin receptor blocker, beta blocker, mineralocorticoid receptor

6.5 Interview findings

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

6.5.1 Observed association between symptoms and BoT was recognised by participants

The majority (n=26) of participants agreed that symptoms interacted with self-care work, based on their experience of living with and managing CHF. Participants described how symptoms influenced task difficulty in both self-care work and activities of daily living. They explained how the relationship between symptoms and self-care work was dependent on symptom severity or activity attempted and provided multiple examples of how the relationship was situational (Table 13).

> "You don't know on a day-to-day basis if it is going to be a good day or bad day. So that can be quite frustrating. One day you'll get really breathless cleaning your teeth and another day you'll manage it perfectly well." (T141 F53yo)

Four participants were unsure that the association was true for them but stated that it was hard to evaluate for multiple reasons including (a) it might be true for others, (b) the influence of co-morbidities made it difficult to view the relationship for CHF symptoms alone, (c) self-care work was seen as so valuable that even when symptoms made the work more "annoying" they described the work as easy despite high demand on time or energy (Table 13). These four individuals still shared experiences within their interviews reflecting on times where symptoms did alter the difficulty of self-care work.

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

Table 13: Exemplar quotes illustrating participants' thoughts and experiences about the statistical association between symptoms and BoT

Observed statistical association between symptoms and BoT was recognised by participants	
True	"But… you know I often find when I've got a cold or whatever you know everything just seems like an effort (laughs) and I think it's because your body's busy fighting whatever and you know you feel drained because of it." (T132 M38yo)
	"Well not to take my tablets but to go to the doctors it is hard. It is hard." (S104 F87yo)
	"I consider that I am lucky umm because I can still do virtually everything easily, but I got a friend who I made through going to the heart group and she is a lot worse than I am. So even getting out of bed for her in the morning is an effort. You wouldn't think that we had the same condition because she is so much worse than I am and she finds it- she does find it hard work to do everything, and to keep things going. So yes, I think your analogy is right, the more you've got the harder it is" (T328 F74)
	"Yes, it does yeah, it can vary in degrees, so like if I'm having a good couple of days then, I'm in, in sort of my mind is clearer. I can focus more, um…I can perhaps try and do a bit more research. But on poorly days um…. physically and mentally I'm weak as a kitten" (T141 F53yo)
	"My life seems to be run by my heart things; I don't find the work hard. I would imagine if I was in a worse state than I am in my physical state, I couldn't walk, I couldn't breathe properly. (…) Attempting to do anything would be really difficult. But personally, I feel very lucky, that my symptoms on the physical side of things aren't horrendous so the work isn't very hard." (L015 F62yo)
	"It impacts you in lots of different ways and I think (…) but also as always it was something that hits you emotionally and you feel that as well. So… um if you're not feeling good um emotionally it affects your physical ability to do things and that sounds odd, but it is true you know!" (L016 M79)

Observed statistical association between symptoms and BoT was recognised by participants	
Unsure	“I think a lot of it, I mean obviously the symptoms can be severe. I think a lot of it depends on the person himself. I mean um… (pause) I had some people myself when I’ve been working [as a nurse] It-- it depends on the person, how well they take to um – heart problems” (T017 F83yo)
	“Well, (pause) I mean the thing is though you are asking me specifically about heart failure, isn’t it? Mine is kind of loaded and that, ‘cause I’ve got diabetes, but these are other factors that I have got to kind of gotta put into that as well. So, it’s not just about cardiomyopathy it’s about diabetes and Lupus. So and they are all kind of—you know… at the moment I’m kind of okay, I’m not 100% (S052 M51yo)
	“(Pause) Yeah (pause) I think that is true of life in general! Yeah, I don’t find any of it difficult. You know as I said you know, if it wasn’t me who showed an interest in my own health care – You know, how do you not… I don’t understand. You know, I know I’ve got to go to hospital, so I don’t think – OH CHRIST! I’ve got to go to hospital, oh woe is me, it’s the end of the world. I’m oh that’s all right then. I hop on the bus, you know, I go out there- I take the positive from it I have a little look round town… I – I - I like to go in and talk to them. They keep – they kept me alive!” (S030 M53yo)
False	“…um no, I think again it’s your attitude of mind, um I talk to myself; I have got you know; my heart condition isn’t ah… it’s like I said I try and see the positive. Doing my pills whether I’m more breathless or less breathless, I don’t know whether it would make any difference because you sit down to do it because it’s not physically exerting to put pills into a small box. Um and in going to places umm if I didn’t have any transport again, if I was more breathless then yes, I would see it annoying and an issue. But if I had it less and I had to go to the doctors, I think, it’s swings and roundabouts.” (T122 F55yo)

6.5.2 Nature of the interaction

The interaction between symptoms and BoT appears to alter with symptom intensity, the activity attempted, and the passage of time. Around half the participants described how they would rate themselves in different places on the spectrum (low symptoms easy work to high symptoms hard work) dependent on the activity attempted or how they felt at a given time (Table 14). Symptom intensity seemed to have a direct influence on the perceived level of difficulty in relation to the work attempted (Table 14). Just over a quarter of participants' experience reflected the following association: easy symptoms meant easy work. The majority of the participants described situations where their experience reflected: manageable symptoms, manageable work or extreme symptoms, overwhelming work. If symptoms and/or work were overwhelming, all work was either delayed or not performed due to decreased personal capacity. Alternatively, patients may rely on support networks to assume the responsibility of self-care, shifting the burden away from themselves. This could also shift the perceived level of difficulty of that task.

> "Um my daughter and granddaughter take me anyway to the [local district hospital] so I've got no problem, so I've always got someone with me." (T108 F72yo)

Table 14: Nature of the interaction between symptoms and BoT

	Exemplar quotes
The interaction is dynamic due to	Activity attempted:
	"No, I don't think I find it a problem I mean um just organising a medication making sure you take it etc um, there's been a couple of times where I've forgotten to take it but literally um it's not been a problem. *Interviewer: And what about something like coming to terms with heart failure and what it means for your life and future, is that different?* Yeah, it can be um I try not to think too long and hard about it. I- it's one of those situations where if you spend a lot of time thinking about it. You get worse. It gets- you get depressed and so on um as I've said to you when you're drifting off to sleep um that's the time when you start thinking about some of these things and um that's not good." (L016 M79yo)
	"Well… sitting still, I can cope with it reasonably well. I mean sitting here talking to you I feel totally fit! You know? But if I got up like to answer the door for my son when he comes round. I'd have to hang off his shoulders until I came round. Um… having started from the I feel perfectly fit condition and so if the activity is of that nature, then I'm edging towards the upper end of the scale" (T137 M78yo)

	Exemplar quotes
	In relation to time:
	"I can quite easily see if I was still struggling like I was a year ago and having to take all these pills and probably even more, but I definitely find-- that I feel that it is you know impacted my life a lot more" (T132 M38yo)
Level of symptom intensity relates to difficulty level of self-care work	Easy:
	"Well I, I, ahh… It [meaning heart failure] don't appear to affect me that much, to be honest." (S107 M87yo)
	"umm I don't- I don't know because I haven't got that many symptoms now like I did beforehand obviously (T037 M68yo)
	Manageable:
	"…because of the heart problems I've got, I tend to be lethargic which makes me very lazy around the house. So, I don't do as much housework as I should, and I can't do it all in one go. I sort of have to take a couple of days to do it." (T145 M59yo)
	"There is always a price to pay. Even if you don't think at the time there is. Even if you think you're feeling quite ok and at this particular time you can achieve this task that you wanted to do, then you will pay the price for it." (T141 F53yo)
	Overwhelming:
	"I can't remember anything! If that's a day of not remembering. Sometimes I remember fine other days I just forget I mean… it's no good saying I shouldn't forget or put it on the fridge or whatever. I've done putting it on the fridge that works to a point, but then you've forgot it's on the fridge. No so it… nothing really helps because it's the memory and the brain." (L032 M80yo)
	"I've noticed as the symptoms have worsened the breathlessness has come on more quickly umm you know the palpitations, the ectopics, leg weakness, and general feeling weak um… and so um…it affects your ability to do things on a day-to-day basis. In your head you…ah… you think you can do things, but then you realize your body's not going to allow you to do that." (T141 F53yo)
	"Yes! There are days where I just can't be bothered whatsoever. I just can't be bothered the depression gets hold of me because of it [heart failure] and I think what is the point of me actually being here? If I wasn't here, then I'd be free of the pain and the problems and whatever problems I may be causing other people I'd be free." (T145 M59yo)

6.5.3 Impact of symptoms on engagement with illness or treatment work

Participants described how breathlessness, fatigue and forgetfulness together with side effects from their medications (e.g., dizziness) increased task difficulty. Thereby influencing the work associated with both self-care and activities of daily living. This effect ranged between minimal to maximal effect (

Table 15). Participants described how when symptoms increased the difficulty of work also increased resulting in four main outcomes: (1) recruit others to do the work, (2) adapt the task, (2) delay the task, or (4) the task is not performed.

Symptoms and treatment side-effects also appear to create an emotional affect on participants. The nature of the interaction appears to vary between a minimally reported affect to an extreme affect (

Table 15). Those who reported minimal emotional affect also reported low symptom burden. Participants cited multiple reasons for the ease of the work such as, perceived good medical treatment, previous life experiences, acceptance of their prognosis, or the support of informal caregivers. But this was not always the case. Some participants with a mild symptom burden reported experiencing a more intense emotional affect. Participants with more intense symptom burden, and emotional affect appeared related to tasks with high personal value, physical limitations, not completing self-care, or wrestling with life-limiting a diagnosis (

Table 15).

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

Table 15).

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

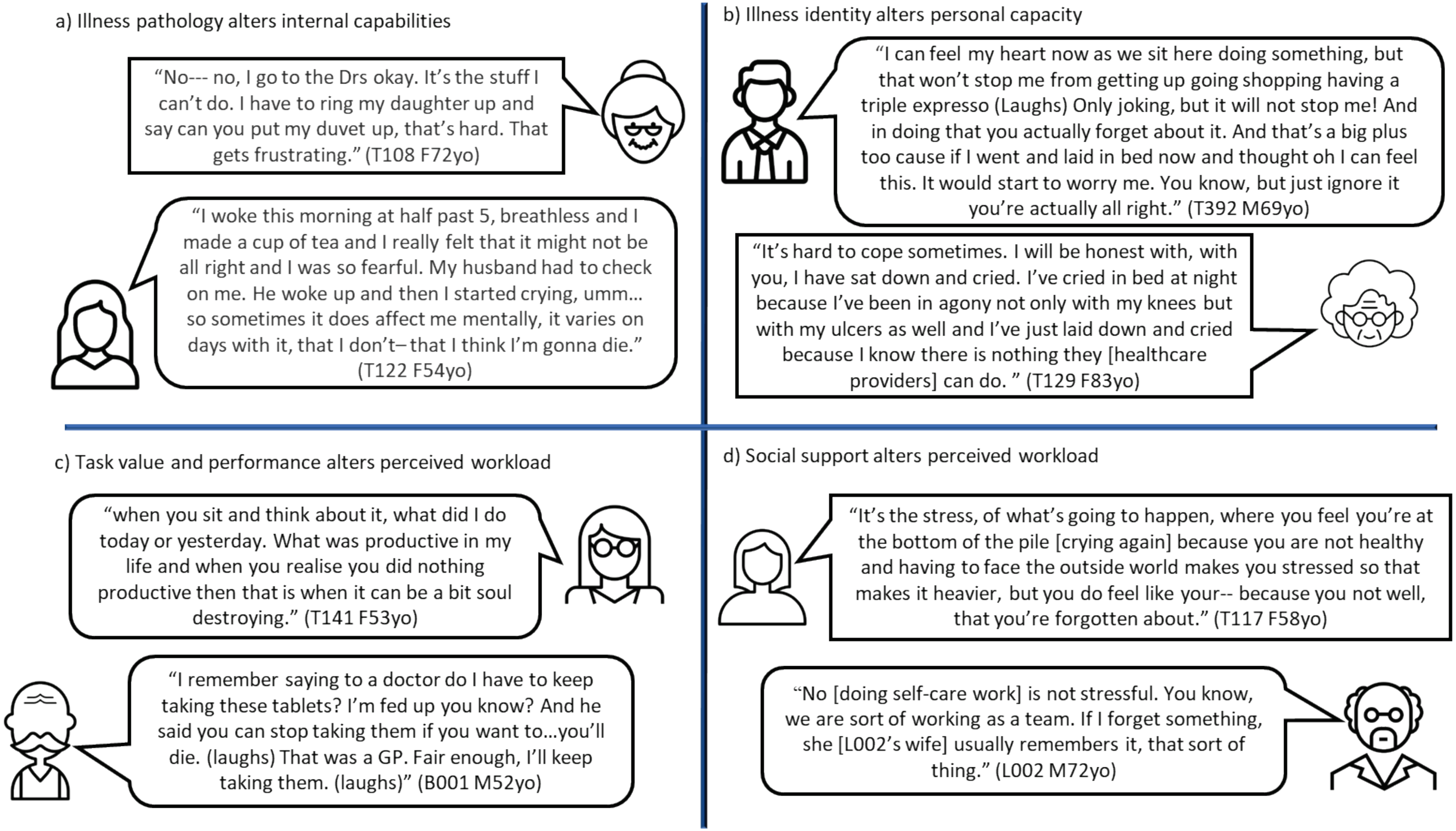
> No…You know, we are sort of working as a team. If I forget something, she [L002’s wife] usually remembers it, that sort of thing.” (L002 M72yo)

Table 15: Impact of symptoms on participant ability to engage in illness or treatment work

	Exemplar quotes
Physical symptoms	Minimal effect:
	“But to be honest it [heart failure] doesn’t affect me” (S107 M87yo)
	Manageable effect:
	“It’s affecting me I- I avoid certain things (…) but I have noticed that when I’m carrying heavy things I quite often start struggling with my breathing as well I’m assuming that’s probably because I’m exerting more energy and then probably struggle a bit more, but I don’t know why?” (T132 M38yo)
	“Definitely the physical implications of it. I have to think about, well I can park or how far it is to walk. Prior to the heart failure that wouldn’t be a problem. But I have, you know, to think is the blue badge space available is… and that sort of thing and that… that’s irritating (S110 M57yo)
	Maximal effect:
	“Well not to take my tablets but to go to the doctors it is hard. It is hard. *Additional Information: daughter adds that her mum wouldn’t even be able to get in and out of a taxi on her own”.* (S104 F87yo)
	“It’s like waking up and thinking, ‘I’m going to get up tomorrow and I’m going to this and I’m going to do that.’ Then you wake up and think I don’t want to get up, or you get up and have a shower and by the time you come back, the bed looks inviting because you are so fatigued. You think I could lay down and go back to sleep. You don’t want to be like that because the sun is shining you want to be out there doing things.” (PHT117 F58yo)
Emotional affect derived from limitations due to symptoms or treatments	Minimal effect:
	Interviewer: so all of that sort of work that’s caused by their heart failure they find that emotionally difficult or stressful do you ever find that? No. More than anything else, I’ve been through in my life and-- no one-- that’s just part of life.” (L032 M80)
	“You have to lead a normal life, or you won’t, but ‘Blimey don’t get any library books out’… you know… that’s what [Jim] said… ‘don’t get any long play records’ (chuckles). It’s TRUE. (claps) You know, you, you know, I go, we go down to cardiology in [local district hospital] there and you sit there and I… I think God! Blimey, I hope I don’t look like this…you know. They are… they’re scared I suppose. They’re scared of their own mortality. You know… I’m well aware that one day…Yeah, and I, I, I say to myself right if there is nothing on the other side then that’s it and if there is then I’ll see my daughter [who died at a young age] again (claps)” (T392 M69yo)

	Exemplar quotes
	Manageable effort:
	"YES, not being able to do those things could be a bit depressing. I'm not a depressive person, but whatever you want to call it, but it does have that effect… those limitations." (T137 M78)
	"If I forget to take my pills then that really puts me in a quandary, and if I drink too much wine. It puts me into a massive panic. I forget. Yeah, my mind, my mind actually closes over. I forget things very easily, so it frightens me, I put alarms on my phone to take my pills. I have to make it public to remind myself." (T122 F54yo)
	Maximal effect
	"It's a bit of a (sigh) a round- circle if you like because there is just no end to it all. 'Cause I get depressed about the heart condition which causes the anxiety which makes me even more depressed. And then I get anxious about being depressed about a condition which I wish that I didn't have, But I do have. And it doesn't seem to be um… an end to it." (T145 M59yo)
	"It impacts without a doubt with every day and with your future and how much that is fear of aggravating the current and existing symptoms and how much of it is just me being careful. I couldn't differentiate. (…) I don't wanna end up in [hospital] again, and if I don't end up in [hospital] I'm gonna end up in a box. (…) I've got to be sensible. So, the fact that that is there at the back of my mind IMPACTS on ANYTHING I want to do." (T144 F86yo)
	"It's the stress, of what's going to happen, where you feel you're at the bottom of the pile [voice emotional] because you are not healthy and having to face the outside world makes you stressed so that makes it heavier, but you do feel like your-- because you not well, that you're forgotten about." (T117 F58yo)

In characterising the interaction between symptoms and BoT we noticed that there were factors which appear to influence or mediate the relationship. These factors provided by interview participants were grouped into four categories: (a) illness pathology, (b) illness identity, (c) task value and performance, and (d) available social support structures. These observations were throughout the data set, but exemplar quotes and examples are provided (Figure 15).



a) Illness pathology alters internal capabilities

"No--- no, I go to the Drs okay. It's the stuff I can't do. I have to ring my daughter up and say can you put my duvet up, that's hard. That gets frustrating." (T108 F72yo)

"I woke this morning at half past 5, breathless and I made a cup of tea and I really felt that it might not be all right and I was so fearful. My husband had to check on me. He woke up and then I started crying, umm… so sometimes it does affect me mentally, it varies on days with it, that I don't– that I think I'm gonna die." (T122 F54yo)

b) Illness identity alters personal capacity

"I can feel my heart now as we sit here doing something, but that won't stop me from getting up going shopping having a triple expresso (Laughs) Only joking, but it will not stop me! And in doing that you actually forget about it. And that's a big plus too cause if I went and laid in bed now and thought oh I can feel this. It would start to worry me. You know, but just ignore it you're actually all right." (T392 M69yo)

"It's hard to cope sometimes. I will be honest with, with you, I have sat down and cried. I've cried in bed at night because I've been in agony not only with my knees but with my ulcers as well and I've just laid down and cried because I know there is nothing they [healthcare providers] can do. " (T129 F83yo)

c) Task value and performance alters perceived workload

"when you sit and think about it, what did I do today or yesterday. What was productive in my life and when you realise you did nothing productive then that is when it can be a bit soul destroying." (T141 F53yo)

"I remember saying to a doctor do I have to keep taking these tablets? I'm fed up you know? And he said you can stop taking them if you want to…you'll die. (laughs) That was a GP. Fair enough, I'll keep taking them. (laughs)" (B001 M52yo)

d) Social support alters perceived workload

"It's the stress, of what's going to happen, where you feel you're at the bottom of the pile [crying again] because you are not healthy and having to face the outside world makes you stressed so that makes it heavier, but you do feel like your-- because you not well, that you're forgotten about." (T117 F58yo)

"No [doing self-care work] is not stressful. You know, we are sort of working as a team. If I forget something, she [L002's wife] usually remembers it, that sort of thing." (L002 M72yo)

Figure 15: Exemplar quotes illustrating the interaction of symptoms with intervening factors. Icons from various artists on https://thenounproject.com (256)

Illness pathology: Observations from participant interviews described how the factors around CHF illness pathology were noted to alter physical and mental functions (internal capabilities) (Figure 15a). While this might be attributed directly to CHF or treatment side-effects, decreases in capabilities were also described in relation to comorbidities and the cumulative effect of illness(es), hence why we described this factor more broadly as illness pathology. The resultant limitations from symptoms influenced the perceived difficulty of a given task. Additionally, these processes also appeared to affect task performance, which could lead to further emotional affect and/or create additional work in recruiting help.

> "You, you get to the point where the symptoms start to um… outnumber the need to do something. So, like more difficult, it becomes the less likely you are… to either carry on doing that certain thing or even attempt to start to do that thing." (T145 M59yo)

Illness identity: Participants varied in how they viewed themselves and their illness. While symptoms often informed this viewpoint, other factors like previous life experiences and personality also seemed to shape illness identity (Figure 15b). Illness identity appeared to alter the perception of symptoms, the difficulty of the self-care work and individual capacity influencing overall BoT. As an intervening factor illness identity offers some explanation for anomalies in the data. For example: T392 (Male, 69 years old, HFrEF) who experienced benefits from treatments, rated symptoms and BoT as very easy. His personality and previous life experiences-built personal resilience. He viewed CHF as a challenge and refused to let illness affect his life. Despite having symptoms, he refused to acknowledge them. He viewed self-care work at home as a habit and visits to the doctor as valuable, creating minimal BoT. In comparison, T137 (Male, 78 years old, HFrEF) was on optimal medications but desired more treatment options for unresolved symptoms. He rated his symptoms as severe, but his burden as low. He believed his age and illness characteristics excluded him from desired treatments. He was discharged from specialist heart failure care and rarely sees any medical professionals. He has adapted his life to incorporate self-care tasks as a habit. When his symptoms change, he does not seek help as he has been told there is nothing more that can be done.

> "I feel as though I've been shunted. Like in a railway shunter. Like I've switched at the points and I'm sitting waiting. I don't have any prospects or things that can be done for my condition that will improve it." (T137, M78yo)

Task value and performance: The value assigned by participants altered the perceived difficulty of a task, influencing self-care difficulty. While sometimes this is straightforward (high value = easy task), the assignment of value can also be complex. If a task was difficult or has negative side effects, then the difficulty level is less straightforward (Figure 15c). High value on difficult tasks can result on reporting lower difficulty regardless of energy or effort expended. For example: T 144 and T384 (female, 86 & 90 years old, HFpEF) both described how medication management took a lot of time and energy to perform, but they both described how they valued that task. It made them feel like they were contributing to improving their health, despite the energy and effort required.

> "I know that I'm still mentally alert, but I wonder about some of the other people, who may not be as old as me, who are not as mentally alert as me. How the devil do they sort them [medications] out!? (…) maybe they've got a way at the pharmacy or whatever, but that would take some sorting cause they are not all the same- some are morning only, some are evening only, some are three times a day. I do this job when I'm more alert and when I'm not weary or anything. It's an am [morning] job. Because without a doubt it's a job." (T144, F86yo)

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

Available support structures: The support structures accessible to participants were wide-ranging (e.g., family friends, healthcare professionals, etc.). Support structures were seen as a positive influence by the participants, increasing their capacity to perform the work successfully by improving availability of resources (Figure 15d). Participants also gave examples where well-intentioned support from family or friends added to burden as it lowered their sense of self or changed their role affecting their illness identity.

> "Well as I say, it worries me, because as I've got to ask people all the time to take me [to health appointments]. And [daughters name] never complains" (S104 F87yo)

Alternatively, when support was required/desired but not received from healthcare providers or other support structures this decreased participants' capacity by lowering the accessible resources when CHF symptoms changed. For example, T129 (Female, 83 years old, HFpEF) despite reporting living with a moderate amount of symptoms, reported low burden. Her self-care tasks were habitual and attending her local surgery was not physically possible, reducing her self-care work associated with CHF.

> "I don't go to the doctors anymore because I umm- I'm in a wheelchair and I've got one of those electric scooters. And- and it's not always possible to get into the doctors, not in one of those [scooters] and I could never walk into one." (T129 F83yo)

6.6 Discussion

These findings provide evidence that symptoms interact with a person's ability to participate in the work of self-care, providing explanations for why PETS workload index scores were lower than expected (135), in the identification of intervening factors. All participants described situations where symptoms of CHF had made the work of illness management more difficult, where the more intense symptoms became, the more difficult the work of self-care.

6.6.1 Factors which influence symptoms in CHF

CHF symptoms are subjective and may be difficult to assess by patients and healthcare providers. Symptoms alter a person's perceived capabilities, in spite of optimal medical treatment (13, 56). Nordfonn, Morken (162) described this as more than physical processes and includes emotional challenges around, accepting CHF diagnosis, the work of self-care, and alterations to identity. A person's illness identity may alter how patients report their symptoms, due to personal levels of adaption to illness. Participants described living limited lives enforced by symptoms of CHF, treatment side effects or comorbidity symptoms. By considering a person's structural resilience may explain the variability of the scores they reported. Patients may adapt and limit their lives to cease any activity that exacerbates their symptoms, hence limiting symptom burden. Alternatively, participants who described how the illness had stolen their life and who were engulfed by illness often reported more intense symptom burden, commonly observed in patients with unsatisfactory healthcare interactions.

6.6.2 Factors which influence BoT

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

While this reassignment of work to a loved one may appear to alleviate the burden, Gallacher, May (59) and Jani, Blane (63), described how informal caregivers added to patients' self-care work by requiring communication and organizational work. Together with the added feeling of guilt due to reliance on others (162, 257) this may impact on resilience. This may help to explain why the correlation was weak between symptoms and workload index, but strong between symptoms and impact index, which captured how engagement with self-care work affects the participants' sense of self (135).

In interviews, participants spoke of self-care tasks, not captured in PETS workload index (e.g., healthcare coordination and exercise), as factors which were heavily influenced by symptoms. In our sample, participants reported that symptoms could decrease accessibility to healthcare services and previous negative interactions made them less likely to seek assistance from those healthcare professionals. Previous research findings also reported that healthcare interactions are key to patients' perceived BoT (59, 63). The exclusion of those tasks in the workload index may have affected the statistical associations.

6.6.3 Model to explain how symptoms and BoT interact

The interaction between symptoms and BoT was not as straightforward as we had expected - Figure 16 sets out a model of the complex interaction.

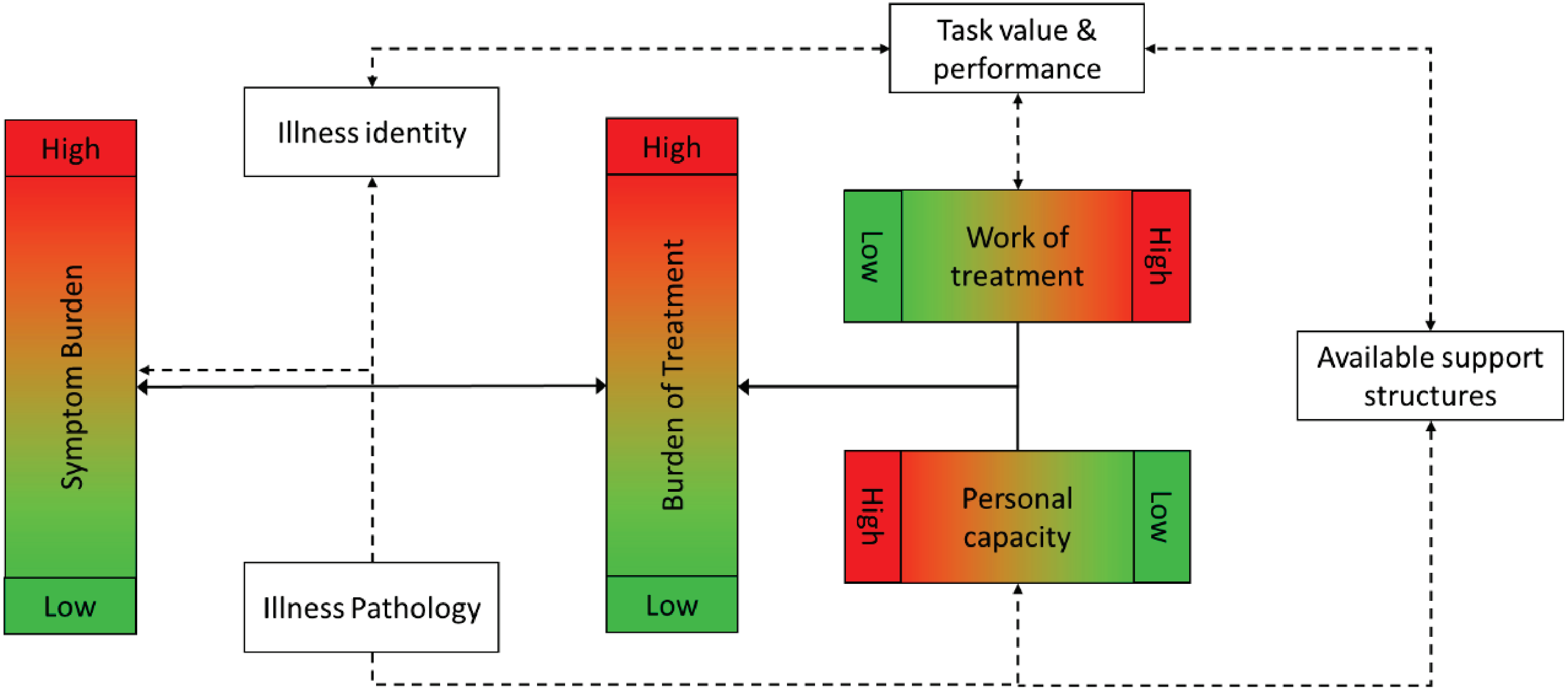


Figure 16: Model of how symptoms interact with BoT. Solid lines represent a relationship that was observed in the survey and interview data set. Dashed lines represent a relationship that was observed in the interview data set.

In describing the interaction of symptoms with the work of participating in their care, patients with CHF acknowledged that symptoms could affect their ability to do this work, but factors present in their lives might alter how they reported on the difficulty of those tasks. Firstly, in considering symptom burden, illness pathology factors including CHF specific processes, co-morbidities, and treatment side effects must be considered. The limitations imposed by symptoms resulting from illness pathology informs illness identity and influences a patient's capacity. Affecting how tasks of self-care are valued and performed and were influenced by the role of available support structures. The support structures availability may be altered by illness identity and pathology, through multiple processes (e.g., physically unable to attend medical appointments, social isolation caused by not wanting to be a burden, etc.).

Secondly in considering BoT, the balance of self-care work and personal capacity needs to be examined. In the interviews, participants explained how the work of treatment (self-care) was influenced by their illness identity which informed the value assigned to a task and the results of performing tasks. The difficulty of the work was also informed by the accessibility of available support structures that ranged from loved ones to healthcare services. Personal capacity was influenced by illness pathology altering internal capabilities; physical, mental and emotional. When the self-care work outstripped personal capacity, the person would turn to available support structures to increase their capacity by recruiting others to perform the work of treatment. If assistance was not accessible the work was not performed. The interaction of symptoms with BoT is complex, with identified factors appearing to mediate both symptom burden and dimensions of BoT, which then influences how they relate to each other. The model helps explain the broad distribution of data observed and statistical associations.

6.6.4 Limitations

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

An acknowledged limitation of the sequential explanatory mixed method study design used is the lengthy timeframe to complete data collection (151). A pragmatic approach was taken using interim analysis to inform our interview schedule. The final survey results were used to inform the analysis of the interview data.

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

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

6.7 Conclusion

BoT is the balance between workload and individual capacity, where the workload (self-care work) in chronic illness is thought to outstrip patients' capacity. To date perceived failures to engage in self-care are commonly attributed to health literacy and healthcare system complexity. Symptoms, by their very nature, can decrease a person's capacity and increase workload difficulty. If that person has available social support, then this decrease in capability may not be noticed by healthcare professionals. If they lack that support then the work is likely to be put off, or not performed, which may result in hospital admission, where commonly CHF patients are labelled as non-compliant. The novel observation in our research highlights that contrary to current thoughts, these readmissions may not be due to poor health literacy or a lack of motivation. Instead, the nature of CHF illness and persistent symptoms may keep patients from engaging in this work.

Symptoms of CHF can stop a patient from engaging with their self-care work. This can be a direct interaction (e.g., legs too swollen to mobilise to healthcare appointments) or indirect (e.g., a life stripped of value due to symptoms, becomes depressing to live). Our results are helpful to clinicians for patients on maximal medical therapies with ongoing persistent symptoms, as it offers the opportunity to explore other symptoms and factors not typically assessed in heart failure clinics. By incorporating BoT into clinical evaluation health professionals can enhance care coordination and patients' social support networks.

6.8 Acknowledgements and declarations

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Linda Morris and Kirsten Hobday (medical secretaries at PHU) transcribed 60% of the interviews.

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Declaration of Interest: Professor Alison Richardson is a National Institute for Health Research (NIHR) Senior Investigator. Carl May and Alison Richardson collaborated to develop burden of treatment theory.

6.10 Author contributions

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

Chapter 7 Discussion and integration of research results: Paper 6

7.1 A condition specific theory of treatment burden in heart failure and a translational clinical model

Austin, RC, Schoonhoven, L, Richardson, AR, Kalra, PR, May, CR. A condition specific theory of treatment burden in heart failure and a translational clinical model. Journal of the American Heart Association; *Planned for submission*.

7.2 Abstract

7.2.1 Background

Chronic illness management work is delegated through self-care regimens. Chronic heart failure (CHF) self-care guidelines are informed by theories of self-care in heart failure and chronic illness but does not consider the burdensome work of self-care. Burden of treatment (BoT) theory defines the workload of treatment and considers the capacity of the patient alongside the impact of performing that work. The influence of symptoms has not been evaluated in these theories. This paper offers the CHF specific BoT theory, describing the interaction of symptoms with BoT.

7.2.2 Methods

Using a four-step process, theoretical and research work was integrated to build a CHF specific BoT theory. First, it is commonly observed that CHF patients struggle to engage in self-care, underpinning the current theory development. Second, a qualitative evidence synthesis identified sensitising concepts and a preliminary model was developed. Thirdly, empirical research informed the characterization of key constructs and interactions between them. Finally, the constructs were mapped into the CHF specific BoT theory and translational clinical model.

7.2.3 Results

The CHF specific BoT theory explains how symptoms interact with BoT resulting in either symmetric or asymmetric relationships, mediated by four factors: illness pathology, illness identity, task value and performance, and available support structures.

7.2.4 Conclusions

The CHF specific BoT theory facilitates the understanding of the ways interactions between treatment and symptom burden shape adherence to self-care regimens. This theory may have implications for how clinical care is delivered, through the consideration of symptoms and BoT.

Keywords: heart failure, self-care, burden of treatment, theory, clinical model

What is new?

- The CHF specific BoT theory offers a new way of thinking about non-adherence to self-care
- The CHF specific BoT theory shows how CHF symptoms affect patient identity and capacity to perform self-care tasks, and how health care providers may influence patient-experienced burdens.

What are the clinical implications?

- A clinical model of patient capacity is offered as a way to aid the incorporation of the concept of BoT as a component of clinical evaluation
- Four patient types are defined, which when combined with the CHF specific BoT theory, may enable clinicians to identify modifiable factors to ease treatment burden

7.3 Background

Illness provokes the pursuit of symptom relief. Actions taken to alleviate symptoms and treat the illness have been termed self-care or self-management. Self-care involves a person utilising their personal abilities or activating the support of those around them (capacity) to engage with the tasks required to manage the illness or its treatment (workload). This paper aims to describe how this process might be affected by persistent symptoms of chronic heart failure (CHF). It offers a model which describes how symptoms interact with burden of treatment (BoT) influenced by illness identity.

CHF is a syndrome related to an insufficiency of the heart to deliver adequate oxygenated blood to tissues. CHF is prevalent in the USA (258, 259) the UK (2, 3) and worldwide (estimated at 64.3 million people) (258, 260, 261). It is responsible for growing demands on healthcare systems, clinicians, patients and support networks (4, 5). It is associated with impaired quality of life, and high mortality rates (3, 5). Patients with CHF often present with non-specific symptoms such as breathlessness, fatigue, and oedema (1) making diagnosis difficult (3, 8). Non-specific symptoms are used to monitor response to treatments, illness stability and progression by clinicians and patients (1, 3). Major pharmaceutical and device interventions have helped transform prognosis of patients with CHF (1, 3, 7), but symptoms are not consistently reduced (13).

In the US and many other countries, the increasing prevalence of chronic disease has encouraged healthcare policies directed at promoting self-care. Patients with stable illness on optimised treatments may be discharged from specialist services into primary care (5). Because CHF cannot be cured, self-care regimens aim to improve health-related quality of life by controlling symptoms and slowing disease progression (1, 3, 17, 20). These call on patients to combine three kinds of self-care work: maintenance, monitoring, and management (19, 20, 262). This work may require significant health literacy and expert knowledge, the ability to navigate complex healthcare systems, and self-efficacy and motivation to engage in sometimes complex and often demanding tasks (26, 118).

The evidence that self-care interventions yield positive effects on patient outcomes is uncertain (24, 25). Poor adherence is commonly reported and is often attributed to poor outcomes and quality of life (17, 20-23). The proposition that underpins this paper is that for some patients and caregivers the workload of care and self-care delegated to them through self-care programs can exceed their capacity to perform it (51). When delegated workload overwhelms personal capacity, treatment burden can be structurally induced, and patient and caregiver adherence may begin to decline (51, 62, 118, 263). These structural mechanisms can overwhelm even highly motivated patients who appear well equipped to perform the tasks and routines that are important components of self-care across multiple conditions (65, 66, 127, 134, 189, 264).

In this paper, we explore the ways treatment burden is experienced in CHF and the ways this experience is shaped by the burden of symptoms. The paper builds on an empirical investigation of a UK population of people with heart failure (132, 134-136), and presents two linked results of this work: (a) a condition specific theory of treatment burden in heart failure, and (b) a translational clinical model derived from this theory. Together they facilitate understanding of the ways that interactions between treatment and symptom burden shape adherence to self-care regimens. The model may have broader relevance to the wide range of illnesses in which self-care regimens are designed and implemented in an attempt to improve patient care.

7.4 Methods

Mixed methods integration tools were utilised alongside a theory building framework to combine the research conducted within the SYMPACT research study (133). While the separate components of this research previously described their methods and analysis (134-136). This paper takes the opportunity to describe the methods for the data integration and theory building methods.

7.4.1 Data integration methods

Feilzer (141) and Bazeley (265) state that mixed methods research is valuable in describing complex phenomena and mixing data across multiple phases of the research process. Aligning with the abductive analysis approach (168, 266) taken in the research project. Iterative cross-fertilization as described by Bazeley (267) was utilised in the development of the offered theory (Figure 17).

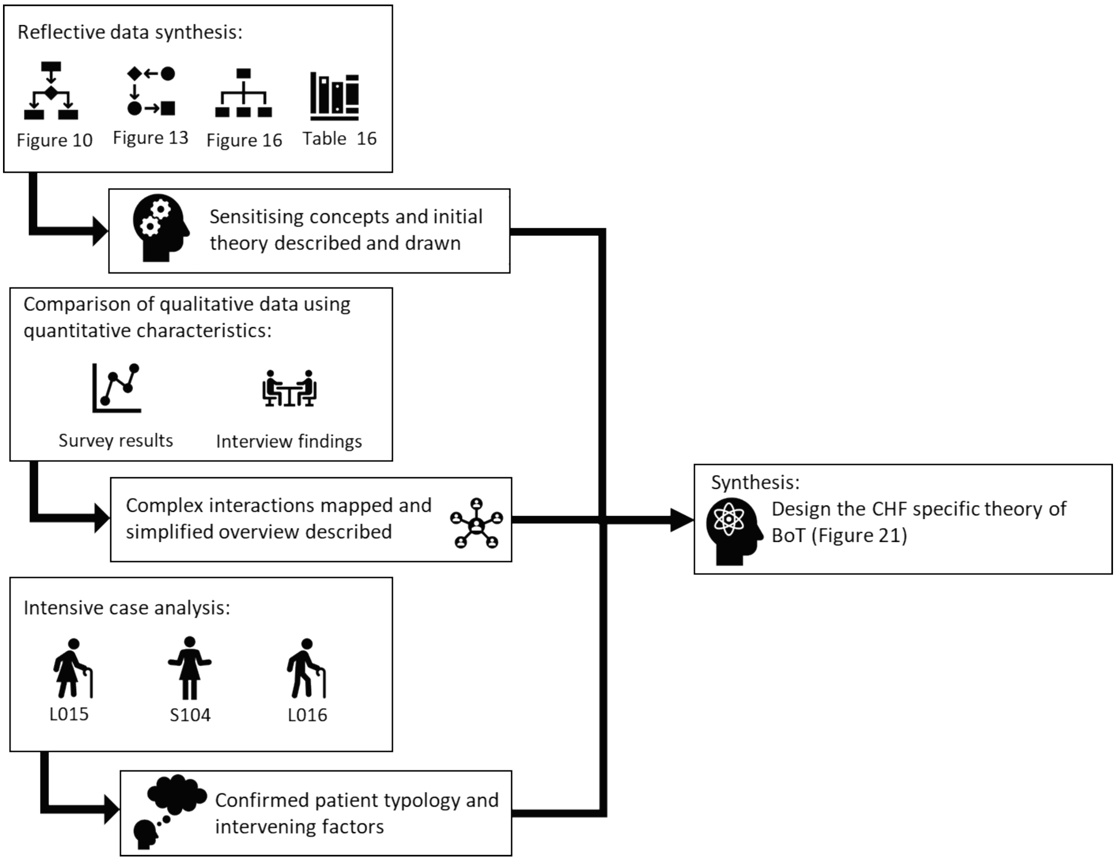

Figure 17: Overview of mixed method integration tools utilised

Results and findings from the research study SYMPACT were narratively combined through a reflective process that included other relevant research studies, described in the theory building section. A deliberate comparison of interview data was conducted to test the initial theory. Using the scores from questionnaire responses and clinical characteristics the themes and codes were mapped according to symptom and BoT intensity and intervening factors identified (Appendix J). The map was then simplified to create a diagram of initial concepts and compared to previous models to refine the initial theory and model. Finally, multiple case analysis of interview data was undertaken (Appendix K). Case selection was informed by examining survey results and selecting three participants whose data differed from the original hypothesis. Together the three methods of integration were synthesised into the final CHF specific BoT theory with integrated clinical model (Figure 21).

7.4.2 Theory building methods

There is no generally accepted method for theory-building (268). We followed the approach taken by May et al (118), and Hunt and May (169), which links theory-informed evidence synthesis with empirical research and aims to produce a set of constructs. The process is described in Figure 18.

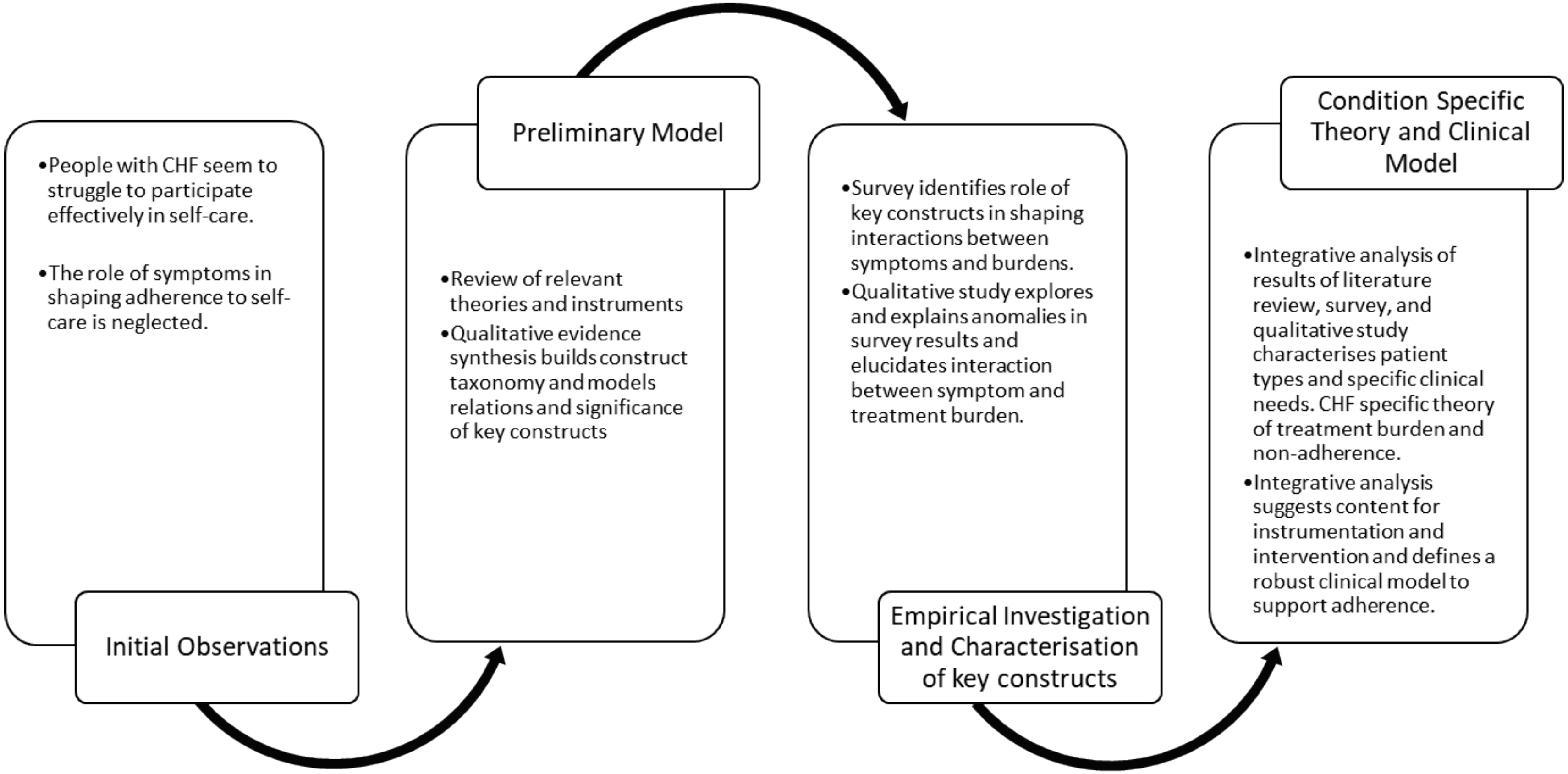

Figure 18: Development of the condition specific theory and clinical model. CHF, chronic heart failure

1. **_Initial observations_**: Work underpinning this theory began with two observations: (a) the repeated occurrence of patients with CHF appearing to struggle with effective participation in self-care; and (b) the absence of attention to the role of symptoms in theories and conceptual models that characterise their participation in care (132).

2. **_Identification of sensitising concepts and development of a preliminary model_**_:_ After scoping relevant theories (132), we undertook a qualitative systematic review of relevant literature (134). The included articles (n=35) were subjected to both quantitative and qualitative content analysis. Quantitative content analysis identified 1800 relevant concepts or descriptors that were subsequently incorporated into a taxonomy of CHF symptom effects in patients' lives. Qualitative content analysis characterised how symptoms appeared to infrequently drive patients to self-care engagement, impeded participation, and formed barriers to the performance of self-care. Both analytic approaches showed symptoms increased illness workload, reduced capacity for action, and made completing self-care tasks more difficult. This work led to a simple process model of interactions between patient capacity, self-care work, and symptoms (Figure 19). The research suggested that symptoms of CHF may do more than alter a patient's *physical* performance in relation to self-care work.

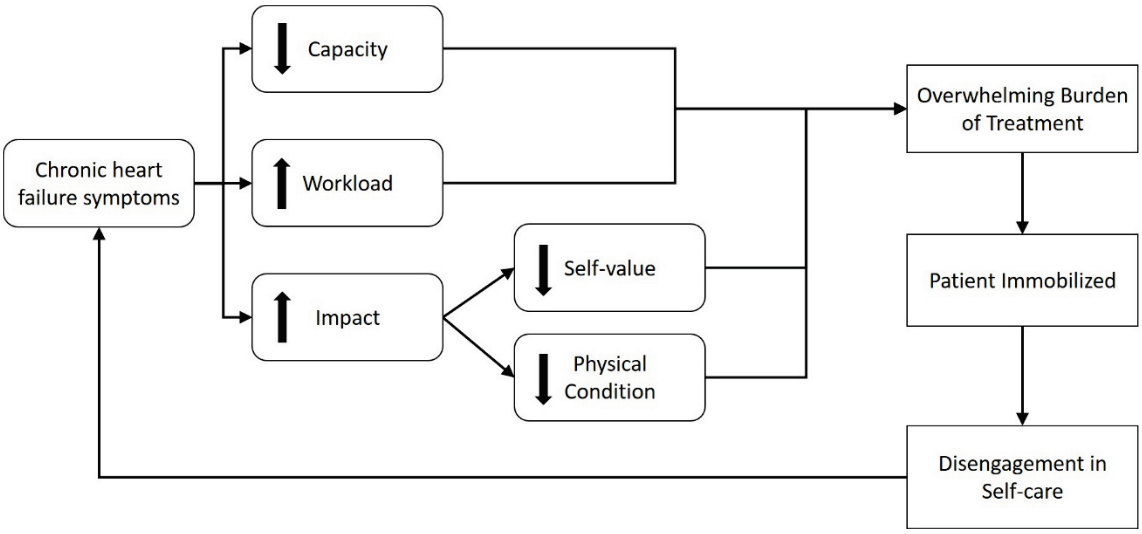

Figure 19: Interactions between symptom and treatment burden: preliminary conceptual model (after, *Austin, Schoonhoven (134)*)

3. ***Empirical characterisation of key constructs****:* A survey of 333 people with CHF (135) explored interactions between symptoms, capacity, and workload. The established and validated instruments that were used, were informed by theoretical constructs identified and refined within the taxonomy developed earlier. The survey showed symptom burden is associated with burden of treatment through complex interactions. Higher levels of combined burdens were in key areas of self-care behaviours (nutrition and hydration, exercise) likely to be affected by physical and mental fatigue consequent of CHF self-care. The survey also showed that treatment burden could be exacerbated by poor quality interactions between patients with CHF and health professionals. A qualitative sub-study of participants in the survey (n=33) (136) further explored these complex interactions and sought explanations for anomalies in the data, in particular drawing attention to the important role of illness identity in shaping perceptions of both symptoms and treatment burdens. Analyses of these data led to an empirically grounded theory that incorporated structural, interpersonal, and individual components.

4. ***Integration of theoretical constructs and development of a clinical model***: Sensitising and modelling work focused on first and second-order analyses of empirical data. These led to a map of relevant concepts (Figure 20).

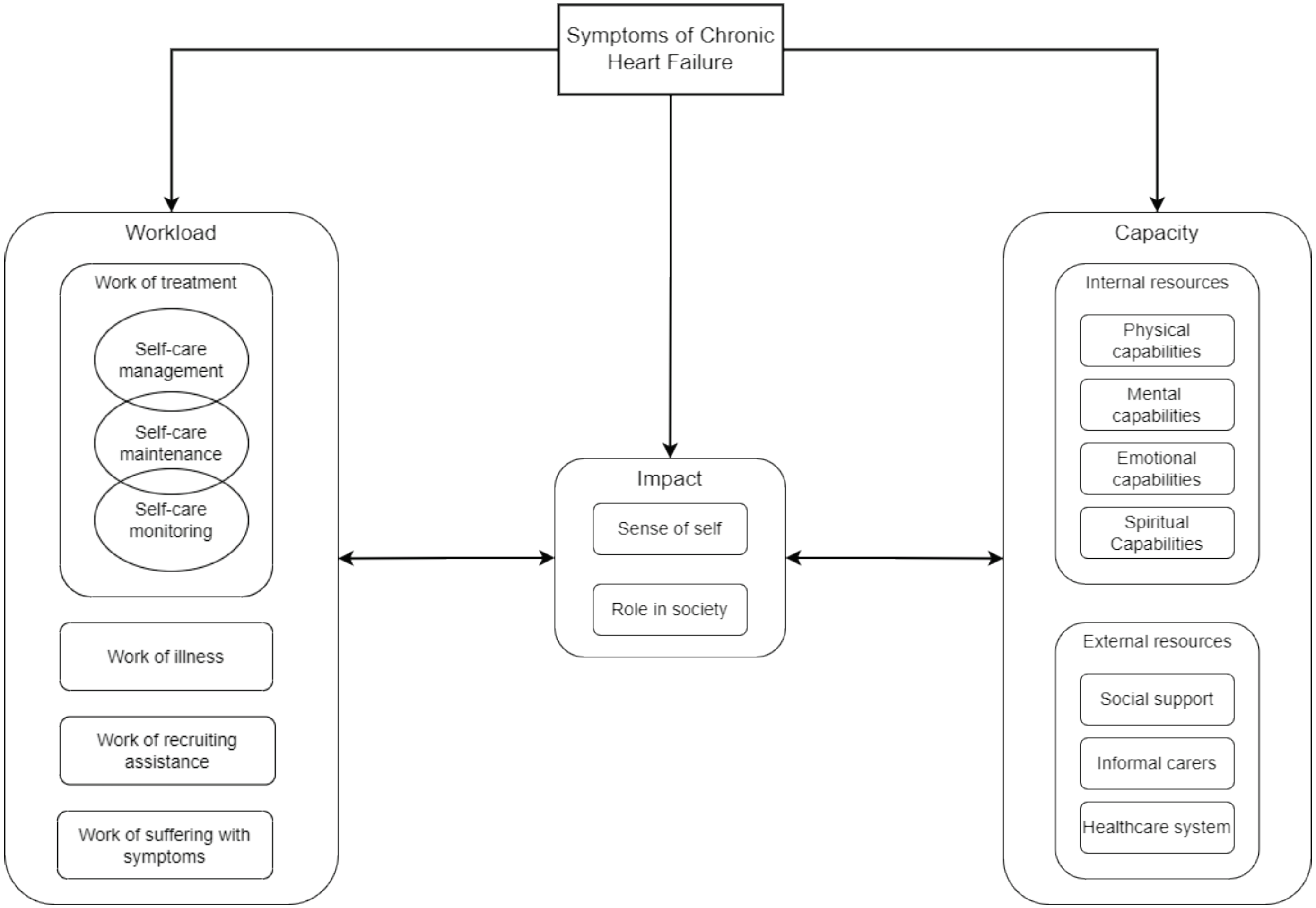

Figure 20: Foundation of CHF specific burden of treatment theory. Ovals represent elements from theory of self-care chronic illness. Rounded rectangles represent elements from various theories of burden of treatment

This sets out the significance and relationships between constructs derived from field research and presented through quantitative and qualitative analysis of existing literature (134), a survey of patients (135) and qualitative interviews (136). The map of relevant concepts was created by combining the models drawn at the end of each phase of research (Figures 10, 13, 16, 17). To ensure that the model did not merely duplicate already existing theory but added value to it, its constructs were then compared with those of the situation-specific theory of heart failure self-care (18, 76, 262), middle range theory of self-care of chronic illness (19, 117), and BoT theory (118) together with the growing empirical literature on BoT (Table 16). The initial map of the interaction between symptoms and BoT was drawn (Figure 16). It was refined and expanded to outline a set of inferences which described the interaction of symptoms and BoT. The resulting condition specific theory with integrated clinical model is shown in Figure 21.

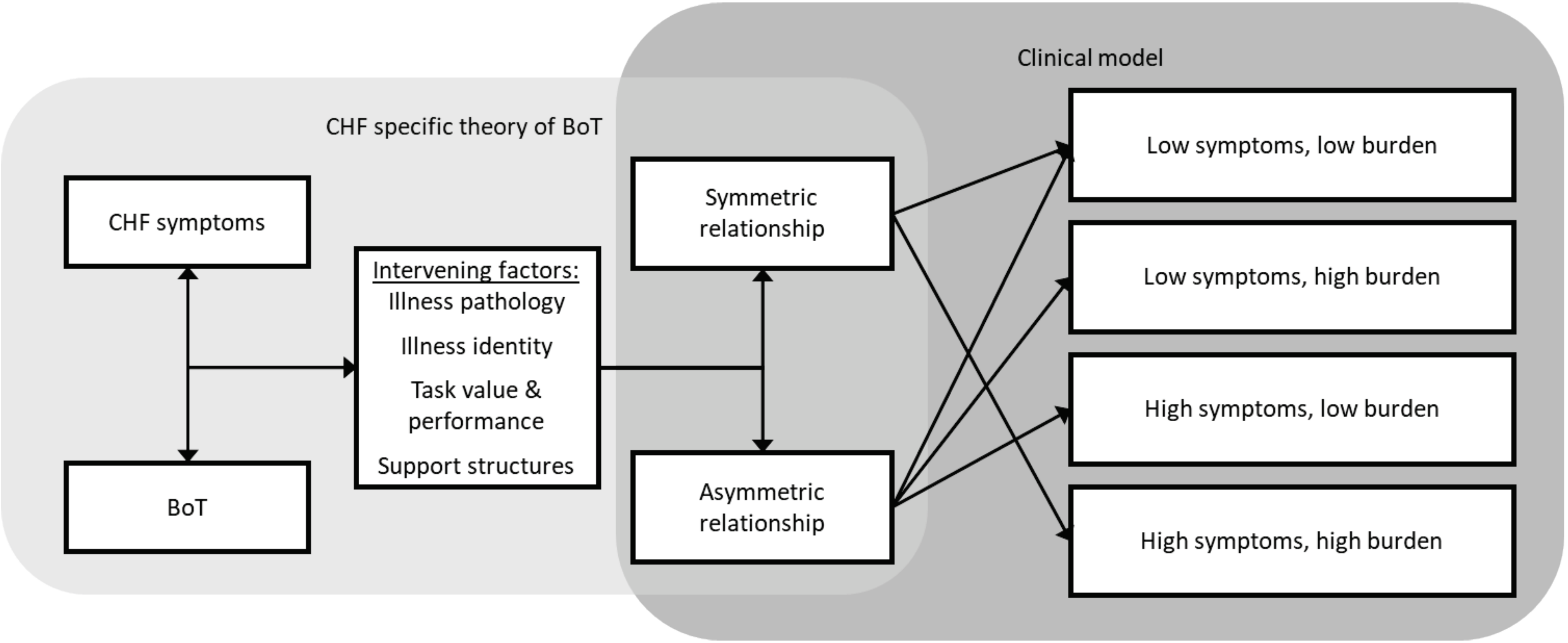

Figure 21: CHF specific BoT theory with integrated clinical model describing how CHF symptoms interact with BoT and results in four patient types. CHF, chronic heart failure; BoT, burden of treatment.

Table 16: Comparison of treatment work between BoT and self-care theories with resultant tasks assigned to patients

BoT components of workload	Self-care components of workload	Resultant tasks for patients
Health literacy, utilization of illness and treatment knowledge (59, 63-65, 118, 123, 124, 126, 128, 129, 131, 162, 252)	*While not outlined in practical tasks of self-care (20) improving patient knowledge is commonly described as an intervention for improving self-care (19, 76)	Learning about illness(es), its progression together with treatment(s) and their consequences
Treatment and medication adherence (59, 63-66, 118, 123, 124, 126, 128, 129, 162, 252)	Self-care maintenance: take medications as prescribed (18-20, 76, 117)	Medication management and adherence, vaccinations, self-care engagement, enduring side-effects
Enactment of lifestyle behaviour changes (59, 64, 65, 118, 123, 124, 126, 128, 129, 162, 252)	Self-care maintenance: enact lifestyle behaviours (18-20, 76, 117)	Reduce sodium and fluid intake, limit alcohol, use food supplements, be physically active, maintain healthy sleep, smoking cessation, no recreational drug use, adapt travel and leisure
Monitoring of symptoms and evaluation of treatments and self-care regimens (63-65, 118, 123, 124, 126, 129, 162, 252)	Self-care monitoring and management: observation of self for changes in signs and symptoms and responding appropriately to any changes (18-20, 76, 117)	Monitor: breathing, oedema, chest pain, appetite, fatigue, cough, wheezing, thirst, palpitations, dizziness, activity levels, weight, pulse, blood pressure, fever, diarrhoea, vomiting and mood. Recognise changes in the above factors. Adjust: diuretics and other medications, activity level, and diet. Consult healthcare professionals if appropriate

BoT components of workload	Self-care components of workload	Resultant tasks for patients
Accessing, attending and affording healthcare services (55, 59, 63-66, 118, 123, 124, 126, 128, 129, 131, 162, 252)	Self-care management: responding appropriately to any changes in signs and symptoms (18-20, 76, 117)	Consult a healthcare professional if there is a change in signs and symptoms, attend regular health appointments, co-ordinate and arrange healthcare appointments, medication management with pharmacy, navigate complex and siloed healthcare services
Acquisition and coordination of support from social support network (55, 59, 63-66, 118, 123, 124, 126, 128, 129, 131, 162)	Self-care management: responding appropriately to any changes in signs and symptoms (18-20, 76, 117)	Ask for help from friends and family, consult others when making decisions
Biographical work due to the impact of illness and its treatments (55, 118, 123, 124, 128, 131, 162, 252)	*Patients are considered experts who engage in naturalistic decision-making process relying on self-efficacy and confidence to inform their response (18, 20, 76)	Adjusting to the limitations imposed by physical alterations, adapting illness work into everyday work, altering sense of self from increased dependence on others

Research Ethics Committee approval for the work described in this paper was granted by the University of Southampton Ethics Committee (ERGO: 41287) and the Nottingham HRA1 Research Ethics Committee, Health Research Authority (MREC: 18/EM/0339, IRAS: 247773). Likewise, the research trial was registered on the ISRCTN registry: ISRCTN11011943; https://doi.org/10.1186/ISRCTN11011943

7.5 A CHF specific burden of treatment theory

The transition from a paternalistic set of ideas about healthcare relationships (32) to the current model that assumes patients are responsible for the management of their illness (3, 32, 33), is founded on the notion that motivated and engaged patients will actively participate in adherence to medical treatments and behavioural lifestyle alterations. Engagement in self-care is argued to result in improved health outcomes and decreased hospitalisations (32, 76, 117). Self-care, as a concept, has often neglected the sometimes overwhelming work that chronic illness can place on the individual (35, 50, 118, 269); the persistent and progressive symptoms of illness; adverse effects from treatments; and the complex demands of healthcare systems themselves (13, 21-23, 36, 50, 52, 59, 63, 65, 66, 118, 127, 234, 235).

The CHF specific BoT theory offers a new way of understanding the longstanding problem of non-adherence to self-care. It states that symptom burden interacts with treatment burden. These interactions are not immutable but are shaped by four intervening factors including illness pathology, illness identity, task value and performance, and available support structures. It is founded on two primary assumptions.

1) The perceived level of difficulty for tasks related to the management of illness (workload) is influenced by the patient’s capability and resources (capacity)
2) CHF symptoms are non-specific and progressive. Optimal treatment does not guarantee symptom relief and may have negative side effects.

In the work that follows the concepts of workload and capacity will be refined within the context of CHF. Self-care will be explored to see how it contrasts with workload as defined by BoT. The role of symptoms will be explored and tested against the underlying structures of both self-care theory of chronic illness and heart failure together with BoT theory. The offered theory focuses on people with an illness who clinically are referred to as patients.

7.5.1 Illness and treatment work of patients with CHF

The framework of BoT within CHF was first described as three main components of workload, capacity, and impact (132). The influence of symptoms on these components of BoT was described to be mainly negative interactions where symptoms, at best, made the workload of CHF more difficult, decreased their personal capabilities and impacted negatively on their sense of self (134). What follows is the definition of the components of BoT within the CHF context where the influence of symptoms has been observed in our and others' research.

7.5.1.1 Workload

Eton, Ramalho de Oliveira (58) defined workload as “the demands made on a patient’s time and energy due to treatment for a condition(s) as well as other aspects of self-care” (58 p. 40). In BoT theory (118), workload was categorized as both the work associated with mobilizing capacity and enacting delegated tasks (118). This is paralleled in other models of chronic illness (18, 19, 76, 117). Considered together, a comprehensive description is formed of both the work of illness and treatment (Table 16). The pervasive effects of symptoms are often missing from such accounts. Charmaz (36) described the influence of chronic illness symptoms including the accepted decreases of functional performance with resultant impact on a person’s identity. BoT theory acknowledges that symptoms will impact on an individual’s functional performance, altering their personal capacity (118). The situation-specific theory of self-care in heart failure acknowledges the influence of ‘problem factors’, which are prevalent in CHF, on naturalistic decision-making processes (e.g., multi-morbidity, mild cognitive impairment, alterations in physical functioning and mental health). These factors may decrease self-efficacy (76). The lived experience of these effects includes psychological distress from both accepting a life-limiting diagnosis and the reduction in personal capabilities (63, 134, 135, 162, 252) as well as the work of suffering with symptoms.

To summarise, symptoms have been observed to affect the difficulty of performing self-care workload (134-136, 252), and these are exacerbated by the ways that healthcare systems contribute to the difficulty of illness management (59, 63, 162, 252). In Figure 20, we show how the CHF specific BoT theory, therefore, includes the work described in self-care and treatment burden theories.

7.5.1.2 Capacity

BoT theory defines capacity as a complex and dynamic concept. Shippee, Shah (62), defined capacity as *abilities* (physical/mental functioning, literacy and attitudes/beliefs), *resources* (socioeconomic and social support) and *readiness* to manage the treatment work. These qualities are not assumed to belong to the individual patient alone, and also involve the mobilisation of social support and social capital within networks of family, friends, and others who intervene to share the load when workload becomes overwhelming (118). Research has refined the definition of capacity as a combination of personal capabilities (physical, mental, emotional, and spiritual), resources (socioeconomic status, literacy, social support network, informal caregivers, healthcare services, finances, life workload, environment, society perception of illness), together with readiness (personal resilience and adaptability to reframe personal biographies and relationships) (62, 64-66, 118, 127, 130, 131). Research in CHF examining BoT has demonstrated that symptoms can decrease patients' capacity by decreasing physical, mental, and emotional capabilities (134-136). In Norway, Nordfonn, Morken (131) have suggested that patient capacity for self-care was reliant on the ability to build resilience through adaptive coping strategies and accessibility support structures. In Scotland, Gallacher, May (59) pointed to the ways that healthcare services inaccessibility greatly added to workload and decreased capacity. CHF patients' propensity to delay in seeking care—even in taxpayer funded healthcare services—could be an indication of that perceived inaccessibility, and could be combined with decreased capabilities from symptoms both altering symptom perception (76, 117) and the effort to complete that task being outside of the patient's abilities (136).

Symptoms of CHF have been observed to alter patients' abilities, resources and readiness to manage work associated with treatment. The CHF specific BoT theory (Figure 20) is updated to reflect the additional work required by the activation of support structures, the influence of symptoms decreasing patients' capacity, and how that impacts illness identity.

7.5.1.3 Impact

The work of managing and living with illness has consequences on patients' sense of self and their role within society, first described as “reciprocal impact” in 1985 by Corbin and Strauss (35). Impact, as a concept in BoT literature, is typically included within the component capacity (118, 126). Instead, we considered it as a separate component of BoT (Figure 20) as it appeared to both effect workload dependent on capacity (58) and be a disruptive force resultant from treatments and side effects (127). Impact was defined as how the individuals' perception of self and their role within society altered due to both performing the treatment workload (self-care) and limitations imposed by symptoms and treatment side-effects (132, 134). In research that explored BoT in CHF where impact was quantified (patient experience of treatment and self-management (124) statistical correlations were observed between quantified impact index, psychological distress and emotional affect (135, 252), symptoms (135), and quality of life (135, 252). These observations were corroborated in qualitative research (136, 162). The presence of symptoms, despite medical treatment, altered how patients viewed their abilities with repercussions on their perceived role within families and society. Further, healthcare providers' view of reported symptoms also altered a patient's willingness to access healthcare services.

The CHF specific BoT theory incorporates the influence of symptoms on impact (Figure 20), the persistence and subjectiveness of symptoms can heighten patients' sense of worthlessness in the face of the lost personal capabilities. If patients experience healthcare interactions that devalue the patients reporting of those symptoms, the impact on the patient is compounded. The patient's experience of symptoms within their personal life, treatments, and healthcare interactions informs their illness identity.

7.5.2 Intervening factors alter the workload and the capacity to perform that work

7.5.2.1 Illness pathology

Specific CHF illness pathology factors can alter symptom experience, available treatments and healthcare services pathways (3, 13). In earlier papers, we observed that symptoms influence BoT, as perceived symptom intensity increased so did BoT intensity (134, 136). Other research has outlined how co-morbidities (59, 76, 134, 136, 270) and CHF treatments (3, 13, 134, 136, 270) add to the burden of symptoms. Further, symptoms can contribute to delay in seeking treatment (20, 76, 234, 235) and imposed limitations that extend across activities of daily life (13, 134, 136). Symptoms also alter a patient's sense of self imbued with an inherent loss of valued activities and roles, through an increased dependency (134, 136, 162). Thus, illness pathology as an intervening factor is broad (Figure 21), not limited to CHF pathology. It encompasses comorbidities, treatment side effects, and resultant disease specific healthcare service delivery pathways, with their inherent variable levels of support.

7.5.2.2 Illness identity

Illness requires patients to re-write personal biographies as the body becomes displaced from the original sense of self (36, 37, 118). The formulation of an illness identity was observed (Figure 21), where an illness journey was supplemented by life experiences (136). Oris, Rassart, Prikken (271) outlined four constructs of illness identity:

- Engulfment where illness dominates, sense of self is defined by illness. Our research showed symptoms dominate patients' lives discouraging engagement in self-care, particularly if a task causes symptoms (134, 136, 162). Patients' lives are defined by inescapable symptoms, sometimes reinforced by healthcare services; if symptoms are not alleviated (13, 162) or if symptoms are dismissed (136).
- Rejection is where illness is excluded as a part of the person's identity. Our research demonstrated these patients may discount symptoms and while self-care work might be adapted into daily life, those tasks can create resentment or grief (134, 136).

- Acceptance is where identity adapts to incorporate illness. Our research confirmed limitations imposed by symptoms resulted in life adaptations (37, 131, 136), subsequently, patients underestimated symptoms and underreported the effort and energy involved in self-care work (131, 134, 136).
- Enrichment, where illness is viewed as the enabler to personal growth, is not observed in our research, in the context of self-care engagement.

7.5.2.3 Task value and performance

Limitations enforced by symptoms alters workload performance (Figure 21); a simple task presents a series of logistical, physical, and emotional challenges affecting the task value and performance (134, 136, 162). Interactions with healthcare providers, or personal experience with treatments, can alter the value assigned to tasks (134, 136). Assigned high value meant difficult tasks were viewed as easy or vice versa if a task was not valued (136, 162). Self-care tasks beyond the patient's capabilities required recruiting assistance from support structures (118, 136), with concurrent emotional cost (135, 252).

7.5.2.4 Available support structures

The role of support structures was striking (Figure 21). Due to the frequency, clinically and in the literature, of reported high levels of poor self-care adherence; we had expected the workload index scores to be high. The survey of symptoms and BoT in CHF reported a mean workload index of "very easy" (135), similar to results from Norway (252). In our qualitative research, three justifications for why the workload was easy were observed: (a) illness identity of acceptance where self-care work was habitual, (b) support structures had assumed or were delegated the self-care work, or (c) inaccessibility of healthcare services resulting in limited self-care work (136). The importance of informal caregivers in this patient population is well documented (189, 257, 272, 273) and this can come with an emotional burden (135, 162, 257). It may be that patients will report easy work regarding their self-care tasks, as they are no longer responsible for this work, shifting the burden to the informal carer (136). Although the NHS provides free healthcare, inadequacies in systems structure and varying quality of interactions with healthcare providers alter patients' willingness to access healthcare systems (60, 63, 136), observed in multiple chronic illnesses and countries (65, 66, 131, 162, 252).

7.6 A clinical model of patient capacity in chronic heart failure

Examining the description of BoT, specific to CHF, and the varying influence of the above intervening factors provided insight into common patient types observed in both our research

(135, 136) and clinical settings. In a personalised experience of CHF, symptoms interact with BoT, which is mediated by illness pathology and identity, the value and performance of tasks, and availability of support structures, resulting in two outputs a symmetrical or asymmetrical relationship. These outputs and the resultant four patient types (Figure 21) create the clinical model of patient capacity in CHF.

Symptoms alter more than workload involved in CHF self-care; they can form a barrier to engagement in self-care (134). The interaction of symptoms and BoT may also be influenced through a complex interaction of intervening factors leading to the possibility of reporting BoT disproportionate to their symptom experience (135, 136).

The management of CHF outstrips the available resource of specialist clinicians (5, 274). Clinical evaluation has been streamlined to focus primarily on symptoms (breathlessness and oedema) which are linked to illness decompensation or treatments. Total symptom experience and BoT should also be evaluated, due to the relevance of other symptoms on self-care engagement (21, 134-136, 275, 276). CHF symptoms should be considered as an indicator of the capability to do self-care work alongside subsequent alterations to identity. Chronic illness self-care is heavy and hard work calling for the investment of at least 50-80 hours per month (273).

The clinical model derived from our theory building work (Figure 21) proposes that the interaction between CHF symptoms and BoT results in two relationship types: symmetric and asymmetric which leads to four patient types. While not discussed here a moderate experience is similarly influenced by the intervening factors, but the more extreme ends of the spectrum provide clearer examples. The four patient types were observed first in the survey results (Figure 11) where specific data points were contrary to the original hypothesis (low symptoms = low BoT and high symptoms – high BoT, in the context of patients' clinical presentation). These were described in chapters five and six as unexpected results. Integration of those results characterised the four patient types described in the following sub-sections. Appendix K provides exemplar case studies of how these patient types were informed, focusing on the asymmetrical patient types.

7.6.1 Low symptoms, low burden

Patients of this type may be experiencing either a symmetrical or asymmetrical relationship between symptoms and BoT. In a symmetrical relationship, CHF symptom intensity matches BoT intensity, parallel to clinical presentation. In an asymmetrical relationship despite the intensity matching between symptoms and BoT, this may contrast from their clinical presentation. Clinicians must consider if patients in this group are under reporting symptom experiences, due to adaptions to their lives or under reporting workload intensity as social support networks have assumed this work.

7.6.2 Low symptoms, high burden

Patients of this type are experiencing an asymmetrical relationship between symptoms and BoT. Their low reported symptom intensity may be due to a highly limited life engulfed by illness, thus may under report symptom intensity due to a life severely limited. The treatment work may be reported as heavy as it has low value due to symptoms not being relieved, iatrogenic harm, or shame from physical limitations. Lack of available support structures may also increase burden. Clinicians must carefully evaluate the reported symptom intensity around subjective symptoms against other signs of CHF. When reviewing a patient who is perceived to be non-adherent, clinicians should be curious and explore alternative reasons for the behaviour beyond motivation and health literacy.

7.6.3 High symptoms, low burden

Patients of this type are experiencing an asymmetrical relationship between symptoms and BoT. Symptoms may be persistent regardless of optimized treatment. There may be an additive effect from comorbidities and treatment side effects, not routinely evaluated in a streamlined clinical evaluation. They may have enriched lives due to illness, strengthening family bonds that assume much of the treatment workload. Healthcare services are accessible, as their symptoms are high and illness unstable. They feel cared for by engaged healthcare professionals resulting in low burden. Clinicians need to consider a broader clinical evaluation because of persistent symptoms and be aware that heavy reliance on informal carers to assume self-care work has widespread consequences on the health of the family unit.

7.6.4 High symptoms, high burden

Patients of this type are experiencing a symmetrical relationship between symptoms and BoT. Symptoms are intense and lives are limited with no internal capability to perform the work of treatment. Although family may have assumed the work of treatment, the patient’s sense of self-value has been stripped as they are forced into the role of a dependent. The erosion of personal value means regardless of beneficial treatments, those treatments feel burdensome despite their life-sustaining factor as there is no value left in living. Clinicians most frequently encounter this patient type in emergent re-admissions. A careful and thorough history of their experiences may reveal how their non-adherence was influenced by previous negative healthcare interactions providing an opportunity for positive change.

In these examples, there are multiple points where burden of either symptoms or treatment might be alleviated. This model of patient capacity and the CHF specific BoT theory provides promise to unlocking the longstanding issue of self-care non-adherence offering multiple factors where effective change can be wrought. Table 17 offers questions for clinicians to consider around intervening factors when confronted with any of the above patient types.

Table 17: Clinical questions for evaluating mediation factors of CHF specific BoT theory

	Questions about the patient's experiences	Questions about the healthcare services
Illness Pathology	Are symptoms preventing engagement with self-care?	Are current clinical pathways for the patient limiting symptoms evaluation?
Illness identity	Has the patient rejected or accepted illness? Is this altering their clinical reporting?	Are they engulfed by illness? Is there more available support to help?
Task value and performance	Have they experienced benefits from treatment? How is this influencing the self-care work?	Have they experienced side effects from treatments? Has this been discussed?
Support structures	Who is doing the work of self-care? Have informal caregivers assumed this work?	Are there other available resources (patient support groups, community services, etc.) they could access? How can healthcare services be made more accessible?

7.7 Discussion

This paper offers both clinicians and researchers a new framework for understanding the longstanding issue of non-adherence in CHF care. The CHF specific adaptation of BoT theory incorporates elements of the theories of self-care of chronic illness and heart failure. The theory and clinical model are founded on the following propositions.

1) Workload difficulty is influenced by the patient’s capability and resources (capacity) to do that work. Where symptoms, illness pathology and identity, task value and performance, and support structures can alter that interaction.
2) Symptoms of CHF are non-specific, progressive and debilitating. Optimised medical treatments do not guarantee relief. Engagement with self-care may not alleviate symptoms and the presence of progressive symptoms does not signal patient failure in performing self-care work.

3) Capacity is influenced by illness pathology and identity, task value and performance, and available support structures. The resulting interaction with symptoms is either a symmetrical or asymmetrical relationship leading to 4 patient types.

The CHF specific adaptations of BoT theory present a theoretical framework and clinical model which, while in the early stages of development, presents researchers, clinicians, and patients with the foundation to create awareness and educational interventions to improve clinical practices. Further following confirmatory research, using the offered theory as a framework to co-design a restructure of heart failure clinical pathways in a way that will offer better solutions to patient needs without exceeding clinical capacity.

7.8 Strengths and limitations

The CHF specific BoT theory was built on strong theoretical foundations. Individual research work was purposively designed. Each piece of our research presented in this paper has addressed its individual strengths and weaknesses (132-134). BoT theory (118) informed this work as well as provided a framework for the data analysis in two of the research studies. The theories of self-care in chronic illness (19, 117) and heart failure (18, 76, 262) provided a framework for informing the workload of self-care. The concept of illness identity (277) was observed in the findings of the research results and underpinned by constructs of BoT theory. Similar ideas were outlined in the living with chronic illness concept analysis (38) and further research will be needed to determine how the experience observed in this research differs between their work and illness identity research from Van Bulck, Luyckx (277). Data integration across the research project SYMPACT helped to identify and characterise four patient types. This is the first time the experience of patients with CHF was described in terms of how symptoms interact with BoT alongside the role of intervening factors. More research is needed to confirm these patient types and their relationship and importance in clinical interactions and patient outcomes. Integrating multiple forms of research together enabled the characterisation of theoretical constructs that informed the CHF specific BoT theory. While this theory offers possible outcomes of the interaction between symptoms and CHF and claims these influence engagements in self-care and clinical outcomes, further research is now needed to test the theory.

7.9 Conclusion

The CHF specific BoT theory set out in this paper and the resultant translational clinical model present an alternative framework for viewing the parallel problems of patient non-adherence to self-care regimens and the overwhelming demands placed on healthcare services by chronic illnesses like CHF. A thorough examination of the sensitising theoretical concepts informed both the theory and model based on a variety of research. It offers a framework for informing the development of a purpose-built tool to measure BoT in CHF, with the prospect of incorporation into clinical evaluation of CHF patients, and for testing CHF interventions. Although there is a need for confirmatory research, this theory argues that treatment work is hard and heavy and that engagement in self-care does not guarantee an improved outcome for patients.

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7.12 Author contributions

RCA drafted this paper. RCA designed the CHF specific BoT theory with guidance and support from CRM, LS, and PRK. Interpretations of the constructs and their mapping were discussed between all authors and then described by RCA. CRM, LS, AR, and PRK critically reviewed the manuscript for intellectual and clinical content. All authors approved the final version of the paper. RCA is the guarantor.

Chapter 8 Thesis conclusion

Due to the overwhelming demand created by chronic illness, healthcare systems (including the NHS) have shifted the responsibility of chronic illness management onto patients and by proxy their loved ones (30). Informed by principles of self-efficacy, the current model of healthcare services (HCS) has become a blend of paternalistic medicine and an expert patient model, reliant on self-care strategies in the management of chronic illness. Healthcare professionals (HCPs) are expected to assign and educate the chronically ill in complex and burdensome self-care regimens (18-20, 76, 117). Patients are expected to be experts in their illness experience, accept and integrate the self-care regimens, to then seek care appropriately when there is a change in their illness. However, patients with CHF are reputed to fail with self-care regimens and poor adherence are blamed for increasing HCS burden and costs (20-22, 278, 279). In CHF care it is acknowledged that there are not enough clinicians to meet demand (5, 274). The 2020 NICOR heart failure audit reports that the majority of patients with CHF do not receive the specialist care they require nor are they placed on therapies indicated by guidelines (5).

The majority of CHF management is placed on the shoulders of ill patients, who may not receive the specialist care recommended by the European Society for Cardiology (3). When inevitably they return to healthcare services, a change in illness status is often blamed on non-adherence due to poor motivation and knowledge (20). A holistic view of the patient and their circumstances are not routinely taken into consideration. Typical clinical evaluations centre on symptoms of breathlessness and oedema. But these symptoms are often only considered markers of illness progression, decompensation, or treatment effectiveness. Symptoms of CHF are not considered a factor that might influence a person's ability to engage in self-care work. Treatment work is mounted on chronically ill patients, with poor quality of life, as the philosophies underpinning the current healthcare systems dictate these actions. When patients fail to do this work, the prevailing theories inform clinicians and researchers that more education is needed resulting in more work being assigned to ill patients and overwhelmed clinicians. In short, the current care pathways of CHF do not consider the impact of symptoms, burden of treatment or the interaction of these concepts.

8.1 Justification for the development of a CHF specific BoT theory

8.1.1 Use of different theories

The work presented in this thesis is underpinned by three theories, theories of self-care in chronic illness (19, 117) and heart failure (18, 76), and BoT theory (118). The theories around self-care are accepted and established within nursing practice, research studies in heart failure, and healthcare systems. Many clinicians have found value and truth in this theory when working with patients. The theories describe the processes and work that those with chronic illness perform as a part of their self-care. These theories are detailed and informed by a body of research. In brief, these theories work together to describe how self-care is a naturalistic decision-making process where patients who are educated in the value and importance of the work of treatment will engage in self-care work (section 1.3.1). They state that symptoms of illness are a part of that work and may affect capabilities to do that work, but symptoms will also inform the work which patients must complete. Self-care is a combination of self-care maintenance (health promotion practices), monitoring (tracking and responding to alterations in oneself), and management (response to symptoms) (117). Self-care theories assume if a patient engages in self-care; illness stability, improved health status, well-being and QoL, reduced mortality and symptom burden, etc. are some of the positive outcomes experienced. These theories of self-care do not consider the burden of treatment work, the complexities of accessing a siloed healthcare system, or the iatrogenic side effects from CHF treatments.

BoT theory presents a wider viewpoint of the patient experience incorporating the work that is outlined in the theories of self-care. BoT theory acknowledges that demand to complete treatment work is placed on the ill. Illness is hard and heavy work and the work of treatment adds to that work (118). If work associated with illness and its treatment (workload) is unbalanced with a person’s individual capacity (their capabilities and the accessible resources available to share the burden of work) then BoT becomes overwhelming (118, 132). Resulting in poor engagement with self-care, poor QoL and patient outcomes (118). BoT theory is not yet engrained in healthcare systems, but the body of research built on this theory is growing (section 1.3.2).

The philosophical underpinnings of these theories appear opposed, but both have the same goal to improve patient QoL and clinical outcomes. The theories around self-care are underpinned by naturalistic decision-making and self-efficacy, promoting the viewpoint where the patient is viewed as an expert. These philosophies lead researchers and clinicians to assume that failure in self-care is solely the fault of the patient. In the research based on the theories of self-care, the common contribution to failures in self-care are placed on the poor health education of patients and thus they misunderstand, misconceive, and have low knowledge of self-care work (20). The resultant outputs from this research are interventions which focus on improving patients' health literacy, but these interventions had mixed success (24, 25, 272, 278, 280). These theories of self-care do not appear to fully account for the effect that symptoms may have on this process, nor are the other intervening factors discovered in this thesis incorporated. In this thesis, self-care theories were used to inform and complement the definition of treatment work.

BoT theory describes patient agency and focuses on how patients and their caregivers respond to expectations of healthcare services to engage in the work of treatment. In doing so, defining what is the work of a patient (workload), what are their personal and available resources to do this work (capacity), and how will engaging in this work impact on their sense of self and role in society (impact) (62, 118, 126, 189). By defining and explaining the phenomena of treatment burden, BoT theory has identified how these concepts influence the patient's behaviour and choices, providing an alternative explanation for healthcare utilization and adherence (118). The resultant output from this theory is that the patient's experience is shaped by the balance between workload and capacity, together with the impact that doing the work has on the individual (62, 65, 66, 118, 126, 131, 134, 162, 189). In this thesis, BoT theory informed a framework which was utilised to inform the design and analysis of the research. BoT theory became an alternative lens through which the problems of CHF self-care failures were viewed.

At the beginning of this thesis, the concept of *living with chronic illness* was considered and excluded (section 1.2.1). While the importance of psychosocial factors is acknowledged in BoT research (impact and work associated with completing self-care work) my research interest was focused on the impact related to the persistent symptoms of CHF (not typically included in clinical evaluations) on BoT (e.g., iron deficiency, fatigue, and cognition). The results of the study showed that symptoms affect emotional health which can inform their illness identity. Within the thesis, the work around illness identity in congenital heart disease (277) was chosen to help classify my observations as it had salience across both how participants SYMPACT has reported and described their symptoms and BoT. There were similar parallels with how Ambrosio, Senosiain Garcia (38) categorised the ways a patient lives with chronic illness. Further research is needed to better explore how these two different ways of describing and capturing how a person lives with chronic illness are needed.

The differences between these theories shape not just how the patient is viewed, but in how the work of treatment is viewed. Where self-care theories view patients as individuals who are experts able to evaluate the situation and process to determine the right action. BoT theory views the patients as individuals who are engaged in the hard and heavy work of illness and treatment. Self-care theory views the work of treatment as a positive action where even if challenging, engagement in that work will result in beneficial experiences. BoT theory views the work of treatment where ill individuals navigate complex care pathways where engagement with the work of treatment can be burdensome. My epistemological standpoint of critical realism allowed me to view these two different versions of truth, enabling me to pragmatically question and evaluate the phenomena of interest without declaring either of them false.

8.1.2 Use of different methods

In my nursing education, I was taught the hierarchy of evidence (281) which instilled in me the belief that certain methods had varying degrees of value. These messages were reinforced in my experiences as a nurse. At professional conferences rarely were literature reviews, qualitative synthesis, or qualitative research findings presented. The research work I performed as a specialist research nurse was rarely anything other than deductively informed methods. But my experiences and observations as a nurse led me to believe that deductive research while valuable, it was inappropriate for certain research questions and lacked the valuable features of inductive research.

The article by Feilzer (141) transformed how I thought about varying research methodologies. While the philosophy of using different methods has long been argued in terms of merit, deficits, and its impossibility due to their diametrically opposed philosophical foundations (141, 148, 151, 178, 282, 283). Whereas Feilzer (141) argued that a pragmatic stance where the right method is used for the right question aiming toward a practical solution to a practical problem. The pragmatic view of mixed method research combined with abductive reasoning challenged me to think about integration in my mixed methods research.

8.1.3 Use of data integration

Data integration within study design is the process of connecting, building, merging, and/or embedding the different data types (148, 151). Bazeley (267) presents a process-orientated logic model for integrated analysis designed to help mixed methods researchers combine multiple data sources and approaches to deliver effective and beneficial research applications. In this thesis, integration occurred from design through how conclusions were drawn. In choosing a sequential explanatory design I established a plan to connect the survey data to the interview data through sampling this is evidenced in Chapter 3. Integration can also occur in the interpretation of the data through a narrative approach, data transformation, and joint display (148, 151). Translation of data refers to the process of converting the data from qualitative to quantitative or vice versa, where the narrative approach adds depth and richness to quantitative data. Joint display uses an integration of data in data visualisation to bring out new insights (148). In this thesis, joint display was used in the qualitative evidence synthesis in the creation of the Sankey diagram (134). In Chapter 7 multiple integration methods were used in the development of the CHF specific BoT theory as the final level of integration used.

In using multiple approaches in the design and analysis stages, the integration of data confirmed and expanded the findings. Confirmation is when two different data types confirm the findings of the other. Expansion is the divergence of the data where the insights are expanded through the phenomenon being described from differing or complementary aspects (148, 284). Confirmation was seen in the interview results paper (136) along with expansion observed within the offering of the CHF specific BoT theory (Chapter 7). The final multiple integration methods used to build the offered theory (Chapter 7) provide an example (as described by Bazeley (267) and Tavory and Timmermans (266)) of how the recursive and iterative use of multiple methods can inform the robust development of theory building.

While these aspects of pragmatic mixed methods helped justify doing this style of research, I still struggled to see how they would work together to inform a single idea. The introduction of abductive reasoning changed this for me. Abductive reasoning encourages the recursive and iterative use of multiple pragmatic research methods to answer a research question. Rather than focusing on the differences between philosophical underpinnings of separate methods it instead encourages the idea that those differences allow you to view the problem from multiple angles, working your way through observations, surprises and anomalies until you arrive at a theory that is informed by multiple viewpoints rather than a singular viewpoint (168, 266). This appealed equally to my pragmatic and critical realistic foundations.

The qualitative evidence synthesis (Chapter 4), helped improve my understanding of the literature around the experience of living with and managing CHF. It also unwittingly helped me better understand the importance of knowing and understanding personal philosophical foundations, which I will explore in greater detail in the reflexive account (section 8.3). By using a different framework, based on BoT theory, enabled the identification and characterization of how symptoms interacted with BoT. Provides the evidence for the foundation of explaining an alternative explanation for why those with CHF appear to fail in self-care engagement.

The cross-sectional survey described BoT and symptoms in a UK CHF population. It showed that even research that is based on deductive and positivist philosophies can still be open to different interpretations. The research allowed the exploration of my hypothesis that symptoms directly interact with BoT through statistical correlations. While part of the hypothesis was proven, this work left more questions than answers. The qualitative synthesis strengthened my belief that symptoms and BoT interacted in workload, capacity, and impact. The interactions observed in these data ranged from positive (drive), difficult (impede), and overwhelming (barrier). Results from the survey data demonstrated that the interaction between symptoms and BoT did not appear to be strong or straightforward. The statistical interactions between workload index and symptoms, which were only weak to moderate, made me question the hypothesised interaction between CHF symptoms and patient engagement in their self-care work as a part of their BoT workload.

Conducting semi-structured interviews and analysing these data saw the corroboration of the findings from the qualitative evidence synthesis. This research further identified and characterised the relationship between symptoms of CHF and BoT. The depth of the dataset imbued a sense of responsibility to honour participants by doing my best to convey their individual and collective messages to the clinical and research audience. Data collected in interviews presented in this thesis describes participants' beliefs in the hypotheses and further characterised the relationship between symptoms and BoT. These data also provided possible explanations for the nuances in BoT experienced by patients with CHF captured in the survey.

Theory building integrated all of the above separate pieces. This has the potential to help clinicians better understand those patients who have a more unusual response to the heavy treatment burden assigned by CHF. Using mixed methods has enriched the research presented in this thesis. If only one element of the research was considered, the conclusions would not reflect the complexity of the interactions between patients, their illness, their social networks, and the healthcare system. The foundation of critical realism, together with a pragmatic and abductive approach has facilitated an integration of different data types informing a CHF specific BoT theory.

8.1.4 Foundation of the CHF specific BoT theory

The reading and thinking that I did behind my first publication relating to my doctoral studies, was much more in-depth than presented in the published editorial (132). The editorial was an overview of my thoughts and understanding of the major components, which I wanted to share with other researchers and clinicians. The idea that the work associated with illness and its treatments were burdensome resonated with my clinical experiences and I believed this was important to highlight. I believed that practical definitions around the work of self-care, as defined by the theories of self-care in chronic illness and heart failure, fit within the domain of workload in the BoT theory. Despite their differing philosophical foundations. I believed BoT theory offered new insight as to why failures in self-care for patients with CHF were so prevalent. Not only was the work of treatment difficult but also inadequacies were revealed in patient resources. Insufficient and inaccessible support both within informal caregivers and healthcare systems further upset the delicate balance between workload and capacity. As a research nurse, I have spent considerable time detailing a patient's journey when reporting study events. I saw multiple examples where healthcare systems were failing CHF patients. For example: clinical letters were not received for appointments that were missed resulting in patients being discharged from specialist services. Clinicians cite non-adherence or assumed improvement of patient health to justify the discharge from their service. But how can you attend an appointment you had no knowledge of?

Additionally, CHF symptoms do not always have a logical experiential connection with treatments. For example, with diabetes, you feel dizzy, shaky and hungry. You check your blood sugar. It is low so you drink a sugary drink, then recheck you blood sugar it has improved and typically those symptoms have resolved. Comparatively, in heart failure, you are short of breath and have a cough that won't go away. Your GP has sent you to see a cardiologist who tells you that you have heart failure and there is nothing wrong with your lungs. You are already on heart medications from the heart attack you had a year ago, so the only medication you are given is a tablet that makes you urinate more. You remain breathless, and your cough doesn't change. To me, this created a logical disconnect which might make it more difficult for patients to adhere to their medications and self-care regimens as it did not fit the assumptions of the self-care theories when doing the treatment work results in improved outcomes and decrease of symptoms.

Multiple signs and symptoms of heart failure are non-specific and highly subjective, further complicating a patient's ability to monitor those symptoms and accurately respond to them. For example, fatigue is a symptom that is associated with ageing, low fitness, mental health conditions, poor sleep, CHF, a busy lifestyle, iron deficiency, etc. If you are a typical heart failure patient who is over 60 years, a bit overweight, with low fitness levels and you are feeling more fatigue than normal, how do you know it is related to a worsening in your CHF or the fact that you are a year older, and you are unfit and a bit too heavy?

Finally, in a typical clinical evaluation with a heart failure patient, the tendency is to focus on typical symptoms of oedema and breathlessness. Leaving patients to believe that those are the symptoms that matter for their illness. Changes in cognitive abilities and psychological distress are rarely discussed, despite the evidence that suggests these are related to poor adherence and worse outcomes.

I hypothesised that symptoms of CHF interacted with workload through an alteration of the level of difficulty of the work expected by engaging in self-care. While I agreed that CHF symptoms would alter capacity by an alteration in internal capabilities, I felt this effect was greater than previously postulated and the limitations due to illness pathophysiology could impact on the patient’s sense of self and their role in society which could impact on their readiness to activate external resources.

8.1.5 Iterations of the model throughout the papers

At each stage in the thesis, through adhering to the recursive principles of abduction, I returned to the initial idea and revised it according to the results and findings. This iterative process also altered the study specific research questions and analysis plan. Particularly after generating the survey results whereupon the quantitative data differed from both my hypothesis and the findings from the qualitative synthesis. Without this process of each study informing the next, the theory developed would have been different than what is outlined in Chapter 7.

8.2 Explanation of the significance and novelty of findings

8.2.1 Editorial introducing the research question

The novelty of this publication comes from the fact that this is the first paper in the field of cardiovascular pathology to propose a connection between CHF symptoms and BoT. In recognition of this novelty and the clinical implications these considerations may have, the journal identified it as one of the top ten most useful and influential articles in 2021 (285).

8.2.2 Protocol paper for SYMPACT a mixed method design

The novelty of this publication is that this is the first published protocol to propose to capture CHF BoT and symptoms using a sequential design. The research design described the plan to explore the phenomena of interest using different research methodologies and also served to explore any unexpected results.

8.2.3 Qualitative evidence synthesis

There are two original contributions in this work. First, the use of a Sankey diagram to visualize how the coding was performed in the analysis helped to inform the conclusions drawn. Embedded in this was the use of numbers to highlight the frequency and consistency of the coding. The latter was raised as a concern by one of the reviewers. But the purpose of including the numbers was to demonstrate the prevalence of the codes and themes which I felt was of particular importance as the work used previously published data for a purpose other than it was originally collected for. I believed that this method of data visualization helped to strengthen the conclusions.

Second, the conclusions were a novel contribution as these challenged the prevailing clinical mind-set that symptoms would encourage those with CHF to engage with self-care. Instead, I observed that more frequently symptoms made the work of self-care more difficult or even impossible, through a complex interaction with various domains of BoT.

8.2.4 Cross-sectional survey of patients with CHF

The novel aspect of this research is that this was the first time, in the UK, that BoT was measured with PETS, in a CHF population. To the best of my knowledge, this may have also been the first time the brief PETS was used in a CHF population and purposively compared to both physical symptoms and emotional affect.

While the findings had similarities with data presented by Nordfonn, Morken (252), my publication looked at the collective symptom experience measured by HFSS. Instead of looking at HR-QoL with the MLHFQ, it was primarily used for the physical and emotional sub-scores. Instead of reporting on individual domains in the PETS, it was the first in CHF to report PETS results using the workload and impact indices.

8.2.5 Qualitative Semi-structured interview results

The original contribution of this paper is through utilizing a purposive sequential explanatory design. Quantitative results were explored, and factors proffered that provided clarity and depth to the unexpected findings in the survey. This led to the conclusion that while symptoms do interact with BoT there are other intervening factors which can influence this relationship which alters patient reporting of both symptoms and BoT. This is the first time this observation was made in CHF. It has significant implications on the clinical evaluation of CHF patients as well as challenging the current belief that non-adherence is primarily related to health literacy. The findings instead present a complex model which apportions causes for non-adherence in self-care regimens to multiple intervening factors.

8.2.6 Development of the CHF specific BoT theory

This paper is the first paper to bring together the findings from the body of research within this thesis, together with other research work to present a condition specific BoT theory. The clinical model accounts for the influence of symptoms and other intervening factors (illness identity, task value and performance, and support structures) on patient engagement with self-care. It provides a novel framework for researchers and clinicians to formulate research that accounts for both the work of illness and treatment. It may also help clinicians in adjusting their interactions with patients to consider BoT and how this may impact on patient's ability to perform self-care.

8.2.7 Clinical significance

The body of research included in this thesis presents an alternative view on the long-standing issue of non-adherence to self-care regimens in CHF. It presents evidence for factors other than health literacy and motivation as contributors to this problem. This is clinically significant as it offers clinicians other venues to explore when attempting to assist patients. Given the lack of strong evidence to support the previous success of interventions around improving health literacy and motivation to improve self-care, as described in this thesis, this work provides a new foundation for other interventions to be created and explored. The offered theory may also provide clinicians with a framework to work through with patients who despite being on optimal medical therapies do not appear to benefit. It may help those patients, through identification of factors outside the typical CHF clinical evaluation that may alleviate their treatment burden and may even influence their symptom burden. More research is needed to better understand the interventional and clinical relevance of this theory.

8.3 Reflexive account

8.3.1 Philosophical shift

At the beginning of the doctoral studies, (section 1.4.5.2), I took the approach of a pragmatist to understand and describe my beliefs about what truth is and the formation of knowledge, I viewed this activity as unnecessary as it offered few practical solutions to the clinical problems I observed daily. During the completion of the work undertaken in the qualitative evidence synthesis (134). I realised how important it was to declare and define your underpinning philosophy as a researcher. In the data extracted in the qualitative evidence synthesis, I was struck by how persistently and pervasively the participants in all 35 studies reported that the CHF symptoms they experienced were disrupting their lives. While those researchers would outline that patients' quality of life was poor and that healthcare system complexity added to the difficulties that patients experienced. Their main conclusions were always CHF patients have poor health literacy, need more education, and monitoring to improve their engagement with self-care. These authors did not see what I was seeing that their illness and resultant symptoms were making that work impossible resulting in either a reliance on others to assume that workload or non-adherence. I raise this not to say that they were wrong, but merely as an illustration of how what you believe can influence your interpretation of the data and thereby your conclusions. They had chosen to examine the data believing in the philosophies behind self-efficacy and the theories of self-care. Therefore, it follows that they would likely find that deficits in patient performance of assigned self-care work were related to insufficient knowledge and poor motivation. The same consideration applies to my research work and conclusions, where by using the BoT theory as a framework I concluded that patient resources affected their ability to perform the workload. While I remain a pragmatist, I now have shifted my beliefs around the value of understanding how philosophical underpinnings might alter data interpretation and conclusions drawn. I disagree with Feilzer (141) instead, I would more closely embody a philosophical belief that blends critical realism and abductive reasoning with an element of pragmatism. I seek to find practical solutions to clinical problems. I acknowledge that there may be differing truths but that within those truths there is likely a framework that I can identify, describe and explain. This is accomplished by iteratively examining the phenomena utilising multiple methods in appropriate and systematic ways. Bringing together the observations, surprises and anomalies with my knowledge and expertise to describe models and develop theories. Which will then be subjected to further testing through the application of those practical solutions the theory informs.

8.3.2 Shift in understanding of research

In my nursing and master’s training in Canada, the value and truth of evidence that had been published was a strong thread in my education. I was taught the hierarchy of evidence (281), informing my belief system of the value of the various types of research methodologies. While we were taught to think critically about research, before starting my PhD, the meaning and importance of this was very superficial. This was demonstrated in an experience I had with my first progression review document review by my supervisors. In the draft, I included the definition of self-care according to the theory of self-care. The phrase “self-care is a naturalistic decision-making process” was highlighted and the accompanying comment “Is this true?” taunted me. I was affronted, of course, it was true. The definition was by well-respected authors who based their definition on a breadth of empirical research and theoretical frameworks. It had been used to create a tool which then measured self-care in multiple research studies. Of course, it was true. What I didn’t understand then, was I was being challenged to question my belief in this definition of self-care.

My doctoral studies continued to challenge me on what I believed about truth, best highlighted when I started analysis of the survey responses. In reading the literature around any questionnaire, the presence of statistical tests that assessed validity and reliability was the minimum requirement for selection in my research. I interpreted this as the questionnaire was tested and found to measure the variable I wanted to capture. The scores would be a true representation of that variable. Similar to my belief that self-care was a naturalist decision-making process, I believed that if a questionnaire was developed by reputable researchers, in reputable journal, cited and reviewed by independent researchers; therefore, it would measure the variable it claimed to measure.

Using PETS challenged this belief. First, in the articles I had read about it in how they worded the article, or maybe in how I misinterpreted what they wrote, I believed that PETS included a single summary measure of BoT. I built my statistical analysis plan around that belief and used that belief as the foundation for my power calculations. In the interim analysis when I discovered the reality that there was no summary measure resulting in a more complex dataset. The lack of a summary score required multiple correlations to be calculated, with a subsequent increase of complexity in reporting the results and interpreting them. Further, in calculating the scoring of certain domains in PETS, I questioned some of the decisions made by the authors of PETS. I raise these points not to criticise the PETS and its practical application to research, but to highlight how much my view of other tools and the quantification of complex experiences was beginning to shift. I could now see that while a tool could be statistically valid and reliable, it could not guarantee that it would provide researchers with a true representation of what the participant had experienced. The answer selected could be influenced by participant bias, worries, and interpretations. I began to understand the wider implications of the research. Even in quantitative research, creating knowledge based on observed truth was not as simple as my positivist clinical training led me to believe. I believe that the PETS is a good tool and that it measures some domains of BoT well. But I don’t agree with how it scores some of the dimensions, and I think there are some questions, particularly for CHF patients, that are missing. The other tools, in different ways, also helped to reinforce these revelations. Research is only as good as the tools that you use to capture phenomena and those tools, even if well-developed are open to interpretation, error, and bias.

Once I accepted that despite misgivings, I’d need to use the questionnaires I had chosen. I moved on to the statistical analysis, believing that this process would be black or white. Here I will find if what I hypothesised is true or not according to the tools I used with their inherent inadequacies. I ran the correlations and very proudly shared them with my supervisors and the statistician. The simple question, “is the data normal” opened a new rabbit hole. I plotted histograms, ran normality tests, and plotted Q-Q normality graphs. The verdict was different with every tool. The normality tests came with a caveat that said they might under- or over-estimate normality given the sample size and a variety of other factors (286-288). The histogram and Q-Q plots graphs were no more conclusive as their interpretation is subjective and unreliable (287, 288). When discussing all of these difficulties with Vasiliki Koutra[2], my inner pragmatist recoiled as she introduced me to the fact that statistics also had philosophical foundations which could mean that normality itself might be non-important with in correlations depending on your theoretical statistical underpinning beliefs (286). In reading the book, “Normal sucks”, in which the author, in recounting a personal journey as a child with ADHD and dyslexia, exposed weaknesses in the research which developed the normal curve and science’s pursuit of a normalised experience (138). I began to question if normal was a variable worth pursuing, given the findings in my research.

My lessons around truth continued in the qualitative interviews, participants had a story that they want to tell. Sometimes, no matter how hard I tried to redirect or bring them back to their experiences of CHF, they determinedly told me the story of other health crises, medical repatriation or other life-altering health experiences. Most of those stories did relate to their CHF experience and often influenced their perceived BoT. Due to all the previous experience that I had in conducting this research I was becoming more comfortable with my critical realistic point of view. Truth, in my research, appeared to be a much more fluid concept than what I believed at the beginning of my doctoral studies.

Reflecting now on the comment, “is this true”; my supervisors were not asking if it was right or wrong. Instead, they were asking what I thought about the concept of naturalistic decision-making process, and how that related to my clinical experiences. Now I find myself asking that same question around the findings of my research. Are patient’s experts to the same level as the experts referred to in the research that founded naturalist decision-making? Is it possible for a person who is ill to objectively evaluate the consequences of their actions when plagued by symptoms that have stripped them of all the personality traits they valued? If they are, then shouldn’t healthcare professionals accept those decisions rather than blaming them for non-adherence? I have become a researcher whose research creates more questions than it answers.

8.3.3 Development as a nurse researcher

In the early stages of my doctoral research, I found myself in a very different place, than other PhD colleagues. I had a level of expertise in the early stages of research production, as a research

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[2] Vasiliki Koutra is the statistician who guided and informed the statistical analysis that I performed in the cross-sectional survey study.

nurse, I had read many protocols, completed IRAS forms, and gone through the process of opening research studies multiple times. I had even refined research protocols written by medical colleagues. This was both an advantage and a disadvantage as it meant I placed high expectations on myself.

The disadvantage was that I built a project, which I was constantly reminded by others, that was too big. When encouraged to make it simpler, I believed they did not fully understand the experience I had in research delivery as a research nurse. When it came to the research delivery side of things my expertise paid off. I negotiated the use of an eCRF to collect my data limiting the possible data entry errors, making it possible for multiple users to enter data across multiple sites simultaneously with the ability to have all actions on the database auditable. However, that was as far as my experience took me. I learned that while it might be feasible to get the amount of data collected in a short amount of time, it was up to me to convert it into a format that was usable for analysis purposes, increasing the amount of work I needed to complete the doctoral study.

My doctoral research also opened my eyes to the value and importance of patient and public involvement, and I sought my line manager's support to spend time in my clinical days supporting and establishing the patient research ambassador (PRA) group at PHU. The lessons I learned here have shaped me as a researcher as well as my research presented in my PhD. Each of the publications outlines the support that I received from the PRA group. Some of their work on this project remains ongoing as together we are creating plain English results summary to send to participants and post on the study blog. I am indebted to their help in activities from editing patient facing documents to sense checking my results. As a result of our working relationship, I was invited to present how working with them influence my PhD as well as the importance of PPI work in research (Appendix L).

Covid -19 pandemic brought further challenges to my development as a nurse researcher. While in theory, I knew that amendments happen, due to the restricted time I had to complete data collection I tried to write my protocol and ethics documents in such a way that I wouldn’t need to make any amendments. But just as I had finally finished my first amendment to increase my recruitment targets, I found myself completing a second amendment. Due to the breakout of a global pandemic, I paused recruitment. After discussion with my supervisors, I also volunteered to redeploy to the Intensive therapy unit (ITU) on my clinical days. I had previous ITU experience, and based on the news and rumours I knew ITU would need help. We agreed that while I would have to slow my progress down, I would try to still work on my PhD when I was not in ITU. This proved more challenging than I had anticipated and got worse with the redeployment in the second wave leading to a needed timeline extension. What this taught me is that as a researcher you have to adapt your research not just based on findings or adverse events, but in response to changes in the healthcare environment that you are researching. After I restarted my research in June, between the first and second waves, I did not restart the survey data collection. How CHF patients were receiving care had changed drastically and as I researcher I did not believe that it would be the right thing to combine the survey data pre and post Covid-19. While I conducted the bulk of my qualitative interview after the first wave of the pandemic, amendments I made to the interview schedule captured some of the patient's experiences with the changes in their care pathways. This work, while it influenced my thinking was not the focus of the research presented in the thesis.

All of these lessons helped to develop me into a nurse researcher. I started my PhD not knowing what a clinical academic was other than it meant that I would still work as a nurse while completing my PhD. Through these experiences, I have now learned what it means by walking that path. I have learned to network and collaborate to shine a spotlight on nurses, midwives, and allied health professional researchers. I have seen in my journey how constant contact with the population that you are researching, while yes may lead to more bias in your work, more importantly, it helps you see things that I’m not confident that non-clinical researchers would see due to your familiarity with the clinical pathways. I think when your research is inspired by a clinical problem that you observed, there is an increase in perceived responsibility to the population of interest. I am trying to help those individuals who inspired my research question as well as the 333 individuals who have contributed to my research by informing the CHF specific BoT theory. I carry that responsibility forward into my career. I know these findings will affect all those with CHF who I care for clinically. From my participants' generosity, my career is advancing, and I aim to use this data to inform more research that will hopefully alter their experiences for the better.

8.3.4 Why the CHF specific BoT theory

As a clinical academic, I remained connected and integrated with other clinicians. As my results were emerging, I shared these with nurses and medics. Those who I shared it with would comment on how the findings I shared particularly the four patient typologies made sense to them in their practice. They reported how they regularly saw patients that fit in those typologies. They related to me how in sharing those findings with them they had begun to alter their clinical consultations with patients. The PPI group I worked with throughout the project continually commented on how what I was finding and reporting to them made sense to their experiences across a wide variety of chronic illnesses. I felt that this was the highest commendation my research could have, and this was further acknowledged when co-awarded an early investigator award at the British Society for Heart Failure (the first nurse to receive the honour – Appendix L). This research and its findings are in the very early stages, but I feel that as this research was formulated out of clinical observations and overseen by a nurse keen to ensure the findings had practical applications there is the potential for this framework to help unlock the perennial issue of CHF non-adherence.

As a clinician, at the beginning of this journey, I was confronted with a patient whose experience did not match the existing theory of self-care. The theory offered in this thesis not only helps to explain why he appeared to engage with his self-care despite targeted and personalised education. The CHF specific BoT theory accommodates the individual personal journey through life and illness. It acknowledges that while desirable, self-care engagement does not guarantee an improved patient outcome and that symptoms of CHF are subjective and vague. Its framework gives a clinician a tool with which to explore alternative options for reducing symptoms and BoT which may lead to improved patient experience and quality of life. This will need to be explored in future research.

8.4 Strengths and limitations

The papers covering the empirical research included in the thesis considered specific strengths and limitations: study design (section 3.4.1.6), qualitative evidence synthesis (section 4.6.2), cross-sectional survey results (section 5.6.1), and sub-sample semi-structured interview results (section 6.6.4), and the theory development paper (section 7.8).

Overall, the three empirical investigations included in this thesis could be argued by some as incongruous due to differing methodologies, data types, and contexts, but I viewed these differences as a strength, with each component of the research corroborating, confirming or expanding understanding. Integration of the empirical investigations facilitated the development of a condition specific theory and a model with clinical implications. Thus, pragmatic and abductive use of research methods is a strength of this thesis, allowing for the identification, characterisation, and explanation of the influence of CHF symptoms on BoT. The recursive and iterative process encouraged the alteration of the research plan and design based on the results or findings, permitting and encouraging the researcher to flex with the data and the research environment. The latter proved important in terms of the Covid-19 pandemic.

As a clinical academic, I have learned to balance the contrasting priorities of the clinical and research worlds. As a research nurse, my previous experience in conducting and delivering studies influence how I wrote my protocol and set the research up. Viewed as a strength as it enabled the utilization of technology and high recruitment in a short period. My supervisory team were crucial in constantly challenging personal influences, particularly those resulting from my nursing background. While there may have been individuals who participated in the survey who were known to me, the utilization of other research staff limited personal interaction with those individuals. The survey responses were stripped of identifying details making the identification of specific individuals to me the researcher analysing the data impossible. In the interviews, I did not interview patients who had been under my direct care as a research nurse. Although not a purposive concealment, I did not present myself as a nurse to interview participants. Some participants assumed I was a CHF health practitioner and others took the time to explain to me, as the researcher, the clinical details of their illness and its treatment. Throughout the research process, I kept a research journal where I reflected on and challenged my own bias, thoughts, and conclusions. While I was guided, challenged and supported by the supervisory team and statistical expert, the bulk of the work was performed independently myself. Steps were taken to try and reduce bias, limit errors, and sense check qualitative analysis, through the techniques reported in the publications.

8.5 Areas for further research

8.5.1 Measuring BoT

The scoping review by Sav, Salehi (158), identified that the most promising tools to capture BoT were PETS (124) and the TBQ (161). Both were designed for use in multi-morbid populations, have been translated into other languages (PETS: (289), TBQ: (159, 290)) and have been used in both multi-morbid and disease specific populations (PETS: (291-296), TBQ: (297, 298). My research has highlighted that although the adaptations of PETS into the brief PETS (167) has improved its practical usability in research, there may be other refinements needed to measure BoT for those with CHF to enable the practical inclusion in a clinical environment, to date only one other group has measured BoT with PETS in CHF (252). Since then, the multimorbidity treatment burden questionnaire (MTBQ), which was developed in the UK, similar to the TBQ, is brief with 10 items (129). Like PETS and TBQ, the MTBQ focuses more on capturing the burden of self-care work (medication management and accessing healthcare services) with limited examination of personal capacity. To increase the inclusion of assessing treatment burden in clinical settings the MTBQ researchers are also investigating the possibility of a single measurement tool that assesses treatment burden (299). The research in this thesis has highlighted the factors which appear to mediate the relationship between symptoms and BoT are likely more aligned with elements of capacity or impact alongside illness identity. More research is needed to tailor these tools to capture treatment burden for patients with CHF. The CHF specific BoT theory provides a possible framework for such a tool.

8.5.2 Refining CHF specific BoT theory

The theory offered in this thesis, while robustly informed, requires further investigation and testing to establish and refine the theory constructs. In addition to the need for independent researchers to test this theory, there are three proposed areas of research using the existing data set, to begin the work of testing the CHF specific BoT theory.

The first is a more detailed description and statistical analysis of the survey dataset to explore clinical factors which might influence CHF symptoms and BoT. Factors such as gender, age, number of medications and health issues, type of CHF and illness severity (NYHA and LVEF) will be explored in relation to the symptoms and BoT scores. Multiple linear regression models will be built and tested using explanatory variables to see if they predict the outcome of BoT.

Second, using data not yet utilized from the semi-structured interview dataset, a deeper exploration of the workload experienced by CHF patients is required to test the theory offered in the thesis. Through a detailed description of this work, what patients report as treatment work will be confirmed. This research will help to understand the low workload index scores measured by PETS, as well as test for the presence of intervening factors within the offered theory.

Finally, the CHF specific BoT theory and translational clinical model provide the framework for multiple research projects that span between (a) testing and confirming the theory to (b) developing a clinically applicable tool to measure BoT in CHF populations to (c) testing that tool for its ability to inform clinicians and capture clinically significant changes in BoT.

8.5.3 Incorporation of BoT in research and clinical evaluation

This body of research has highlighted that BoT and illness identity may alter a patient's reporting of symptoms and wiliness to access healthcare services. In CHF there is already an acknowledgement that patients delay seeking support in a timely and appropriate manner (300) and that this is linked to common CHF symptoms and non-specialist care (301). Coupled with the current situation where patient demand is exceeding available healthcare resources (5, 274), the need for a change in CHF care pathways is recognised in cardiology research groups (302-304). Within the data included in this thesis are examples where when a patient's external resources (e.g., informal support/care, friends and family, and healthcare services) are optimized the patient may build an illness identity where their illness is adapted and incorporated into their lives, with resultant positive influences on symptoms, BoT, and QoL. Suggesting that altering current clinical encounters to include a more global assessment of symptoms and BoT may guide clinicians and patients to cooperatively decide on the best treatment regimen which is minimally disruptive. More research is needed to inform the creation of a new framework of CHF clinical evaluation as well as testing those changes for improvements in patient outcomes.

BoT theory used as a framework and as a tool to measure patient experience has been highlighted in this thesis as a strength. Within cardiology research networks there is a growing interest in capturing BoT within interventional research trials. As the tools to measure BoT improve and are incorporated into interventional studies, measured outcomes may also shift towards a more supportive clinical pathway that encourages shared decision making leading to minimally disruptive medicine for those with CHF.

8.5.4 CHF specific BoT theory is central within interventional research

CHF specific BoT theory and the clinical model could also serve as a core element in interventional research. First, an *awareness and educational intervention* aimed at clinicians could be created. This would aim to increase their awareness of BoT and its clinical relevance alongside the CHF specific BoT theory and the clinical model. Such an intervention would aim to alter clinical practices within the current CHF care pathways. Patient and clinician experience of these changes could be captured alongside their clinical events.

Second, by working together with clinicians and patients, researchers could co-design a project that uses the CHF specific BoT theory and the clinical model as the framework to restructure clinical consultations and CHF care pathways. Many researchers in heart failure have acknowledged that the current complex pathways are both a barrier and add a significant burden to both patients and their informal carers. In the UK, clinicians in heart failure have recognized that current CHF pathways do not meet the needs of the patient population. By working together, a new pathway could be created and then tested for its impact on patients as well as healthcare systems.

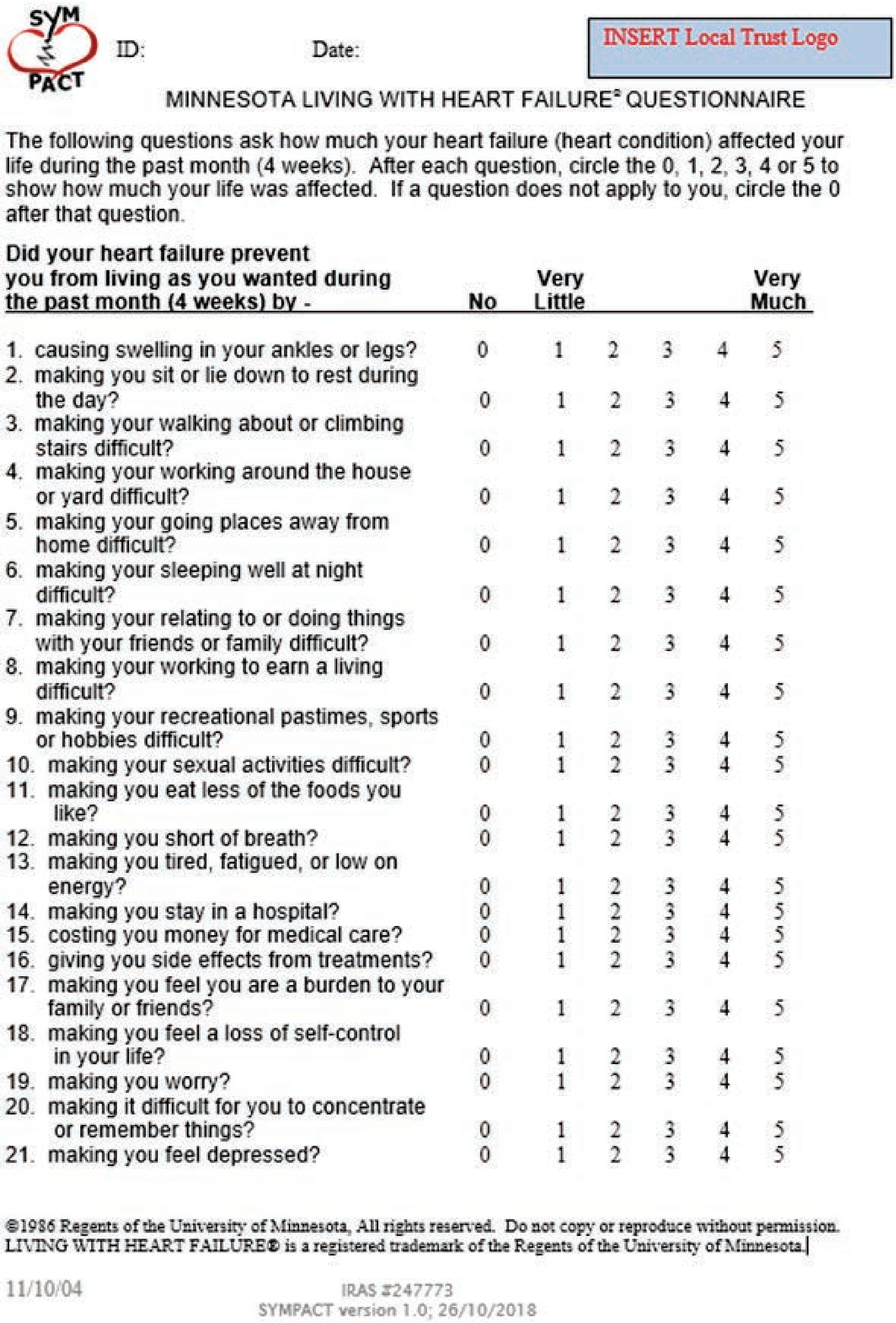
8.6 Thesis conclusions

In answering the overarching thesis research question, the separate elements of empirical research combined to provide an answer. Symptoms of CHF and their emotional affect interact with BoT. Through a process of identification, characterization, and explanation a taxonomy of the interaction of symptoms on BoT was developed, refined, and informed the CHF specific BoT theory. The interaction is both symmetrical and asymmetrical leading to four different patient experiences of symptoms and BoT. The interaction type is influenced by illness pathology and identity, task value and performance, and available support structures. These interactions can have a drastic influence on the underlying direct relationship between symptoms and BoT and thereby offer promise as the basis of interventions aimed at alleviating both symptoms and BoT.

The thesis questions the prominence in CHF literature of self-care failures being blamed on motivation and poor health literacy. It describes how chronic illness can create a situation where patients with CHF are unable to do the work of self-care that was assigned. Occurring either through a direct limitation from physical symptoms, an indirect influence of emotional affect, or a lack of available and accessible support structures. This thesis has highlighted the need to incorporate BoT into clinical evaluations, and intervention development in CHF alongside healthcare policy and provision. The CHF specific BoT theory offers up the suggestion that consideration of BoT alongside illness identity results in an alternative theory describing engagement in CHF care. The adoption of this theory may lead to minimally disruptive chronic illness pathways which considers both patients' burden of treatment as well as the burden that chronic illness places on healthcare services.

Table of Appendices

Appendix A Minnesota living with heart failure questionnaire (MLHFQ)



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MINNESOTA LIVING WITH HEART FAILURE® QUESTIONNAIRE

The following questions ask how much your heart failure (heart condition) affected your life during the past month (4 weeks). After each question, circle the 0, 1, 2, 3, 4 or 5 to show how much your life was affected. If a question does not apply to you, circle the 0 after that question.

Did your heart failure prevent you from living as you wanted during the past month (4 weeks) by -	No	Very Little				Very Much
1. causing swelling in your ankles or legs?	0	1	2	3	4	5
2. making you sit or lie down to rest during the day?	0	1	2	3	4	5
3. making your walking about or climbing stairs difficult?	0	1	2	3	4	5
4. making your working around the house or yard difficult?	0	1	2	3	4	5
5. making your going places away from home difficult?	0	1	2	3	4	5
6. making your sleeping well at night difficult?	0	1	2	3	4	5
7. making your relating to or doing things with your friends or family difficult?	0	1	2	3	4	5
8. making your working to earn a living difficult?	0	1	2	3	4	5
9. making your recreational pastimes, sports or hobbies difficult?	0	1	2	3	4	5
10. making your sexual activities difficult?	0	1	2	3	4	5
11. making you eat less of the foods you like?	0	1	2	3	4	5
12. making you short of breath?	0	1	2	3	4	5
13. making you tired, fatigued, or low on energy?	0	1	2	3	4	5
14. making you stay in a hospital?	0	1	2	3	4	5
15. costing you money for medical care?	0	1	2	3	4	5
16. giving you side effects from treatments?	0	1	2	3	4	5
17. making you feel you are a burden to your family or friends?	0	1	2	3	4	5
18. making you feel a loss of self-control in your life?	0	1	2	3	4	5
19. making you worry?	0	1	2	3	4	5
20. making it difficult for you to concentrate or remember things?	0	1	2	3	4	5
21. making you feel depressed?	0	1	2	3	4	5

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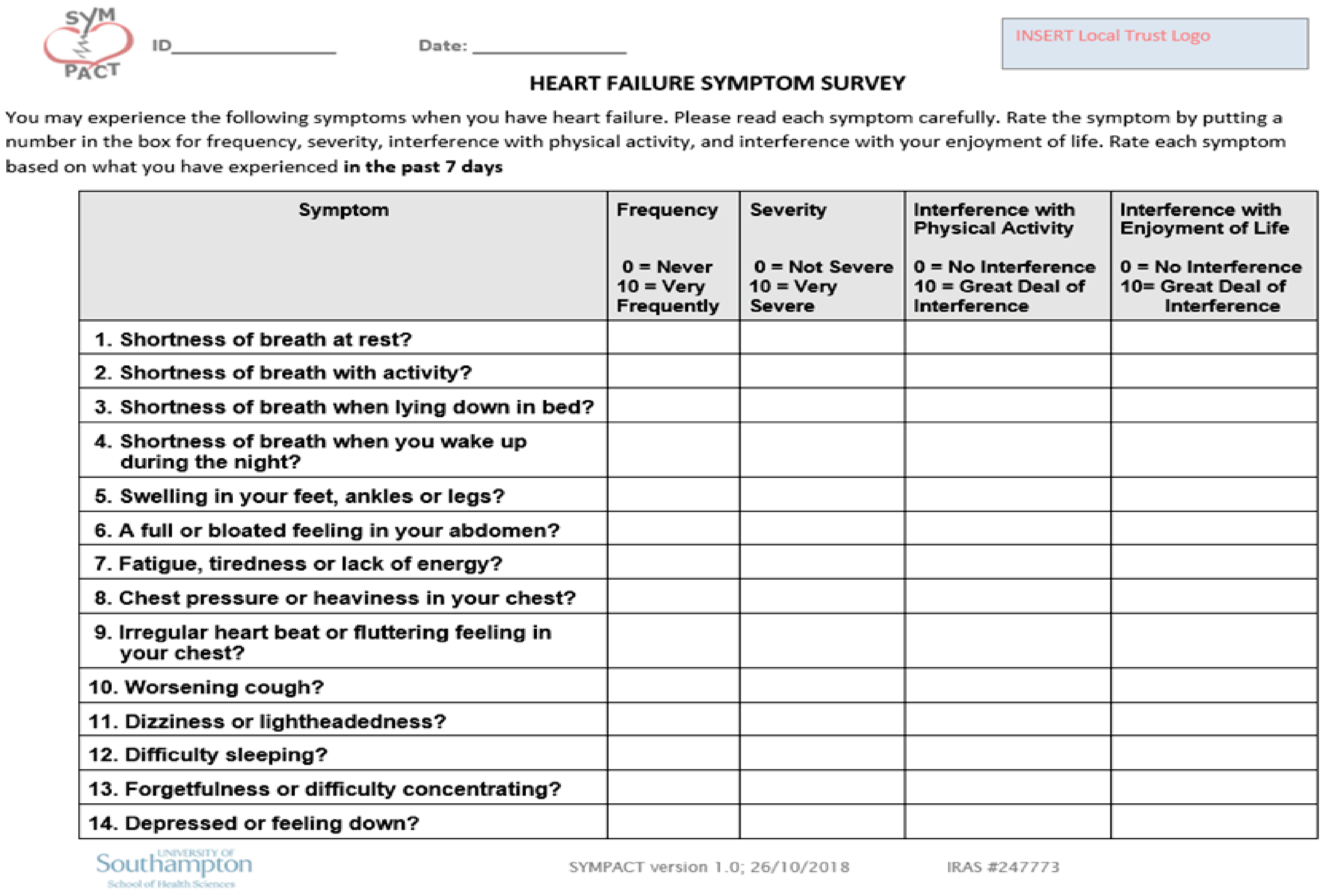
Appendix B **Heart failure symptom survey (HFSS)**



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HEART FAILURE SYMPTOM SURVEY

You may experience the following symptoms when you have heart failure. Please read each symptom carefully. Rate the symptom by putting a number in the box for frequency, severity, interference with physical activity, and interference with your enjoyment of life. Rate each symptom based on what you have experienced **in the past 7 days**

Symptom	**Frequency** **0 = Never** **10 = Very Frequently**	**Severity** **0 = Not Severe** **10 = Very Severe**	**Interference with Physical Activity** **0 = No Interference** **10 = Great Deal of Interference**	**Interference with Enjoyment of Life** **0 = No Interference** **10= Great Deal of Interference**
1. Shortness of breath at rest?				
2. Shortness of breath with activity?				
3. Shortness of breath when lying down in bed?				
4. Shortness of breath when you wake up during the night?				
5. Swelling in your feet, ankles or legs?				
6. A full or bloated feeling in your abdomen?				
7. Fatigue, tiredness or lack of energy?				
8. Chest pressure or heaviness in your chest?				
9. Irregular heart beat or fluttering feeling in your chest?				
10. Worsening cough?				
11. Dizziness or lightheadedness?				
12. Difficulty sleeping?				
13. Forgetfulness or difficulty concentrating?				
14. Depressed or feeling down?				

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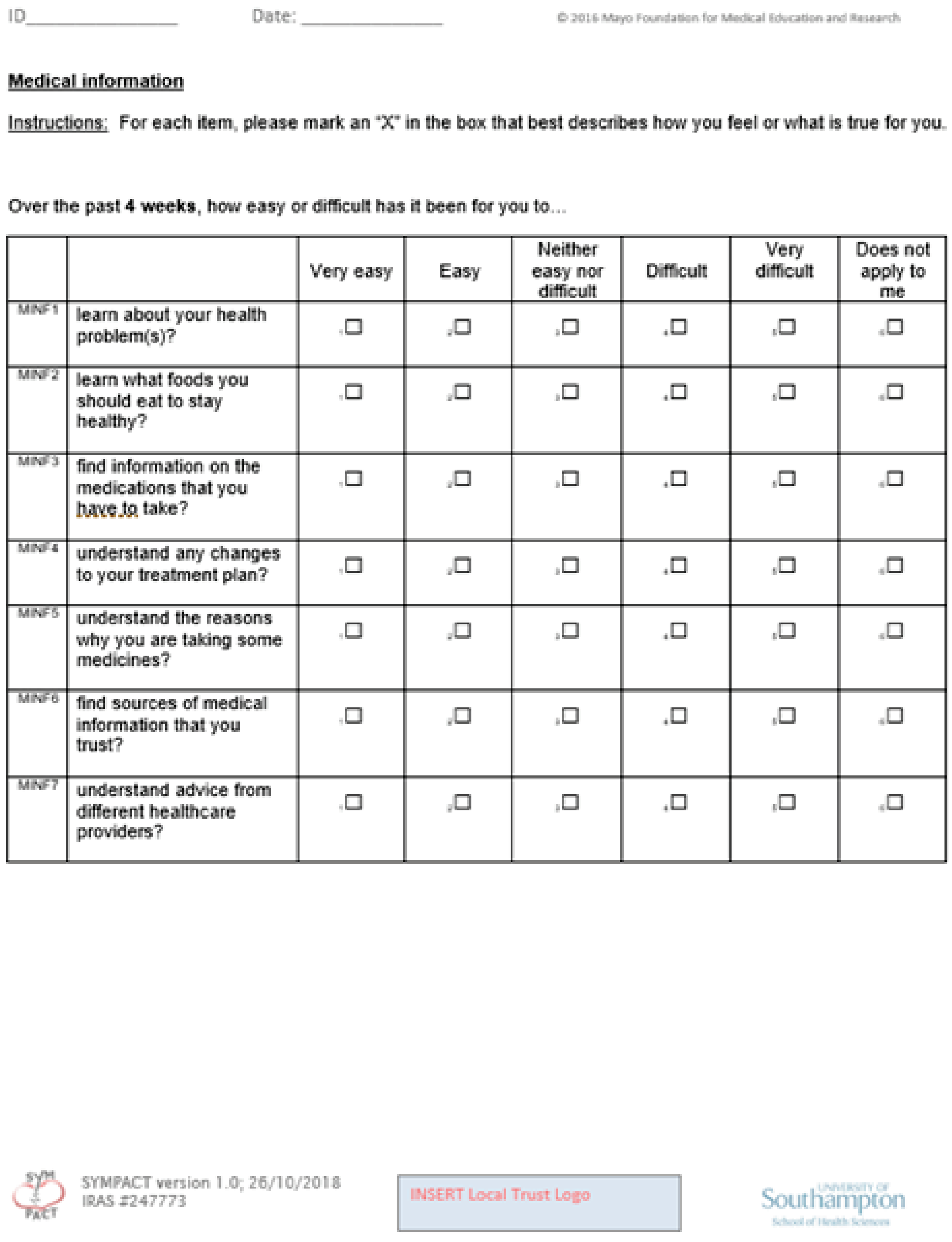
Appendix C Patient experience of treatment and self-management (PETS)



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Medical information

Instructions: For each item, please mark an "X" in the box that best describes how you feel or what is true for you.

Over the past **4 weeks**, how easy or difficult has it been for you to...

		Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Does not apply to me
MINF1	learn about your health problem(s)?	1☐	2☐	3☐	4☐	5☐	6☐
MINF2	learn what foods you should eat to stay healthy?	1☐	2☐	3☐	4☐	5☐	6☐
MINF3	find information on the medications that you have to take?	1☐	2☐	3☐	4☐	5☐	6☐
MINF4	understand any changes to your treatment plan?	1☐	2☐	3☐	4☐	5☐	6☐
MINF5	understand the reasons why you are taking some medicines?	1☐	2☐	3☐	4☐	5☐	6☐
MINF6	find sources of medical information that you trust?	1☐	2☐	3☐	4☐	5☐	6☐
MINF7	understand advice from different healthcare providers?	1☐	2☐	3☐	4☐	5☐	6☐

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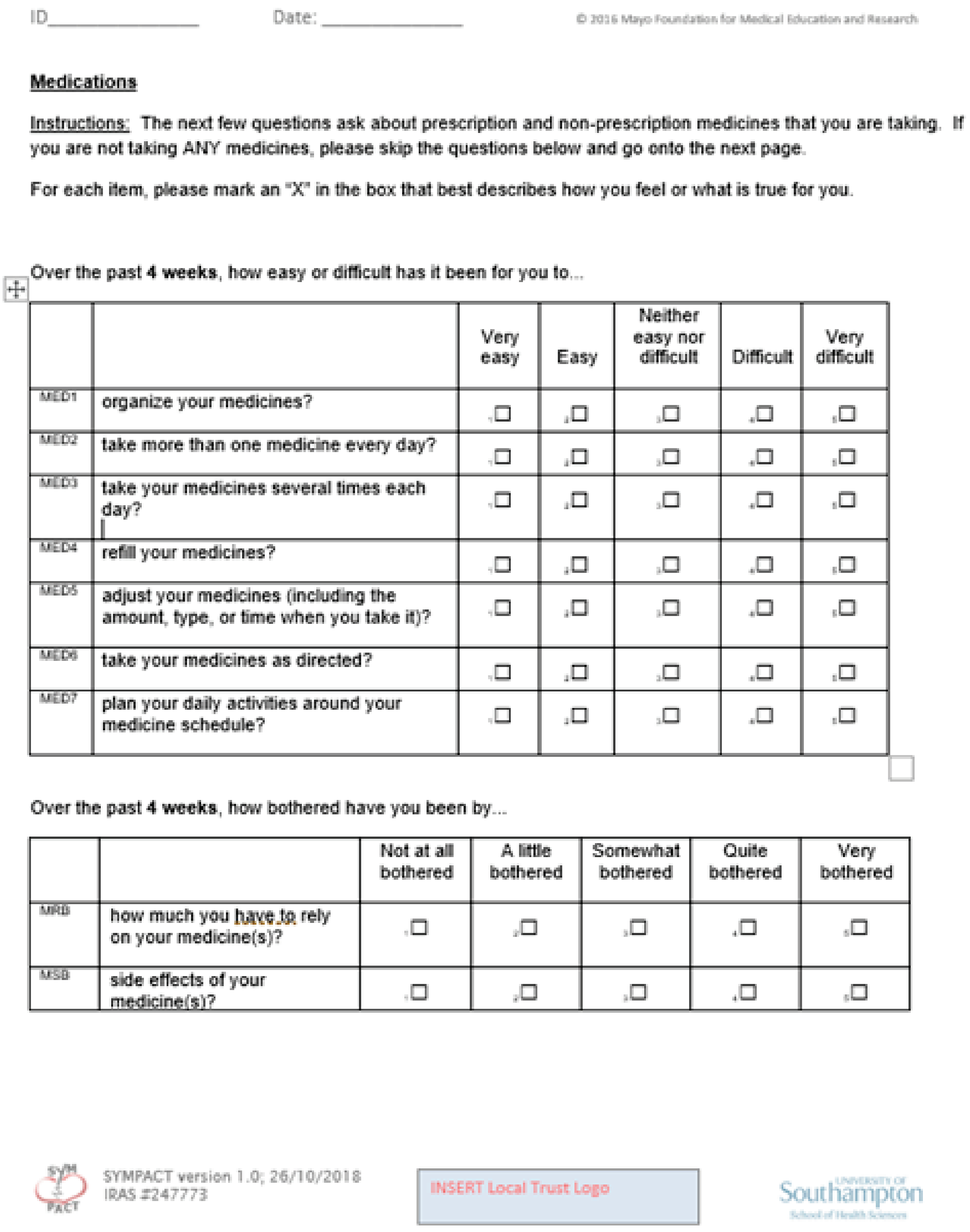

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Medications

Instructions: The next few questions ask about prescription and non-prescription medicines that you are taking. If you are not taking ANY medicines, please skip the questions below and go onto the next page.

For each item, please mark an "X" in the box that best describes how you feel or what is true for you.

Over the past **4 weeks**, how easy or difficult has it been for you to...

		Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult
MED1	organize your medicines?	☐	☐	☐	☐	☐
MED2	take more than one medicine every day?	☐	☐	☐	☐	☐
MED3	take your medicines several times each day?	☐	☐	☐	☐	☐
MED4	refill your medicines?	☐	☐	☐	☐	☐
MED5	adjust your medicines (including the amount, type, or time when you take it)?	☐	☐	☐	☐	☐
MED6	take your medicines as directed?	☐	☐	☐	☐	☐
MED7	plan your daily activities around your medicine schedule?	☐	☐	☐	☐	☐

Over the past **4 weeks**, how bothered have you been by...

		Not at all bothered	A little bothered	Somewhat bothered	Quite bothered	Very bothered
MRB	how much you have to rely on your medicine(s)?	☐	☐	☐	☐	☐
MSB	side effects of your medicine(s)?	☐	☐	☐	☐	☐

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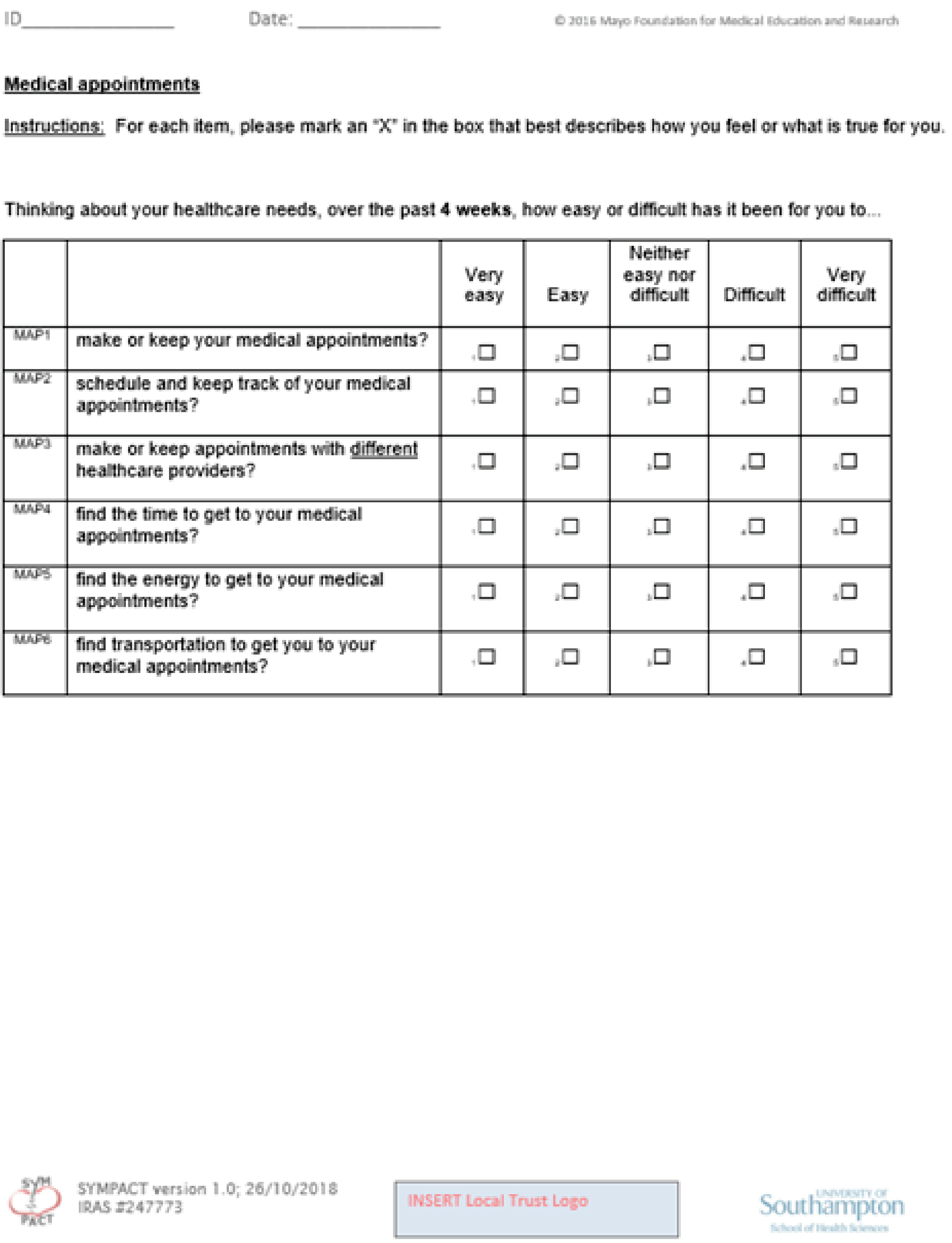

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Medical appointments

Instructions: For each item, please mark an "X" in the box that best describes how you feel or what is true for you.

Thinking about your healthcare needs, over the past **4 weeks**, how easy or difficult has it been for you to...

		Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult
MAP1	make or keep your medical appointments?	1☐	2☐	3☐	4☐	5☐
MAP2	schedule and keep track of your medical appointments?	1☐	2☐	3☐	4☐	5☐
MAP3	make or keep appointments with different healthcare providers?	1☐	2☐	3☐	4☐	5☐
MAP4	find the time to get to your medical appointments?	1☐	2☐	3☐	4☐	5☐
MAP5	find the energy to get to your medical appointments?	1☐	2☐	3☐	4☐	5☐
MAP6	find transportation to get you to your medical appointments?	1☐	2☐	3☐	4☐	5☐

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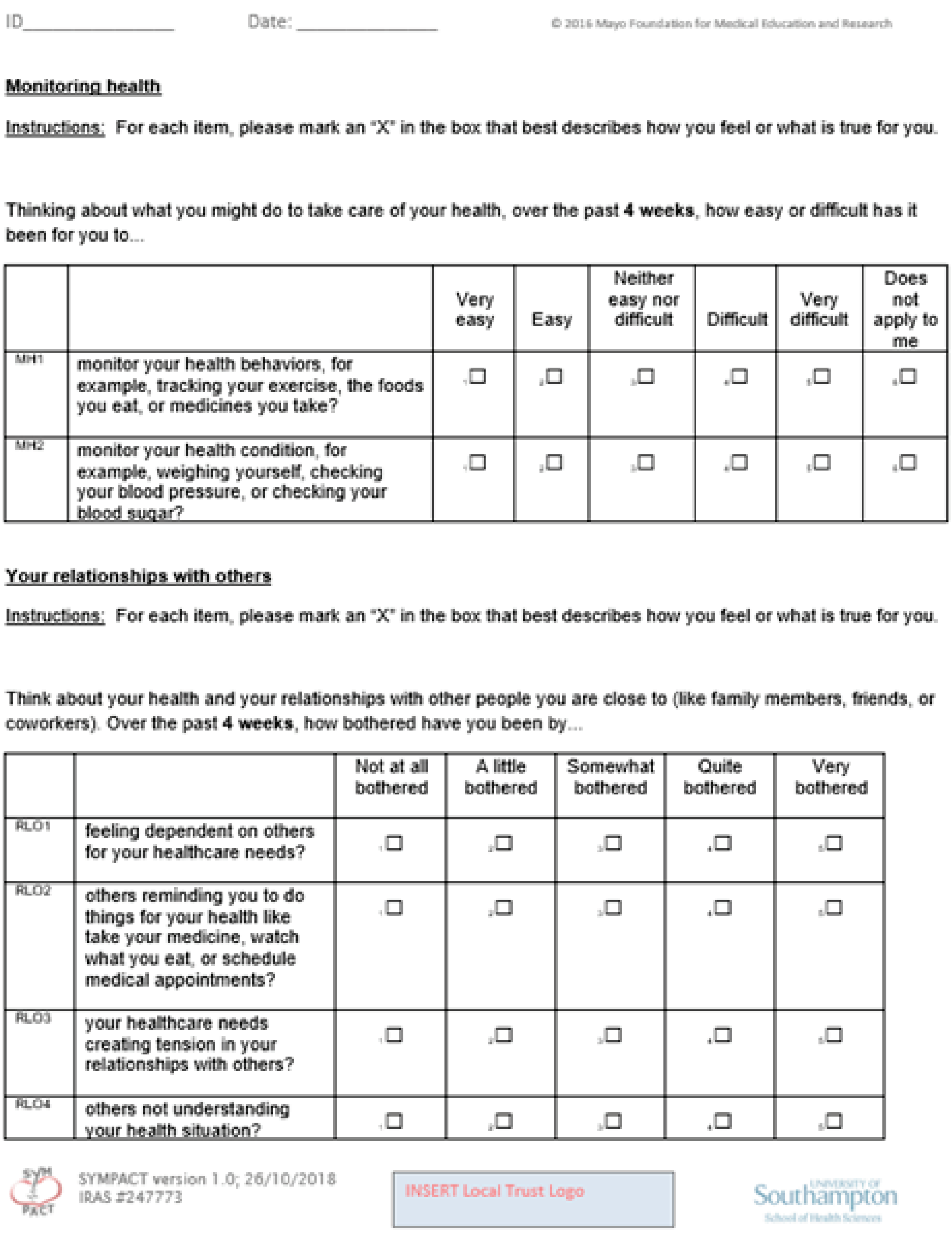
Appendix C



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Monitoring health

Instructions: For each item, please mark an "X" in the box that best describes how you feel or what is true for you.

Thinking about what you might do to take care of your health, over the past **4 weeks**, how easy or difficult has it been for you to...

		Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Does not apply to me
MH1	monitor your health behaviors, for example, tracking your exercise, the foods you eat, or medicines you take?	☐	☐	☐	☐	☐	☐
MH2	monitor your health condition, for example, weighing yourself, checking your blood pressure, or checking your blood sugar?	☐	☐	☐	☐	☐	☐

Your relationships with others

Instructions: For each item, please mark an "X" in the box that best describes how you feel or what is true for you.

Think about your health and your relationships with other people you are close to (like family members, friends, or coworkers). Over the past **4 weeks**, how bothered have you been by...

		Not at all bothered	A little bothered	Somewhat bothered	Quite bothered	Very bothered
RLO1	feeling dependent on others for your healthcare needs?	☐	☐	☐	☐	☐
RLO2	others reminding you to do things for your health like take your medicine, watch what you eat, or schedule medical appointments?	☐	☐	☐	☐	☐
RLO3	your healthcare needs creating tension in your relationships with others?	☐	☐	☐	☐	☐
RLO4	others not understanding your health situation?	☐	☐	☐	☐	☐

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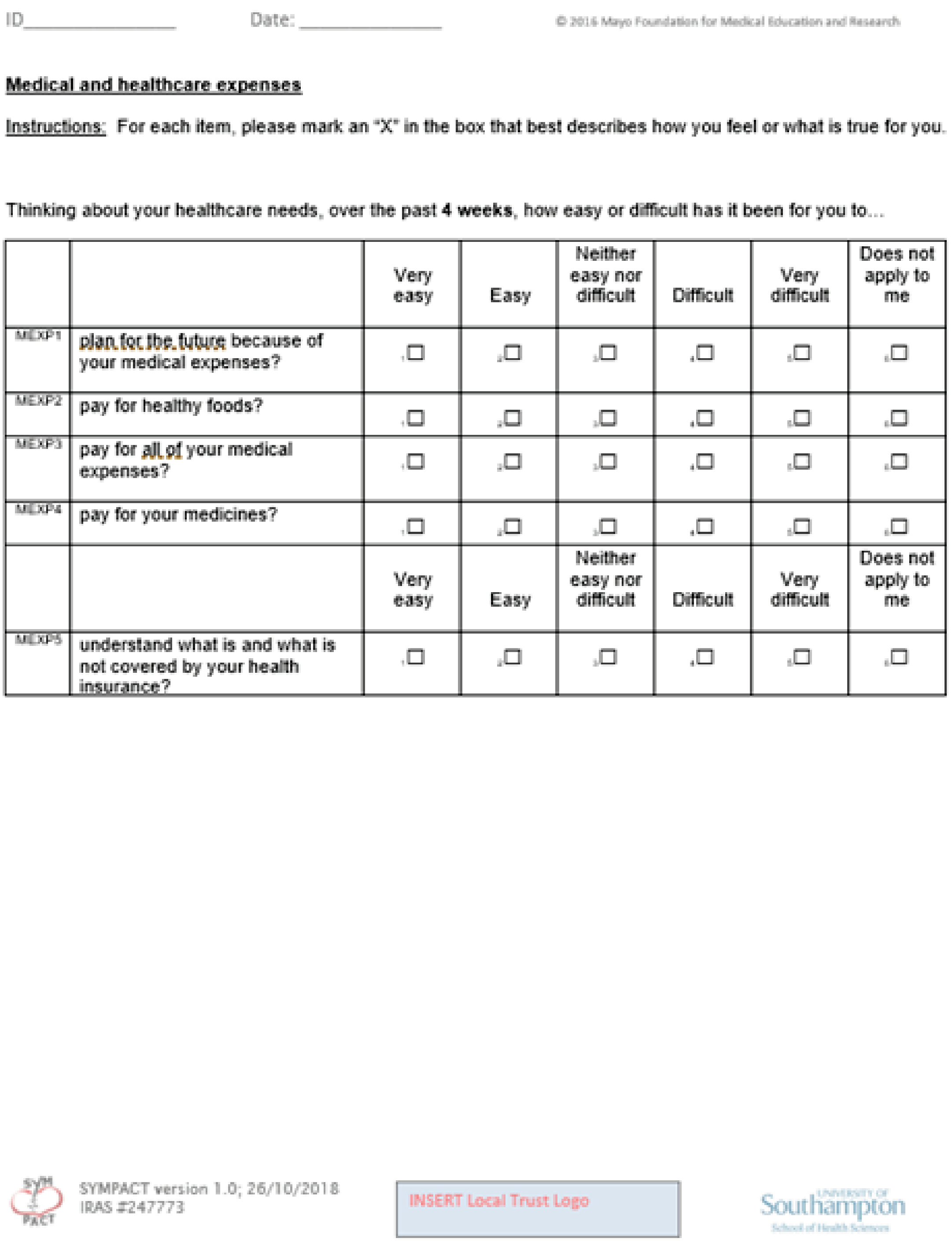

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Medical and healthcare expenses

Instructions: For each item, please mark an "X" in the box that best describes how you feel or what is true for you.

Thinking about your healthcare needs, over the past **4 weeks**, how easy or difficult has it been for you to…

		Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Does not apply to me
MEXP1	plan for the future because of your medical expenses?	$_1$☐	$_2$☐	$_3$☐	$_4$☐	$_5$☐	$_6$☐
MEXP2	pay for healthy foods?	$_1$☐	$_2$☐	$_3$☐	$_4$☐	$_5$☐	$_6$☐
MEXP3	pay for all of your medical expenses?	$_1$☐	$_2$☐	$_3$☐	$_4$☐	$_5$☐	$_6$☐
MEXP4	pay for your medicines?	$_1$☐	$_2$☐	$_3$☐	$_4$☐	$_5$☐	$_6$☐
		Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult	Does not apply to me
MEXP5	understand what is and what is not covered by your health insurance?	$_1$☐	$_2$☐	$_3$☐	$_4$☐	$_5$☐	$_6$☐

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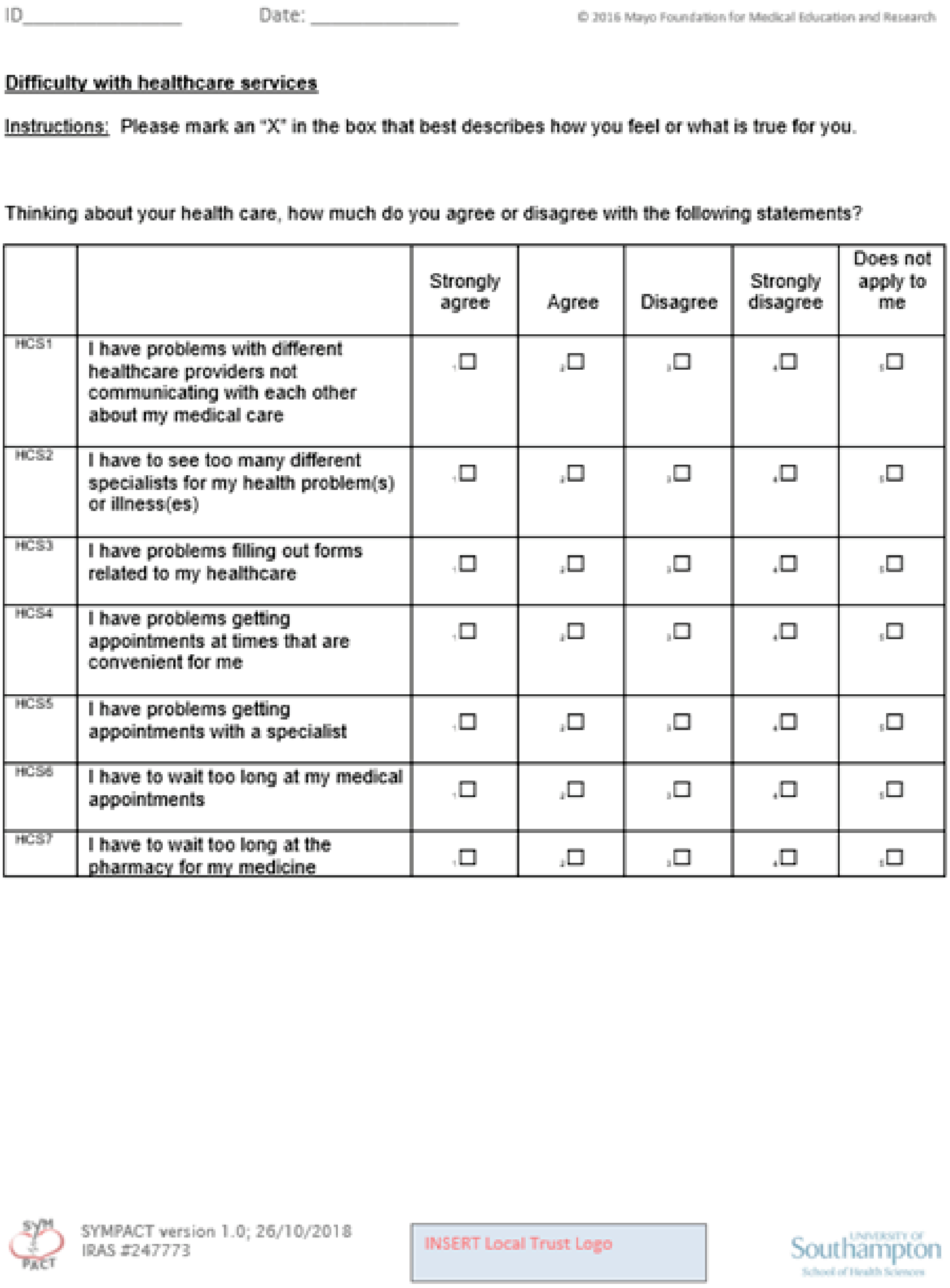

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Difficulty with healthcare services

Instructions: Please mark an "X" in the box that best describes how you feel or what is true for you.

Thinking about your health care, how much do you agree or disagree with the following statements?

		Strongly agree	Agree	Disagree	Strongly disagree	Does not apply to me
HCS1	I have problems with different healthcare providers not communicating with each other about my medical care	☐	☐	☐	☐	☐
HCS2	I have to see too many different specialists for my health problem(s) or illness(es)	☐	☐	☐	☐	☐
HCS3	I have problems filling out forms related to my healthcare	☐	☐	☐	☐	☐
HCS4	I have problems getting appointments at times that are convenient for me	☐	☐	☐	☐	☐
HCS5	I have problems getting appointments with a specialist	☐	☐	☐	☐	☐
HCS6	I have to wait too long at my medical appointments	☐	☐	☐	☐	☐
HCS7	I have to wait too long at the pharmacy for my medicine	☐	☐	☐	☐	☐

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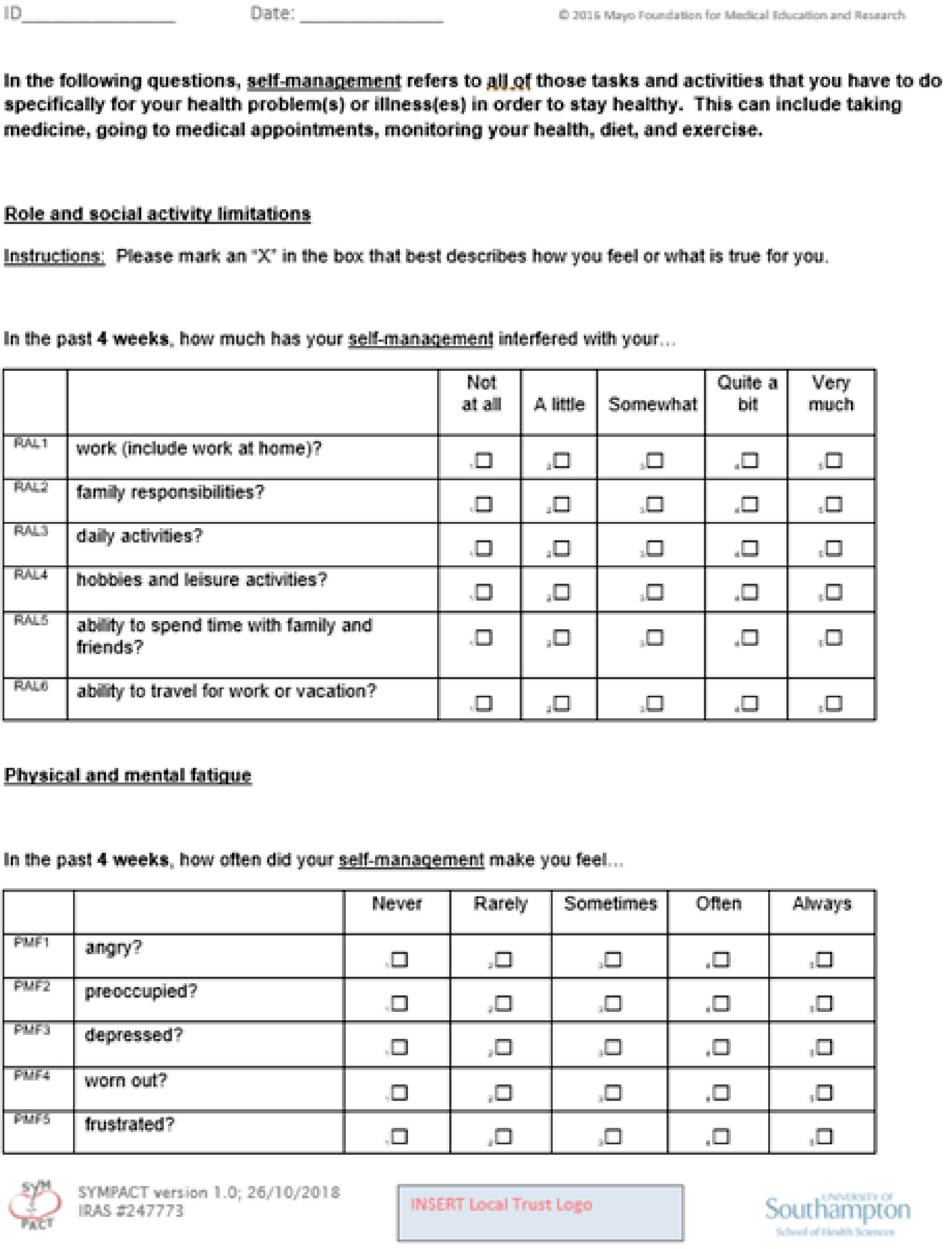

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In the following questions, self-management refers to all of those tasks and activities that you have to do specifically for your health problem(s) or illness(es) in order to stay healthy. This can include taking medicine, going to medical appointments, monitoring your health, diet, and exercise.

Role and social activity limitations

Instructions: Please mark an "X" in the box that best describes how you feel or what is true for you.

In the past **4 weeks**, how much has your self-management interfered with your…

		Not at all	A little	Somewhat	Quite a bit	Very much
RAL1	work (include work at home)?	1☐	2☐	3☐	4☐	5☐
RAL2	family responsibilities?	1☐	2☐	3☐	4☐	5☐
RAL3	daily activities?	1☐	2☐	3☐	4☐	5☐
RAL4	hobbies and leisure activities?	1☐	2☐	3☐	4☐	5☐
RAL5	ability to spend time with family and friends?	1☐	2☐	3☐	4☐	5☐
RAL6	ability to travel for work or vacation?	1☐	2☐	3☐	4☐	5☐

Physical and mental fatigue

In the past **4 weeks**, how often did your self-management make you feel…

		Never	Rarely	Sometimes	Often	Always
PMF1	angry?	1☐	2☐	3☐	4☐	5☐
PMF2	preoccupied?	1☐	2☐	3☐	4☐	5☐
PMF3	depressed?	1☐	2☐	3☐	4☐	5☐
PMF4	worn out?	1☐	2☐	3☐	4☐	5☐
PMF5	frustrated?	1☐	2☐	3☐	4☐	5☐

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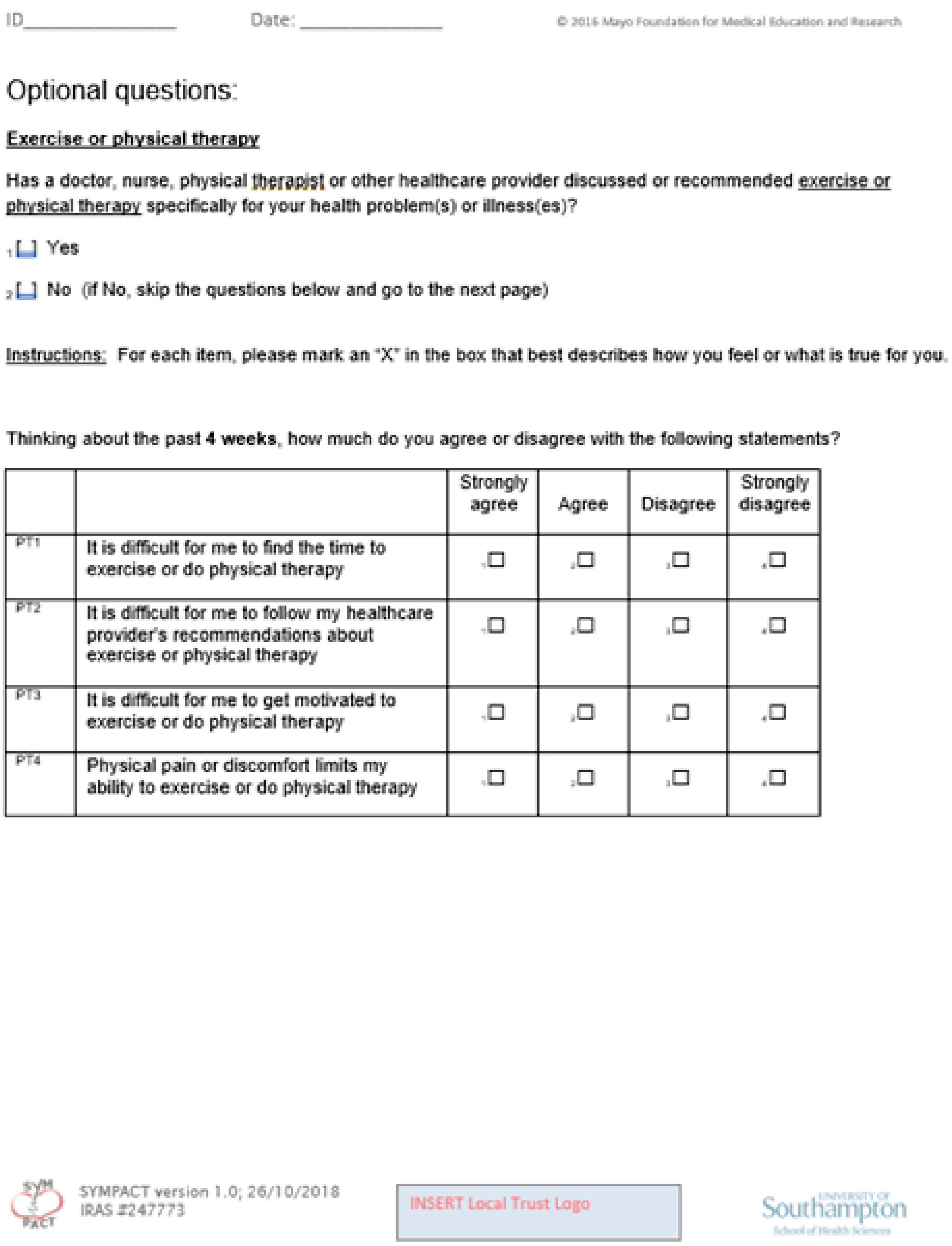

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Optional questions:

Exercise or physical therapy

Has a doctor, nurse, physical therapist or other healthcare provider discussed or recommended exercise or physical therapy specifically for your health problem(s) or illness(es)?

1☐ Yes

2☐ No (if No, skip the questions below and go to the next page)

Instructions: For each item, please mark an "X" in the box that best describes how you feel or what is true for you.

Thinking about the past **4 weeks**, how much do you agree or disagree with the following statements?

		Strongly agree	Agree	Disagree	Strongly disagree
PT1	It is difficult for me to find the time to exercise or do physical therapy	1☐	2☐	3☐	4☐
PT2	It is difficult for me to follow my healthcare provider's recommendations about exercise or physical therapy	1☐	2☐	3☐	4☐
PT3	It is difficult for me to get motivated to exercise or do physical therapy	1☐	2☐	3☐	4☐
PT4	Physical pain or discomfort limits my ability to exercise or do physical therapy	1☐	2☐	3☐	4☐

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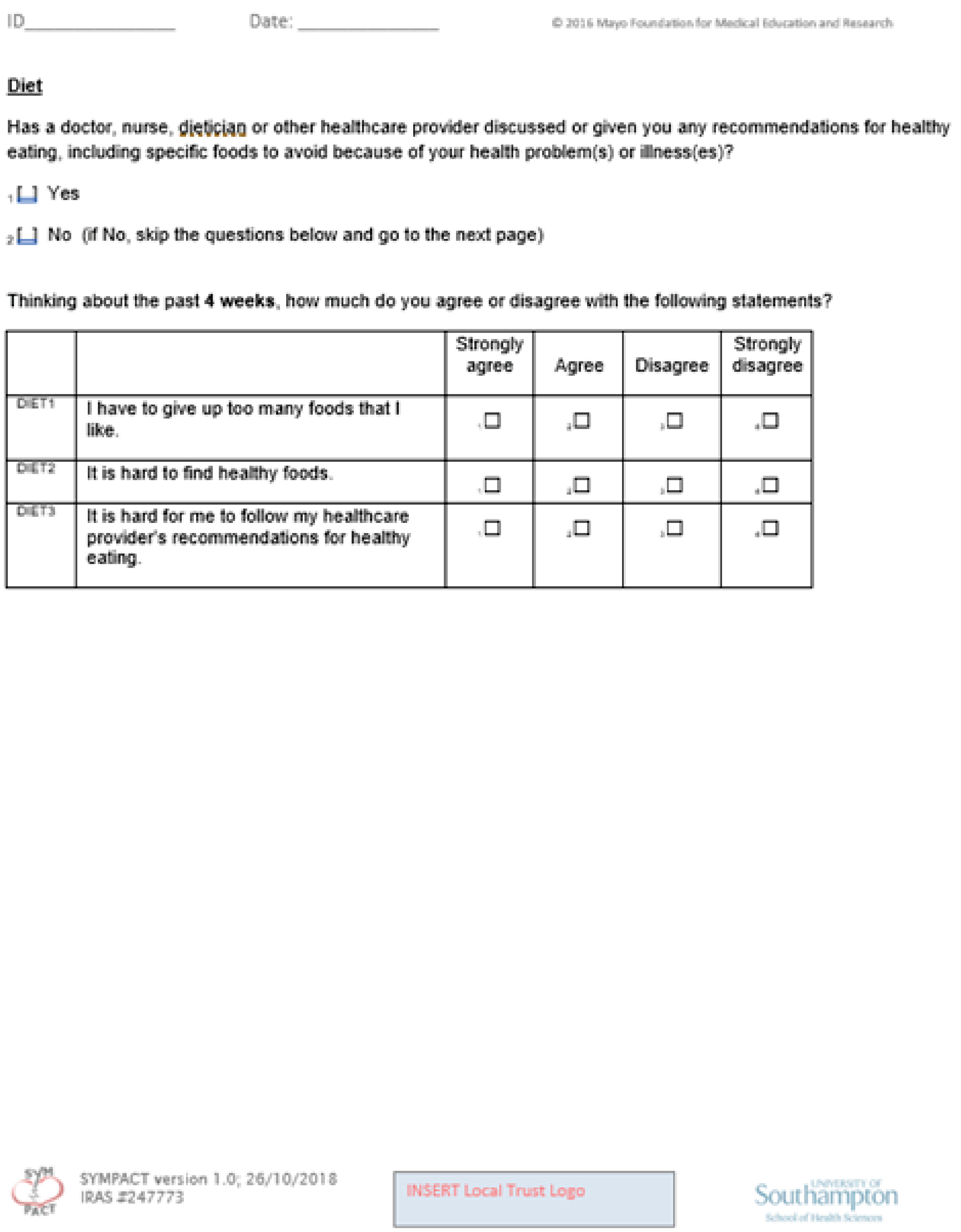

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Diet

Has a doctor, nurse, dietician or other healthcare provider discussed or given you any recommendations for healthy eating, including specific foods to avoid because of your health problem(s) or illness(es)?

1☐ Yes

2☐ No (if No, skip the questions below and go to the next page)

Thinking about the past **4 weeks**, how much do you agree or disagree with the following statements?

		Strongly agree	Agree	Disagree	Strongly disagree
DIET1	I have to give up too many foods that I like.	1☐	2☐	3☐	4☐
DIET2	It is hard to find healthy foods.	1☐	2☐	3☐	4☐
DIET3	It is hard for me to follow my healthcare provider's recommendations for healthy eating.	1☐	2☐	3☐	4☐

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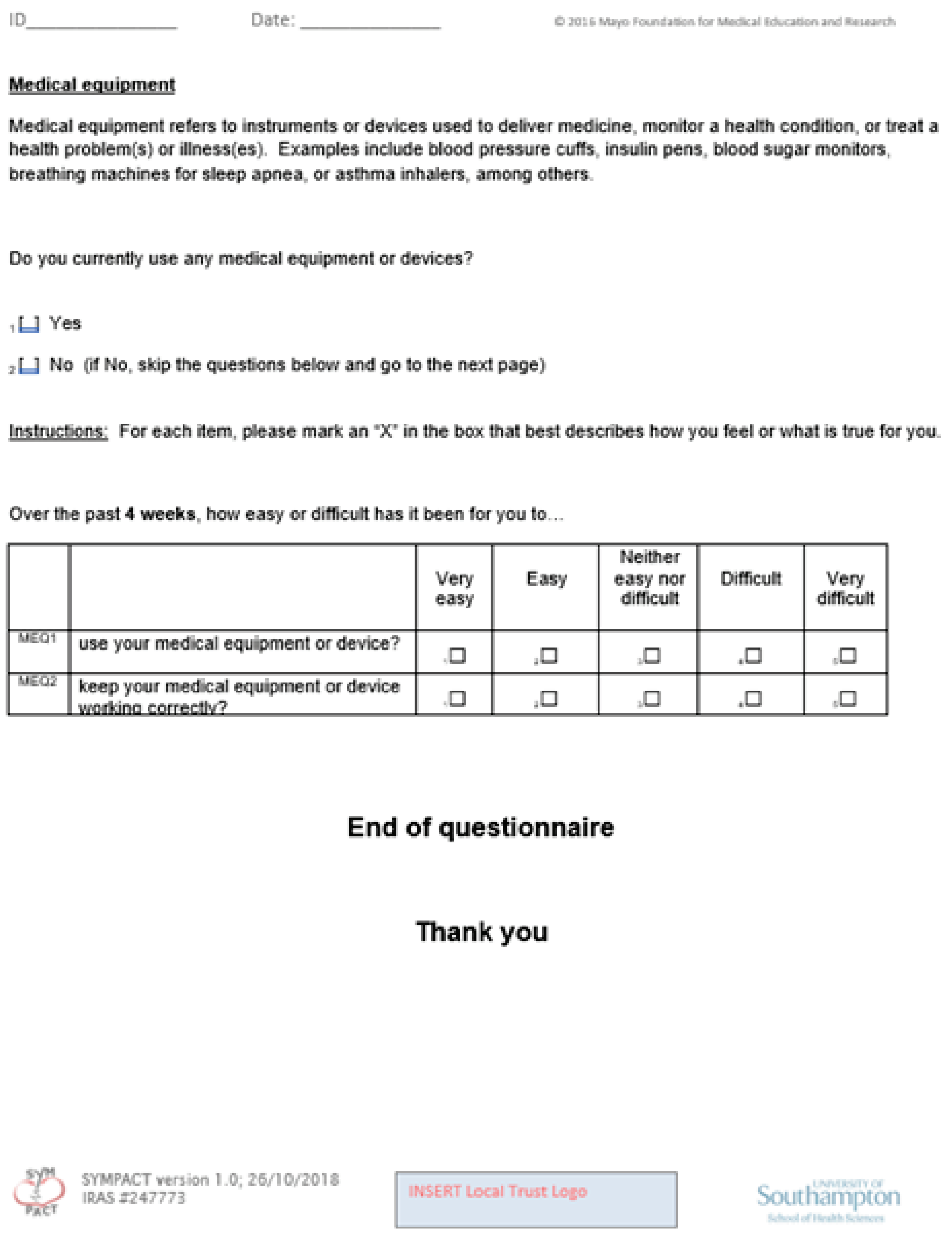

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Medical equipment

Medical equipment refers to instruments or devices used to deliver medicine, monitor a health condition, or treat a health problem(s) or illness(es). Examples include blood pressure cuffs, insulin pens, blood sugar monitors, breathing machines for sleep apnea, or asthma inhalers, among others.

Do you currently use any medical equipment or devices?

1☐ Yes

2☐ No (if No, skip the questions below and go to the next page)

Instructions: For each item, please mark an "X" in the box that best describes how you feel or what is true for you.

Over the past **4 weeks**, how easy or difficult has it been for you to…

		Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult
MEQ1	use your medical equipment or device?	1☐	2☐	3☐	4☐	5☐
MEQ2	keep your medical equipment or device working correctly?	1☐	2☐	3☐	4☐	5☐

End of questionnaire

Thank you

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Appendix D Interview schedule for SYMPACT Phase II

D.1 Work that informed the interview schedule

Theme	Eton, Ridgeway (123)	Nordfonn, Morken (162)	Tran, Montori (161)	Karamanidou, Weinman (160)	Gallacher, May (59)
General Introduction	Tell me how you're doing these days. What types of health problems are you dealing with right now?	Could you tell me about your health problems? Could you tell me a bit about your history with Heart failure?	Could you tell us about what you have to do to take care of your health?	How long ago were you diagnosed? Since then, have you thought any more about what has caused your condition?	Tell me about what was happening when you were started on *medications.* Have you ever had problems with *list symptoms)*? Can you tell me about this?
Daily management of the disease	What kinds of things do you have to do to treat or care for your health condition? Do you monitor your condition? What type of monitoring do you do and how often? Have you had to learn anything new skills to care for yourself?	What do you have to do to take care of yourself and the disease? Could you tell me how you monitor your symptoms? How do you manage the disease in daily life? How do you cope in daily life with self-management? Did you learn new skills to do this?	What aspects of your care have the most impact on your life?' What is the burden associated with the *list the things they bring up*?	What other changes has it been necessary for you to make? What do you think about your diet and fluid restrictions? Do you think it's necessary to follow your treatment regimen? What do you feel would make it easier for you to stick to this?	Do you know of any signs or symptoms to look out for that would suggest you should seek medical advice? Please describe any advice you've received relating to your condition.

Appendix D

Theme	Eton, Ridgeway (123)	Nordfonn, Morken (162)	Tran, Montori (161)	Karamanidou, Weinman (160)	Gallacher, May (59)
Impact	Thinking of all of the things that you do to care for your health, how would you say they affect you or your life? Do your treatments or self-care affect your work, or your social and family life?	How would you describe how all the things you do to take care of yourself and how it affects you? How much space does handling the work you have to do in relation to your disease, take in your life?	How would you rate the constraints associated with your diet? How would you rate the burden associated with the recommendations from your doctors to practice regular physical exercises?		Does having this condition affect your work? Describe how having a condition is viewed by your employer and your work colleagues. Does having this condition affect life at home?
Treatment adherence	Are there times when you find that it is difficult to do all of the things that you have to do to maintain your health? Do you ever cut back on doing things for your health? Are there things that you do to make the management of your health condition easier	Do you sometimes feel that it's hard to do all these things to take care of your health? Do you ever skip any of the things you should do? Tell me about how much time you: spent on medication), getting to appointments and examinations in the last month. How much time have you spent on exercise and diet, based on advice from health professionals? Do you think you follow their advice?	How often do you have to take your medication? What do you do to remind yourself to take your medications or to manage your treatment? Are there certain things you have to consider when taking medications? Are the health appointments you have to attend an inconvenience? How much of a bother is self-monitoring? How much time and how much of a bother are health appointments?	What kind of medication are you on? Do you know what it works for and how? What do you think about your medicine? Is it effective? Do you have any concerns about medication? How important do you think it is to follow doctors' advice? Do you sometimes forget to take medication doses? What do you find is the most difficult thing to manage? How often do you get feedback on how you are doing?	How do you find taking the medicine the doctor has prescribed for you? Are you taking medications for any other illness? Do they bother you in any way? Are you worried about side effects? Do you think it is important to take your medicine? What effect do the medications have on your condition? How do you get your medications?

Theme	Eton, Ridgeway (123)	Nordfonn, Morken (162)	Tran, Montori (161)	Karamanidou, Weinman (160)	Gallacher, May (59)
Relationship to health professionals	Tell me a little bit about the relationships that you have with your health care providers. Is communication between you and the providers particularly good or bad? Can you give an example to illustrate this?	Could you tell me about your relationship with different health professionals? How is the communication? Do you have any examples?	How would you rate the burden associated with taking care of the paperwork from health insurance agencies, welfare organizations, hospitals and/or social care?	How do you find doctors and nurses react to 'bad' lab results? Do you find that helpful/unhelpful? Fair/unfair?	Have you been told anything about this symptom by a doctor? Have you asked them to explain your condition? How involved do you feel you are in decisions about your treatment?
Social support	In caring for your health, do you get support from other people? Who? What kinds of things do they do to help you? Has your health care ever created tension between you and other people?	In relation to your heart failure, do you get any help from others? Who helps you? How do they help you? Did this ever cause any tension between yourselves and others?	What is the impact of your healthcare on your social relationships? For example, how do you feel about the need for assistance, are you ashamed to take your medication in front of people?	How about your family? How do they deal with everything? What do they do to help? Are you happy with the support provided by friends, family and hospital staff?	Please describe how your having such a condition is viewed by your family and friends. Does having this condition affect your leisure activities? Does this condition prevent you from doing anything?
Emotions	For some people, the personal work of caring for their health condition can be emotionally challenging, is this true for you? Are there any things that you do to "stay positive"?	For some, the personal work they have to do in relation to the disease is emotionally challenging. Is this something you can relate to? Is there something you do to keep your spirits up?		How do you see your illness developing in the future? In the next months, years?	What are your expectations for the future in view of this condition?

Theme	Eton, Ridgeway (123)	Nordfonn, Morken (162)	Tran, Montori (161)	Karamanidou, Weinman (160)	Gallacher, May (59)
Finances	Has your health care affected you at all financially?				Do you have to pay for any of your prescriptions?
Relating their experience to concept of BoT		How do you experience self-management of your disease? Are there other things that make it difficult to live with the disease?			
Capacity		If you picture a set of scales, on the one side, your disease and on the other side, your capacity to handle the disease, what do you think about the relationship between them? How do you perceive your capacity in daily life?			

Theme	Eton, Ridgeway (123)	Nordfonn, Morken (162)	Tran, Montori (161)	Karamanidou, Weinman (160)	Gallacher, May (59)
Information seeking		Could you tell me about how you and your next of kin collect information, if there is something you want to know more about your disease?		How happy are you with the information you have been given about your treatment?	Have you looked for information or advice about your condition? Is there any information you would like?
Final question	Is there anything else that you would like to tell me about today regarding your health conditions and how they are cared for?	Is there anything else you would like to tell me about, in relation to your disease/health condition or how you handle it?	Do other aspects of the workload of healthcare bother you?	Are there other ways in which you would like the hospital to help you? If yes, what?	Are there any other ways in which health professionals could offer you more help with your condition? Do you belong to any support group? Are there any issues you would like to mention that I haven't covered?

D.2 Original interview schedule

BoT Domain	**Theme**	**SYMPACT Phase II Interview schedule**
Introduction	Introduce the research ideas and set the context for the interview	• Introduce self and study • Purpose and length of the interview • Procedures of the interview • Invite and receive informed verbal and written consent (voluntary participation, right to stop to have a break and to withdraw, confidentiality, recording the interview, any questions)
Workload	Illness management and monitoring	• Would you tell me what it is like to live with your heart condition? *Probe around symptoms using HFSS responses.* • Can you tell me what you do at home to take care of your heart condition? *Prompts: Take medication, monitor condition, attend appointments, lifestyle behaviours, etc…* • How do you monitor your heart condition? *Probe around self-care tasks (use MLHFQ responses)* • Are there any specific symptoms that you keep track of? How? Why? *Prompt: explore the symptoms further and if they believe related to heart failure or other co-morbidity.*
	Assigned work from healthcare professional	• Can you tell me about how you go about doing the tasks that your doctor/nurse wants you to do for your heart condition? Does anyone help you? What makes this harder? *Probe on symptoms, emotions, and knowledge (use examples reported in questionnaires)* • Are there things you do that make doing all these tasks easier? *Prompts: pill box, calendar.*
	Health literacy	• How do you find out more information about your heart condition? *Prompts: Health care provider, GP, magazine, support group, others with your condition.* What makes you motivated to find out more about your condition? What makes it harder?

BoT Domain	**Theme**	**SYMPACT Phase II Interview schedule**
Capacity	Individual ability factors; helping or hindering engagement in the work of illness	• If you picture a set of scales, on the one side, you have your heart condition and on the other side, you have your ability to manage it; what makes it harder to keep this balanced? *Prompts: Symptoms, healthcare system navigation, etc… making it harder. Intrinsic strength, social support, and spirituality making it easier*. • What are the key things that improve/decrease/change your ability to cope in daily life? (*Probe using responses from questionnaires, and external resources*)
	Resources: relationship with healthcare professionals	• How would you describe your experience with the doctor/nurse specialist who helps you with your heart condition? Have you ever felt like they don't listen to the symptoms you report? Tell me about that. (*If present use examples from questionnaire responses*)
	Resources: social support	• Do you get help in managing your heart condition from others (family or friends)? Can you tell me about that? Is there anything that makes this harder/easier? *Prompt: Tension in your relationship, changes to the relationship due to a decrease in ability.* (*If present use examples from questionnaire responses*)
	Resources: emotional capacity through illness management	• Some people with your heart condition can find the tasks/work they have to do is emotionally stressful, have you felt this way? Can you tell me about that? *Probe on emotional impact (use PETS responses)*
	Resources: finances in illness management	• Has your heart condition affected you financially? *Prompts: pay for medications, buy healthy food, pay for help, pay for exercise/gym membership, not able to work due to symptoms.*

BoT Domain	**Theme**	**SYMPACT Phase II Interview schedule**
Impact	Self-value (What can I do? Who am I? Things that make it harder to be me)	• Does your heart condition impact your life? If yes, how much? If not, why do you think that is? (*use PETS responses as probes*) • Has your heart condition changed your role in life? If yes, how much? If not, why do you think that is? *Prompt: Change in relationships, employability, recreational activities, in self. Time and energy spent on health (Use PETS and MLHFQ responses)* • Do you always do (miss/skip/forget) what you are supposed to do to manage your heart condition? If yes what and why? *Prompt: forgot, inconvenience of treatment, unwanted side effects.*
Conclusion	Thoughts on BoT	• Thinking about this idea of the (work and) impact of managing illness, do you think this is true to your experience?
	Final insights	• *Review highlights of what was said:* Have I understood you correctly? Is there anything I haven't understood? • Is there anything you think I have missed? Anything else you would like me to know about how you go about managing your condition and what makes it harder or easier? • What is the one thing that you wish the doctors/nurses would help you with more? • What is the one thing that you feel would make it easier for you to do the tasks of managing your heart condition? Thank you for participating and reassure confidentiality

D.3 Final interview schedule

Purpose	Main questions	Prompts
	Would you tell me what it is like to live with heart failure?	-symptoms reported as prevalent in HFSS
(1) Experience of managing CHF	(a) Can you tell me what you do at home to take care of your heart failure?	-take medications, monitor symptoms, attend health appointments, and lifestyle behaviours.
	(b) Do you monitor your condition?	- daily weights, blood pressure, etc…
	(c) Are there specific symptoms you keep track of?	- explore symptom experience further
	(d) Does your heart failure impact or change your life?	-ask around changes to self or role, employability, recreational activities, etc…
(2) Factors that might make managing heart failure more complex	(a) Can you tell me how you go about doing the tasks that healthcare professionals want you to do for your health?	-does anyone help you? What makes this harder?
	(b) Do you ever not do these tasks?	-If they answer yes, ask for more details.
	(c) Are there things you do that make these tasks easier?	-tips, tools, and additional support structures in place
	(d) How would you describe your experience with the doctor/nurse specialist who helps you with your heart condition?	- have you ever felt like they don't listen to your symptoms? Tell me about that.
	(e) Do you get help in managing your heart condition from others (family or friends)?	-Can you tell me about the help you receive? Does this make it easier or harder to do the tasks?
	(f) Some people with your heart condition can find the tasks/work they have to do is emotionally stressful, have you felt this way?	- Have you felt this way? Can you tell me about this?
	(g) Has your heart condition affected you financially?	- explore the cost of medications, in-home support, etc… NB: only ask this question if they indicated a financial cost in their questionnaire responses.
	(h) How do you find out more information about your heart condition?	- healthcare professionals, support groups, literature, internet

(3) Participant experience in the context of BoT	(a) Briefly explain interim results from the survey, where possible show a simple correlation graph. Then ask, do you think that this relationship is true?	-ask for examples of how this is true for them, did this change due to Covid? Does this apply to others with heart failure?
	(b) Picture a set of scales (or seesaw) on one side you have your heart condition and all the things you have to do to manage it. On the other side, you have your abilities and resources (family members, healthcare providers, etc…). What happens to the seesaw?	-encourage them to explain which end of the seesaw is up or down. Asked about what changes the direction of the seesaw.
	(c)What are key things that improve/decrease/change your ability to cope in daily life?	
	Review the researcher's understanding of participant experience.	-allow participants to confirm or correct the researcher's summary
	Is there anything else that you want to add?	

Appendix E Qualitative evidence 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 CHFs 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 discurs$ 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 research 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 CHFs or HF or HFpEF or HFrEF).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]

13. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12

14. exp qualitative research/

15. qualitativ$.ti,ab,kw.

16. exp interview/

17. interview$.ti,ab,kw.

18. focus group$1.ti,ab,kw.

19. grounded theory/

20. (grounded theor$ or grounded study or grounded studies or grounded research or grounded analys$).ti,ab,kw.

21. phenomenology/

22. phenomenol$.ti,ab,kw.

23. ethnography/

24. ethnonursing research/

25. (ethnograph$ or ethnonurs$ 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 discurs$ 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 ethnonurs* or "ethno-graph*" or "ethnonurs*") or AB(ethnograph* or ethnonurs* or "ethno-graph*" or "ethno-nurs*")

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 discurs* analys* OR AB discourse* analys* OR AB discurs* 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 cardial OR myocardia*) W/3 (failure* OR decompensat* OR incompeten* OR insufficienc* OR dysfunction*))) OR TITLE-ABS-KEY ("heart failure" W/3 (congestive OR diastolic OR systolic) OR ("preserved ejection fraction" OR "reduced ejection fraction")) OR TITLE-ABS-KEY ("CHF" OR "CHFs" 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 consumer* OR personal OR carer* OR caregiver* OR "care-giver*" OR family* OR families) 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*) OR ABS (patient* OR client* OR user* OR consumer* OR personal OR carer* OR caregiver* OR "care-giver*" OR family* OR families) W/3 (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*) OR KEY (patient* OR client* OR user AND * OR consumer* OR personal OR carer* OR caregiver* OR "care-giver*" OR family* OR families) W/3 (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*) OR TITLE (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 O

R scared OR bother* OR unbother* OR pleased OR displeased* OR concern* OR burden* OR hassl AND * 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*) OR ABS (patient* OR client* OR user* OR consumer* OR personal OR carer* OR caregiver* OR "care-giver*" OR family* OR families) W/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 "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 AND * 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*) OR KEY (patient* OR client* OR user* OR consumer* OR personal OR carer* OR caregiver* OR "caregiver*" OR family* OR families) W/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 "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 AND * 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*) OR TITLE-ABS-KEY ("life experience*" OR "lived experience*" OR "actual experience*" OR "real experience*") AND (title-abs- KEY ((heart* OR cardiac OR cardial OR myocardia*) W/3 (failure* OR decompensat* OR incompeten* OR 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 "CHFs" 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 incompentenc* OR insufficen* OR dysfunction*))

3 **TOPIC:** ("diastolic heart failure" OR "systolic heart failure")

4 **TOPIC:** ("congestive heart failure")

5 **TOPIC:** (CHF ORCHFs OR HF OR HFpEF OR HFrEF)

6 #5 OR #4 OR #3 OR #2 OR #1

7 **TOPIC:** (qualitativ*)

8 **TOPIC:** (interview*)

9 **TOPIC:** ("focus group*")

10 **TOPIC:** ("grounded theor*" or "grounded study" or "grounded studies" or "grounded research" or "grounded analys*")

11 **TOPIC:** (phenomenol*)

12 **TOPIC:** (ethnograph* or ethnonurs* or "ethno-graph*" or "ethno-nurs*")

13 **TOPIC:** (story or stories or storytelling or narrative* or narration*)

14 **TOPIC:** ("open-ended" or "open question*" or text*)

#15 **TOPIC:** ("discourse* analys*" or "discors* analys*")

#16 **TOPIC:** ("content* analys*")

#17 **TOPIC:** ("ethnological")

#18 **TOPIC:** ("purposive sampl*")

#19 **TOPIC:** ("constant comparative" or "constant comparison*")

#20 **TOPIC:** ("theoretical sampl*")

#21 **TOPIC:** (theme* or thematic*)

#22 **TOPIC:** ("emic" or "etic" or hermeneutic* or heuristic* or semiotic*)

#23 **TOPIC:** ("data saturat*")

#24 **TOPIC:** ("participant observ*")

#25 **TOPIC:** (humanistic* or existential* or experiential* or paradigm*)

#26 **TOPIC:** ("social construct*" or postmodern* or "post-modern*" or poststructural* or "post-structural*" or feminis* or constructivis*)

#27 **TOPIC:** ("action research" or "cooperative inquir*" or "co-operative inquir*")

#28 **TOPIC:** ("human science")

#29 **TOPIC:** ("biographical method*")

#30 **TOPIC:** ("life world")

#31 **TOPIC:** ("theoretical saturation")

#32 **TOPIC:** ("group discussion*")

#33 **TOPIC:** ("direct observation*")

#34 **TOPIC:** ("mixed method*")

#35 **TOPIC:** ("observational method*" or "observational approach*")

#36 **TOPIC:** ("key informant*")

#37 **TOPIC:** ("field study" or "field studies" or "field research*" or "field work*" or fieldwork*)

#38 **TOPIC:** ("semi-structured" or "semistructured" or "unstructured" or "un-structured" or "informal" or "indepth" or "indepth")

#39 **TOPIC:** ("face-to-face")

#40 **TOPIC:** (("guide" or "structured") near/5 (discussion* or questionnaire*))

#41 **TOPIC:** (TOPIC: (heidegger* or colaizzi* or speigelberg* or "van manen*" or "van kaam*" or "merleau ponty*" or husserl* or giorgi* or foucault* or corbin* or glaser*))

#42 #41 OR #40 OR #39 OR #38 OR #37 OR #36 OR #35 OR #34 OR #33 OR #32 OR #31 OR #30 OR #29 OR #28 OR #27 OR #26 OR #25 OR #24 OR #23 OR #22 OR #21 OR #20 OR #19 OR #18 OR #17 OR #16 OR #15 OR #14 OR #13 OR #12 OR #11 OR #10 OR #9 OR #8 OR #7

#43 **TOPIC:** (((patient* or client* or user* or consumer* or "personal") and (experienc* or perspective* or perception* or opinion* or "account" or "accounts" or attitude* or "view" or "views" or viewpoint* or satisf* or unsatisf* or dissatisf* or disatisf* or 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)

Appendix F **Framework of burden of treatment**

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 to healthcare practitioners for advice or to increase the 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, balanced lifestyle
		Medication management: obtaining and filling prescriptions, taking medications, navigating the 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

Appendix G Table of included articles in qualitative evidence synthesis

Author(s)	Year	Journal	Title (abbreviated)
Ahmad, Barg (227)	2016	*J Card Fail*	Comparing perspectives (…) heart failure management
Allen, Arslanian-Engoren (202)	2009	*Prog Cardiovasc Nurs*	The lived experience of (…) III heart failure: A pilot study
Andersson, Eriksson (224)	2012	*Br J Community Nurs*	Living with heart failure (…) a qualitative patient study
Attenburrow (203)	2016	*Br J Card Nurs*	Live for the day with atrial fibrillation plus heart failure
Chiaranai (197)	2014	*J Cardiovasc Nurs*	A phenomenological study of (…) of living with heart failure
Cortis and Williams (204)	2007	*Int Nurs Rev*	Palliative and supportive needs (…) adults with heart failure
Falk, Wahn (201)	2007	*Eur J Cardiovasc Nurs*	Keeping the maintenance (…) in spite of chronic heart failure
Fry, McLachlan (205)	2016	*BMC Fam Pract*	The implications of living with heart failure (…) analysis
Gallacher, May (59)	2011	*Ann Fam Med*	Understanding patients' experiences (…) process theory
Gowani, Gul (198)	2017	*Br J Card Nurs*	Living with heart failure: Karachi exploratory study
Gwaltney, Slagle (228)	2012	*Br J Cardiol*	Hearing the voice of the heart failure (…) qualitative interviews
Heo, Moser (206)	2019	*West J Nurs Res*	Patients’ beliefs about causes and consequences (…) symptoms
Holden, Schubert (207)	2015	*Appl Ergon*	The patient work system: An analysis of self-care (…) caregivers
Hopp, Thornton (223)	2012	*Soc Work Health Care*	Life disruption (…) American elders with advanced heart failure
Kimani, Murray (200)	2018	*BMC Palliative Care*	Multidimensional needs of patients (…) serial interview study
Mahoney-Davies, Davis (225)	2017	*Br J Card Nurs*	Examining the emotional and (…) of people with heart failure
Malhotra, Cheng Sim Wong (229)	2016	*Proc Singapore Healthcare*	Living with heart failure (…) patients from Singapore
Ming, Hassali (209)	2011	*J Public Health*	Perspectives of heart failure patients (…) from a qualitative study

Author(s)	Year	Journal	Title (abbreviated)
Moshki, Khajavi (210)	2019	*OA Maced J Med Sci*	Dark or bright half of the moon (…) quality of life
Nordfonn, Morken (162)	2019	*J Clin Nurs*	Patients’ experience with heart failure (…) burden of treatment
Nordgren, Asp (221)	2007	*Qual Health Res*	Living with (…) heart failure as a middle-aged person
Paton, Backlund (211)	2007	*Can J Cardiovasc Nurs*	Recalibrating time and space (…) living with heart failure
Pattenden, Roberts (222)	2007	*Eur J Cardiovasc Nurs*	Living with heart failure; patient and carer perspectives
Paturzo, Petruzzo (212)	2016	*Ann Ig*	The lived experience (…) heart failure: A phenomenological study
Piamjariyakul, Smith (213)	2012	*Appl Nurs Res*	Part I: heart failure home management (…) perspectives
Rerkluenrit, Panpakdee (219)	2009	*Thai J Nurs Res*	Self-care among Thai people with heart failure
Retrum, Boggs (214)	2013	*Circulation*	Patient-identified factors related to heart failure readmissions
Ryan and Farrelly (215)	2009	*Eur J Cardiovasc Nurs*	Living with an unfixable heart (…) with advanced heart failure
Sano and Majima (216)	2018	*Int J Nurs Prac*	Self management of congestive heart failure (…) in Japan
Seah, Tan (226)	2016	*J Transcult Nurs*	Experiences of patients living with heart failure (…) study
Shahrbabaki, Nouhi (208)	2017	*J Clin Nurs*	The sliding context of health (…) providers and family members
Tenner (217)	2018	*JACC Heart Fail*	Everybody has a story, and I’m lucky!
Walthall, Jenkinson (199)	2017	*J Clin Nurs*	Living with (…) in chronic heart failure: a qualitative study
Walthall, Floegel (220)	2019	*Contemp Nurse*	Patients experience of (…) advanced heart failure
Woda, Haglund (218)	2015	*J Community Health Nurs*	Self-care behaviors (…) Americans living with heart failure

Appendix H **Codebook for electronic database**

Enrolment and consent details

Question	Variable name	Response options	Rules
Did the participant meet the eligibility requirements for this study?	*ie_eligible*	o Yes o No	Yes = 1 No = 0
Was the participant assigned a Study ID?	*ie_screened*	o Yes o No	Show the field only if: ie_eligible = '1'
Consent type	*cons_type*	o Face-to-face o Postal	Yes = 1 No = 0
Consent form received?	*cons_type*	o Yes o No	Yes = 1 No = 0
Questionnaires received?	*questionnaires_received*	o Yes o No	Yes = 1 No = 0
Consented for anonymised data to be shared with collaborators?	*cons_anon_share*	o Yes o No	Yes = 1 No = 0
Consented to be approached for Phase II?	*cons_phase2*	o Yes o No	Yes = 1 No = 0
Wish to receive the results of the study?	*cons_results*	o Yes o No	Yes = 1 No = 0

Patient information

Visit details

Question	Variable name	Response options	Rules
Were the questionnaires completed at a study site or at home?	*quest_compl_site*	o Study site o Home	
Date of questionnaire completion	*quest_compl_date*	date	*DD-MM-YYYY*
Questionnaire completion:	*quest_compl*	o On my own o With help	
Where is their heart failure care coordinated?	*HF_care*	o Secondary/Hospital o Primary/GP	
Did you as a researcher give the research participant any clinical advice/recommendations?	*clinical_advice_given*	o Yes o No	Yes = 1 No = 0
Please provide details (e.g. what advice was given?)	*clinical_advice_given_details*	Free text box	Show the field only if clinical_advice_given = "1"
Did errors in the patient's consent form prevent the researcher from accessing the patient's data?	*consent_errors*	o Yes o No	Yes = 1 No = 0
Please specify what data was unavailable due to errors in the patient's consent form.	*consent_errors_specify*	Free text box	Show the filed only if consent_errors = '1'

Personal Characteristics

Question	Variable name	Response options	Rules
Date of birth	DoB	date	*DD-MM-YYYY*
Gender	*gender*	o Male o Female o Prefer not to say o Unknown	
Ethnicity/race	*ethnicity*	o White British o White Irish o White Other o White & Black Caribbean o White & Asian o Other mixed backgrounds o Indian o Bangladeshi o Pakistani o Other Asian backgrounds o Caribbean o African o Black other o Chinese o Other	
Please specify	*ethnicity_oth*	Free text	ethnicity = 'Other'
Marital status	*marital_status*	o Married o Separated o Divorced	

Question	Variable name	Response options	Rules
		o Widow o Unknown o Other	
Please specify	*marital_status_other*	Free text	marital_status = 'Other'
Living situation	*living_sit*	o Living on my own o With partner/spouse o With son/daughter/family o Unknown o Other	
Please specify	*living_sit_other*	Free text	living_sit = 'Other'

Health information

Known health issues

Question	Variable name	Response options	Rules
Health Issue	*known_health_issue*	Free text	Users can add up to 40 lines

Current medications

Question	Variable name	Response options	Rules
Medication name	*med_name*	Free text	Users can add up to 40 lines
Dose	*med_dose*	Free text	
Frequency	*med_freq*	Free text	

Recent clinical evaluation

Question	Variable name	Response options	Rules
Does the patient have a recorded Heart Rate available?	*ce_hr_record*	o Yes o No	Yes = 1 No = 0
Heart Rate	*ce_hr*	integer Min: 26 Max: 200	Show the field only if: ce_hr_record = '1'
Heart Rate date	*ce_hr_date*	*DD-MM-YYYY*	Show the field only if: ce_hr_record = '1'
If No, why not?	*ce_hr_no_record*	o No clinical record o Records not accessed o Other	Show the field only if: ce_hr_record = '0'
If other, specify	*ce_hr_no_record_specify*	Free text	Show the field only if: ce_hr_no_record = 'Other'
Does the patient have a recorded Blood Pressure available?	*ce_BP_sys_dia_record*	o Yes o No	Yes = 1 No = 0
Systolic blood pressure	*ce_BP_sys*	integer Min: 80 Max: 210	Show the field only if: ce_BP_sys_dia_record = '1'
Diastolic blood pressure	*ce_BP_dia*	integer Min: 40 Max: 120	Show the field only if: ce_BP_sys_dia_record = '1'
Blood pressure date	*ce_BP_date*	*DD-MM-YYYY*	Show the field only if: ce_BP_sys_dia_record = '1'
If No, why not?	*ce_BP_no_record*	o No clinical record o Records not accessed o Other	Show the field only if: ce_BP_sys_dia_record = '0'
If Other, specify	*ce_BP_no_record_specify*	Free text	Show the field only if: ce_BP_no_record = 'Other'
Does the patient have a recorded Oedema level available?	*ce_oed_lvl_record*	o Yes o No	Yes = 1 No = 0
Oedema level	*ce_oed_lvl*	Free text	Show the field only if: ce_oed_lvl_record = '1'

Question	Variable name	Response options	Rules
Oedema level date	*ce_oed_lvl_date*	*DD-MM-YYYY*	Show the field only if: ce_oed_lvl_record = '1'
If No, why not	*ce_oed_lvl_no_record*	o No clinical record o Records not accessed o Other	Show the field only if: ce_oed_lvl_record = '0'
If Other, specify	*ce_oed_lvl_no_record_specify*	Free text	Show the field only if: ce_oed_lvl_no_record = 'Other'
Does the patient have a recorded NYHA class available?	*ce_NYHA_record*	o Yes o No	Yes = 1 No = 0
NYHA class	*ce_NYHA*	o I o II o III o IV	Show the field only if: ce_NYHA_record = '1'
NYHA class date	*ce_NYHA_date*	*DD-MM-YYYY*	Show the field only if: ce_NYHA_record = '1'
If No, why not	*ce_NYHA_no_record*	o No clinical record o Records not accessed o Other	Show the field only if: [ce_NYHA_record] = '0'
If Other, specify	*ce_NYHA_no_record_specify*	Free text	Show the field only if: ce_NYHA_no_record = 'Other'
Does the patient have a recorded Height available?	*ce_hei_record*	o Yes o No	Yes = 1 No = 0
Height in centimetres	*ce_hei*	decimal Min: 50 Max: 250	Show the field only if: ce_hei_record = '1'
If No, why not	*ce_hei_no_record*	o No clinical record	Show the field only if: ce_hei_record = '0'

Question	Variable name	Response options	Rules
		o Records not accessed o Other	
If Other, specify	*ce_hei_no_record_specify*	Free text	Show the field only if: ce_hei_no_record = 'Other'
Does the patient have a recorded Weight available?	*ce_wei_record*	o Yes o No	Yes = 1 No = 0
Weight in kilograms	*ce_wei*	decimal Min: 40 Max: 180	Show the field only if: ce_wei_record = '1'
Weight date	*ce_wei_date*	*DD-MM-YYYY*	Show the field only if: ce_wei_record = '1'
BMI	*ce_BMI_calc*	round([ce_wei]/(([ce_hei]/100) *([ce_hei]/100)),2)	Show the field only if: ([ce_wei] <> "") and ([ce_hei] <>"")
If No, why not	*ce_wei_no_record*	o No clinical record o Records not accessed o Other	Show the field only if: ce_wei_record = '0'
If Other, specify	*ce_wei_no_record_specify*	Free text	Show the field only if: [ce_wei_no_record] = 'Other'

Recent blood results

Question	Variable name	Response options	Rules
BNP or NT-proBNP result available within 4 months?	*bld_BNP_NT_avail*	o BNP o NT-proBNP o Not available	

Question	Variable name	Response options	Rules
BNP pg/mL	*bld_BNP*	integer Min: 0 Max: 999	Show the field only if: bld_BNP_NT_avail = 'BNP'
NT-proBNP pg/mL	*bld_NTproBNP*	integer Min: 0 Max: 12000	Show the field only if: bld_BNP_NT_avail = 'NT-proBNP'
BNP or NT-proBNP date	*bld_BNP_or_NT_date*	*DD-MM-YYYY*	Show the field only if: bld_BNP_NT_avail = 'BNP' or bld_BNP_NT_avail = 'NT-proBNP'
Haemoglobin results available in the last 4 months?	*bld_Hb_avail*	○ Yes ○ No	Yes = 1 No = 0
Haemoglobin g/L	*bld_Hb*	integer Min: 60 Max: 250	Show the field only if: bld_Hb_avail = '1'
Haemoglobin date	*bld_Hb_date*	*DD-MM-YYYY*	Show the field only if: bld_Hb_avail = '1'
eGFR result available in last 4 months?	*bld_eGFR_avail*	○ Yes ○ No	Yes = 1 No = 0
eGFR	*bld_eGFR*	integer Min: 0 Max: 150	Show the field only if: bld_eGFR_avail = '1'
eGFR date	*bld_eGFR_date*	*DD-MM-YYYY*	Show the field only if: bld_eGFR_avail = '1'

Other studies

Question	Variable name	Response options	Rules
Participation in other research studies (in the past 12 months)?	*oth_studies*	○ Yes ○ No	
Name of study	*oth_studies_name*	Free text	Show the field only if: oth_studies = '1'

Heart Failure Description

Heart failure information

Question	Variable name	Response options	Rules
Heart Failure diagnosed more than 6 months ago	*HF_diagnosed*	o Yes o No	Yes = 1 No = 0
Is the date of Heart Failure diagnosis known?	*HF_diag_date_known*	o Known o Unknown	Show the field only if: HF_diagnosed = '1'
Date of diagnosis	*HF_diag_date*	*DD-MM-YYYY*	Show the field only if: HF_diag_date_known = 'Known'
Aetiology of Heart Failure	*HF_aetiol*	o Ischaemia o Hypertension o Dilated Cardiomyopathy o Unknown o Other	
Other Heart Failure aetiology	*HF_aetiol_other*	Free text	Show the field only if: HF_aetiol = 'Other'
Heart Failure type	*HF_type*	o HFpEF o HFrEF o Unknown o Other	
Other Heart Failure type	*HF_type_other*	Free text	Show the field only if: HF_type = 'Other'
Ejection fraction measurement	*HF_EF_meas*	o Echocardiogram o MRI o Unknown	

		o Other	
Other Ejection fraction measurement	*HF_EF_meas_other*	Free text	Show the field only if: HF_EF_meas = 'Other'
Ejection fraction (most recent)	*HF_EF_value*	Free text	Show the field only if: HF_EF_meas = ('Echocardiogram' or 'MRI' or 'Other')
Ejection fraction date	*HF_EF_date*	*DD-MM-YYYY*	Show the field only if: HF_EF_meas = ('Echocardiogram' or 'MRI' or 'Other')
Has the participant been hospitalised for Heart Failure within the past 12 months?	*HF_hosp_within_year*	o Yes o No	
How many times has the participant been hospitalised for Heart Failure within the past 12 months?	*HF_hosp_year_num*	integer Max: 50	Show the field only if: HF_hosp_within_year = '1'
Has the participant been hospitalised for Heart Failure within the past 3 months?	*HF_hosp_3m*	o Yes o No	Show the field only if: HF_hosp_within_year = '1'
How many times has the participant been hospitalised for Heart Failure within the past 3 months?	*HF_hosp_3m_num*	integer Min: 1 Max: 3	Show the field only if: HF_hosp_3m = '1'

Heart failure hospitalisation

Question	Variable name	Response options	Rules
Hospitalisation start date 1	*HF_hosp_3m_startdate_1*	DD-MM-YYYY	Show the field only if: HF_hosp_3m_num > '0'
Hospitalisation end date 1	*HF_hosp_3m_enddate_1*	DD-MM-YYYY	Show the field only if: HF_hosp_3m_num > '0' and HF_hosp_3m_discharged_1 = '1'
Discharged from hospitalisation 1	*HF_hosp_3m_discharged_1*	o Yes o No	Show the field only if: HF_hosp_3m_num > '0'
Hospitalisation start date 2	*HF_hosp_3m_startdate_2*	DD-MM-YYYY	Show the field only if: HF_hosp_3m_num > '1'

Hospitalisation end date 2	*HF_hosp_3m_enddate_2*	DD-MM-YYYY	Show the field only if: HF_hosp_3m_num > '1' and HF_hosp_3m_discharged_2 = '1'
Discharged from hospitalisation 2	*HF_hosp_3m_discharged_2*	o Yes o No	Show the field only if: HF_hosp_3m_num > '1'
Hospitalisation start date 3	*HF_hosp_3m_startdate_3*	DD-MM-YYYY	Show the field only if: HF_hosp_3m_num > '2'
Hospitalisation end date 3	*HF_hosp_3m_enddate_3*	DD-MM-YYYY	Show the field only if: HF_hosp_3m_num > '2' and HF_hosp_3m_discharged_3 = '1'
Discharged from hospitalisation 3	*HF_hosp_3m_discharged_3*	o Yes o No	Show the field only if: HF_hosp_3m_num > '2'

Appendix I **Maximum variation sampling grid**

Age	LVEF	Questionnaire scores		
		low	mod	high
<44	<45	☒	☒	🚺
	>45	☒	🚹	☒
45-54	<45	🚹 🚺	🚺	☒
	>45	☒	✕	🚹
55-64	<45	🚹	🚹 🚺	🚹 🚺
	>45	☒	✕	🚹 🚺
65-74	<45	🚹	☒	🚹
	>45	🚺	🚹 🚺	🚹
75-85	<45	🚹 🚺	🚹 🚺	🚹
	>45	🚹 🚺	🚹 🚺	🚹 🚺
<85	<45	🚹	🚹 🚺	🚺
	>45	✕	🚺	🚺

Legend
Male 🚹
Female 🚺
Declined ☒
No matching participant ✕

Gender representation by age, LVEF, and questionnaire score. LVEF, left ventricular ejection fraction. NB: a single icon (male or female) represents the presence of that gender in that category and not the number of participants.

Appendix J Comparison of qualitative data using quantitative characteristics

The first step was to use the existing themes and codes generated in the analysis conducted in Chapter 6. Using the survey scores and clinical characteristics of interview participants the interactions between symptoms and BoT were mapped providing a complex overview of how symptoms interacted with BoT (Figure 22).

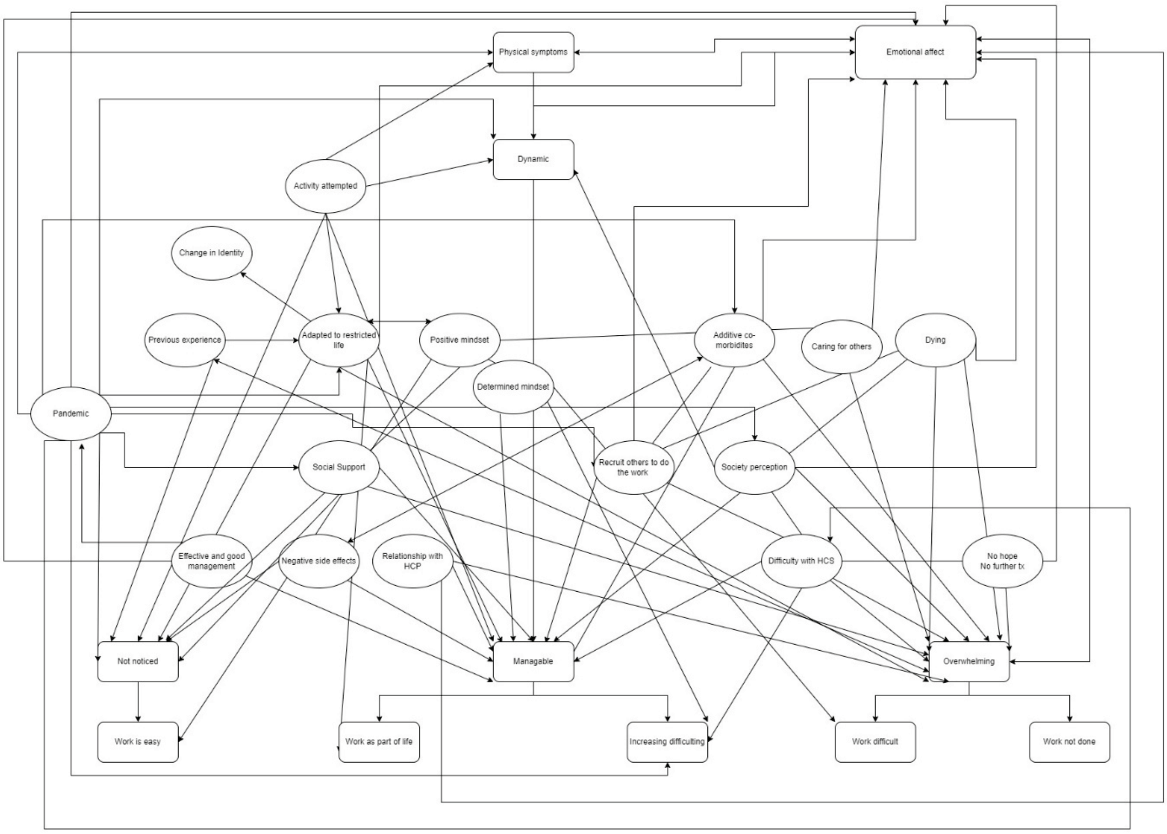

Figure 22: Overview of the relationship between symptoms and burden of treatment. Ellipses represent observed factors that appear to intervene on the relationship, rounded rectangles represent symptoms or their emotional affect (top of the diagram) and how the BoT was perceived by participants (bottom of diagram). HCP: health care professional, HCS: health care system.

The intervening factors were considered carefully against the previously identified intervening factors (Chapter 7) and a simplified model was drawn (Figure 23: Model of how chronic heart failure symptoms interact with illness and treatment work. HCS: health care system.).

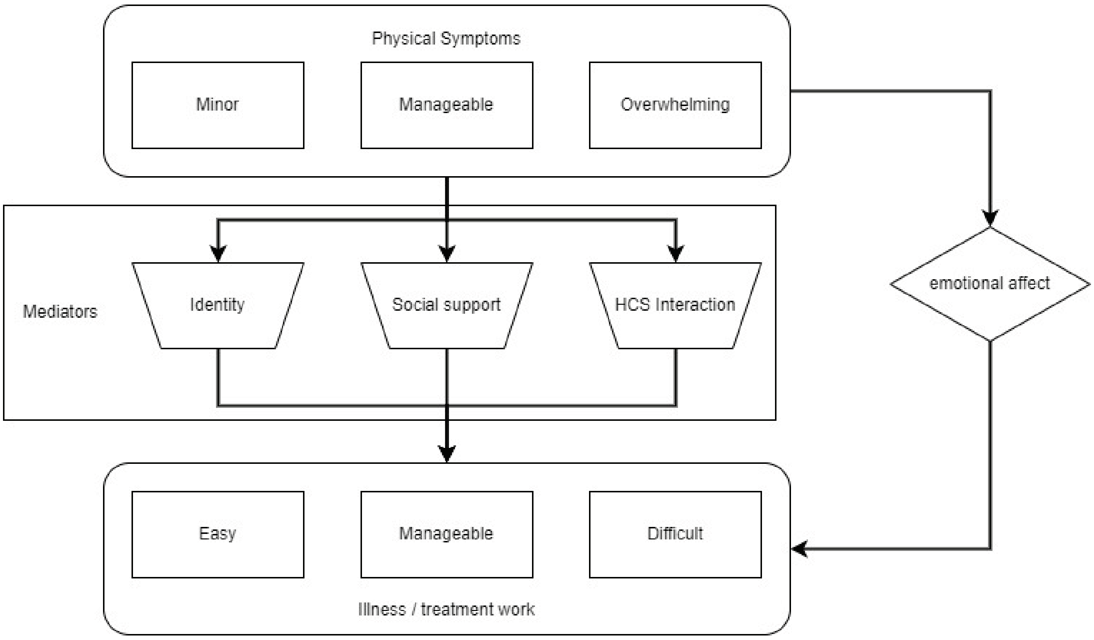

Figure 23: Model of how chronic heart failure symptoms interact with illness and treatment work. HCS: health care system.

The model in Figure 23 was then integrated with the models developed throughout the research project (figures 10, 13, and 16) to inform and refine the CHF specific BoT theory.

Appendix K Case studies to inform patient typologies

Presented here are case studies as exemplars representing the evidence from both the survey data and the interview data in SYMPACT which informed the patient typology as outputs of the CHF specific BoT theory. *Survey results are presented in italics* and interpretations, summaries and quotes from interview data are in normal type font.

K.1 L016: Low symptoms, Low Burden (Asymmetric)

L016 is a white British male, 79 years of age who lives with his wife. At the time of survey completion, he had lived with CHF between 6 - 12 months. His CHF type was HFrEF and at his most recent echocardiogram, his LVEF was recorded as 8%. He has four health issues and is on eight medications.

Symptoms: HFSS 1/10, MLHFQ physical score 9/40, emotional score 5/25

During the interview described how symptoms were a part of his life but described how he adapted life to live within those limitations and passes most work to his family (wife or sons). It may be that he reported low symptoms due to the self-imposed limitations from his symptoms. His journey to diagnosis took a long time. By the time he was seen by a cardiology specialist, his LVEF was dramatically low (8%). He was rapidly implemented on pharmaceutical and device treatments for his CHF, improving his symptoms dramatically. It may be that in thinking about current symptoms he compares them to the beginning of his illness journey when things were a lot worse; therefore, in comparison, current troublesome symptoms are not considered severe. Alternatively, the adaptions he made to his life-limiting activities which are an impetus for symptoms may also mean that when reporting symptoms, he thinks of his typical day which is fairly symptom free. Together these experiences informed his illness identity where he appears to have accepted CHF as a part of his life. This does not mean that he has no symptoms, but that he has adapted his life to life in a way where he does not risk symptom flare-ups.

> "Generally speaking, I can do most things. Um I think the one area that probably I don't do, so I-I find strangely enough lifting objects large objects, you know, um I don't do that now. Because I just, fortunately, I've got 2 sons-in-law who can lift anything (laughing), but you know it's just one of those things you- I'm used to now." L016

Recognising this meditating factor is clinically important as it means that patients who have adapted their life to match their illness may not recognise changes in symptoms due to the limited lifestyle CHR has enforced on them. Further, if they are constantly comparing to symptoms experienced during an existential crisis, they may overlook early signs of illness progression or CHF decompensation.

BoT: workload index 30/100, impact index 13/100, physical therapy and exercise 25/100, difficulty with healthcare services 43/100.

His journey to diagnosis was difficult, it took five trips to his GP surgery before being referred to a specialist. His treatment response was effective and in a relatively short time, he was discharged from specialist services. While he acknowledges that his cardiologist had advised him he could reach out at any time he described feeling torn as his trust in non-specialist services was shaky, but he also felt that the specialist services aren't available to him resulting in feeling abandoned. These experiences should lead to a picture with higher BoT, but he sought additional support through charitable support groups, and by participating in research studies. He described how while those research studies meant more work (long drives) it also meant he received additional checks and time with specialist healthcare professionals. He valued those interactions and it appears that this meant he felt those specialist healthcare interactions enriched his life and were not burdensome despite the additional time, energy, and money they cost.

> "I think um but it's interesting because I've been involved in this research program at the [large heart hospital] I've been getting those checks. I don't think I would've got them otherwise… I've um… had long discussions with the research doctor there who, um was exceptionally good, um but also has the time. And I think you know what it is- is like a lot of things in um you know is- is so important and you know he's sat and talking to me for some time where I- I would never get that with my consultant or my GP um… Absolutely I do and to be honest, if the research doctor said to me, 'do you want to come up and see me every six months I would have done so!" (L016)

His burden score might be lower as he has felt the benefit from effective care overall, despite the difficulties along the way. The high value he placed on regular monitoring has meant that he volunteered for research studies far from his home increasing his treatment workload, but as it was seen to enrich his life (assigned a high value), he did not report it as burdensome. He might be more at risk as when the research study ends, he will find himself bereft of the clinical monitoring he values highly, leading to feeling a loss as to who to seek if his condition worsens as he was discharged from the local specialist team and has lost trust in the primary care services.

Clinically considering the value assigned to healthcare interactions by patients is a key factor in both their perception of symptoms and BoT. Being discharged from heart failure specialist care services is common practice in CHF care based on current guidelines and the overwhelming patient demand. However, multiple interviewees shared how while the healthcare professional entered into these conversations in a kind and considerate way, patients all described feeling bereft this was compounded if their relationship with primary care services was shaky due to previous negative experiences or changes in healthcare services due to the pandemic.

> "Sorry I love the NHS, No, it is the GPs. Now it is so difficult to, to… Speak to anyone or do anything you know? And when you do get there, it's, you know, you get to see it or speak to a doctor on the telephone. Then it's or wait two weeks for a blood test and it could be. I mean, I think the last three times I had a doctor's appointment. It's been up to five weeks, so you know if I've got (chuckles) I've got swollen ankles. I think you know I'm concerned about it and I have to say to myself, 'I am gonna be this concerned about it in seven weeks' time?' Um, you know, it's probably gone away by then, so ... I would say if, say, for example, if my ankles particularly swollen up today, I would you know, I have some water tablets. I would take those, elevate, do the things I could do. See what happened. You know if, if in a fortnight's time you know they're getting bigger or whatever then maybe call the doctor, but if have to go through that system. Is probably worse for my health and then what's going on? It's just the stress of it, you know … It's like I'm cast out to sea, but without a radio, if you like." (B001)

More research is needed to better understand how to avoid these situations, but until then as clinicians remember clinical interactions are important to patients and the tone of that interaction may alter the patient's view on the accessibility of healthcare services leading to delays in seeking treatment.

K.2 L015: Low symptoms, High Burden (Asymmetric)

L015 is a white British female, 59 years of age who is divorced and lives on her own. At the time of survey completion, she had lived with CHF for between 6-12months. Her CHF type is HFrEF. At her most recent echocardiogram, LVEF was 30%. She has five health issues and is on eight medications.

Symptoms: HFSS 4/10, MLHFQ physical score 24/40, emotional score 18/25

She rated her physical symptoms as low to moderate despite living a life where her illness and the treatments (CRT-D) have stripped her of her career, her ability to drive, and elements of her family role. She is still recovering from her cardiac arrest and ITU admission, remaining on sick leave due to the ongoing debilitating symptoms. The fact she required cardio-pulmonary resuscitation (CPR) and a stay in the intensive therapies unit (ITU) has given her a different perspective where in comparison to the near-death experience her current symptoms may be perceived as less significant despite having to limit her activities.

> “I mean like- my life is no worse than anyone else who’s got heart failure. As I say we all experience it differently. And (pause) some people are probably much worse than me, I mean I know there are people who have to walk with oxygen attached.” (L015)

Her previous life experiences with illness and her job as a carer and bereavement counsellor widened her personal viewpoint of what being sick meant. She may be rating her symptoms as lower due to her context and her brush with death. This is important clinically for the same reasons as we already discussed in the L016 case study. Importantly L015 also carries a substantial emotional affect from the limitations imposed by illness, which spoke frequently of in her interview. Her questionnaire scores may be lower than others in a similar situation to her; as she discussed in the interview how her knowledge and skills helped her to access appropriate help and utilise techniques to alleviate that emotional burden.

> “I’ve got lots of strategies that I’ll use and one of them is to talk to myself in the mirror and tell myself to get myself in gear and that sort of thing (laughs). So yes … And again with the GP um I’ve been lucky with them, you can imagine with Covid how hard that things have been. I’ve had a couple of telephone consultations and then she wants me to go in for blood tests to make sure that things are okay with my labs and that is when we had a nice long chat. And again, with her, I know they don’t have the time… and um bless her she was runnin’ round like a headless chicken, but she sat down and she gave me her full attention and we discussed it. And she suggested [name of counselling service] and I told her that I didn’t feel that what I’d had was useful and so she’s given me another one to try, which I haven’t tried yet, I have to be honest, but um… when I’m in the right place I think I’ll phone them up and have a catch up with them.” (L015)

Clinically symptoms of CHF need to be evaluated for signs of treatment response and decompensation events, but CHF symptoms affect patients more than just in pathophysiology. The emotional affect of symptoms together with atypical CHF symptoms need equal consideration in clinical evaluations to better understand the full effect of CHF illness.

BoT: workload index 32/100, impact index 85/100, difficulty with healthcare services 38/100.

In describing the self-care work for CHF, she describes healthcare interactions which meant she felt well looked after, where her specialist CHF team gave her extra time in consultations and performed detailed investigations to support her physical and emotional health. Despite the ease of this self-care work described in the interview and matched by the workload index score. The impact score suggests that this work is not as easy for her. In the interview, she describes a life stolen by the sudden cardiac arrest and resultant CHF. She is emotionally hurt, and her treatments and symptoms continue to damage her. Her symptoms and her CRT-D have taken a large part of who she was; her job, her role as grandma, and her ability to drive. There is a disjunct between how she reported her symptoms (low scores) to how she reported the burden associated with engaging with the self-care work (high impact index score). This was reflected in the interview where her illness identity could be placed between acceptance and rejection may mean she discounts her symptoms but is frustrated and grieving over the loss of who she was resulting in a high burden attributed to doing the self-care work.

> “I say, it’s things like, as I say, feeling guilty about it and people say to me you can’t feel guilty about it, cause you can’t help it. And I know that, but the fact that it put him in that position he is now, and the fact I haven’t got a car. I can’t just get in the car and drive, get away from things. And I used to you know take the dogs for walks and we’d walk bloody miles. Um… (pause) and sometimes it isn’t until you sit and think about it – I try not to- cause then you realise how much you’ve, or I- I’ve realised how much my life has changed. And um… there is nothing REALLY, I can do about that. You know. And that is the biggest thing so…frustrating.” (L015)

While her workload index score was easy she described multiple healthcare appointments, medications, and ongoing issues with her CRT-D which is a substantial amount of work. In the interview, she gave the impression of engaging in the work of self-care, but that impact index score comes at a very high cost (impact index of very difficult). Presents a paradox between her low scoring of symptoms but then rating the impact of her self-care work as extremely high due to the emotional and physical effects of those treatments. Thus, the lower symptom scores may be a function of her illness identity being informed by her survival of a near-death experience.

In a clinical consultation, she may underreport her physical symptoms and it is not typically for emotional health to be addressed unless a patient brings it up. This may lead her to suffer more from emotional distress which may impact on her sense of self and her perceived role. Using BoT, in clinical consultation, may help identify if/how a patient is struggling with the work of self-care. Even if they are finding the tasks easy, treatment burden goes beyond the completion of tasks and incorporates the impact of doing that work on personal biography. If the cost of doing the work of self-care is too costly then the patient may rationalise their non-adherence. Clinicians need to be aware of this possibility and help patients access the additional support structures which in the case of L015, she accessed independently due to her personal knowledge.

K.3 S104 High symptoms, low burden (Asymmetric)

S104 is a white British female, 87 years of age who is a widow living on her own. At the time of survey completion, she had lived with CHF between 3-5 years. Her CHF type is HFrEF. At her most recent echocardiogram, LVEF was 15-20%. She has eight health issues and is on eleven medications.

Symptoms: HFSS 6/10, MLHFQ physical score 40/40, emotional score 2/25

She described a life tormented by symptoms, swollen legs too sore to sleep too swollen to drive or walk. A life limited to her own home and her garden was ignored due to CHF symptoms.

> "I can't walk very far. I mean, some… by the end of the day it's as much that I can do to walk from room to room because I feel so tired." (S104)

These symptoms added to fatigue levels and limited her life so severely that her world was so narrowed that her activity was entirely described around CHF management. Clinically patients in this position may be either in an acute decompensation of CHF or they may be in the final palliative stages of the CHF. Healthcare interactions must be prioritised for these patients but as the case proceeds this is not as easy as it may sound.

BoT: workload index 46/100, impact index 37/100, difficulty with healthcare services 57/100, diet 56/100, physical therapy and exercise 33/100.

Those symptoms only equated to moderate difficulty in the PETS workload index. She described, in the interview, how it was no trouble at all to take her medications and she described how she self-monitored and appropriately responded to changes in her symptoms. For her, the burden of her self-care came when performing tasks which required accessing and coordinating care from healthcare services. She described calling a GP to wait through 11 other callers ahead of her only to be told there were no other available slots with the doctor and to try again tomorrow. When she finally secures an appointment, she is unable to leave her home without help. She is reliant on her daughter to take her to appointments. She often relies on her daughter to arrange her appointment as well as the difficulties she has with getting through complicated automated messaging services or waiting for a telephone cue leave her too frustrated to bother. Thus, she delegates all self-care work other than taking her medications and self-monitoring to her daughter.

> "But of course, somebody has to take the prescription in they won't take the order over the phone. So that's another journey someone's got to do… Well, my daughter does that, yes. She never complains I'll give her, her due there. But she must get fed up with

> always having to run me here, there, and everywhere because she, you know she's got work." (S104)

S104 case demonstrated how by recruiting family members some of the burden from self-care work is passed on. But that the burden, in her case, wasn't about medication management but about attending and arranging her healthcare interactions. She could very clearly communicate the correct clinical path that she needed given her symptoms, but this path was inaccessible and complex. Without the additional support of her daughter, this work wouldn't be performed likely leading to emergency readmission.

Clinically it is important to remember that patients who are admitted in acute decompensations of CHF may have done everything in their capability to manage their condition and may have even tried to appropriately seek help from healthcare services. But the current healthcare system with its complex and siloed care may prove too costly for their illness and limited personal capacity.

These are only brief case studies which showcase some of the possible interactions between symptoms and BoT through resultant patient types. Only asymmetric relationships were showcased as the symmetric relationship is straightforward. The CHF specific BOT theory provides a more detailed framework for how when assessing patients with CHF careful evaluation of their illness experience may highlight new ways to intervene. Subjective symptom assessment needs to go beyond checking for illness progression or decompensation events. How a patient perceives subjective CHF symptoms may offer hints as to their illness identity. In turn, illness identity might influence symptom perception, possibly meaning patients either under or over report subjective symptoms. Those same symptoms may also hold answers as to why patients don't appear to be engaging in self-care tasks as CHF. Further other comorbidities may be preventing them from engaging in the self-care tasks (e.g., arthritis limiting finger movement to pop medications from blister packs). BoT also appears to be influenced by the value that is placed on self-care tasks, if those tasks are seen as enriching or protecting their lives then patients may not rate them as burdensome. Care must be taken when assigning work to patients checking their capabilities and resources to accomplish the assigned work. Gaps between patients' capacity and their workload should be supported by accessing or signposting to other available support structures. The role of healthcare interactions, siloed healthcare services, and care pathways which can only offer support to the very sickest and most complex cases in CHF must be considered for contributions to creating an overwhelming burden of treatment.

Appendix L **Additional doctoral outputs**

Publications (not related to doctoral research)

- Austin, R.C. (2022) Nursing research making waves: co-winning the early investigator award 2021. *Br J Card Nurs,* early view,1-3. DOI: 10.12968/bjca.2022.0017 (302)

- Farquharson, B., Austin, R., Bernhardt, L., Whitehead, H., Barron, C., Damianopoulos, A., Campbell, G., Lawson, C., and Deaton, C. (2021) The lifecycle of the lesser spotted cardiac nurse researcher. *Br J Card Nurs,* 16(8), 1-9 DOI: 10.12968/bjca.2021.0086 (305)

- Austin, R. C., and Bueser, T. (2021) The BANCC research forum: championing cardiovascular nurse researchers. *Br J Card Nurs,* 16(1), 1-3 DOI: 10.12968/bjca.2020.0162 (306)

Posters

- Austin, R.C., Kalra, P.R., Schoonhoven, L., and May, C.R. How SYMptoms and management tasks in chronic heart failure imPACT on a person's life (SYMPACT): Mixed methods study protocol. University of Southampton Research conference, 2019.

- Austin, R.C., Schoonhoven, L., Richardson, A., Kalra, P.R., Husebø, M.L., May, C.R. International PhD Internship: Research observations from Norway. University of Southampton Clinical Academic Conference, 2020.

Presentations

- 2021: Panel: "Clinical Academic Pathways – How can we encourage more NMAHPSs to undertake doctoral study", Wessex Clinical Academic Conference
- 2021: "Surviving the COVID storm" Online webinar; Portsmouth Hospital's University NHS Trust, Cardiology Webinar.
- 2020: "Symptoms and BoT" Portsmouth Hospital's University NHS Trust, Cardiology Nurse Education
- 2019: "SYMPACT: How do symptoms and management tasks impact on a person's life" University of Southampton Clinical Academic Faculty presentation
- 2019: "SYMPACT" How do symptoms and management tasks impact on a person's life" community presentations to Gosport volunteer association, Age UK, and Community cardiology support group.
- 2019: "Clinical Academic" University of Portsmouth and Portsmouth Hospitals NHS Trust, Research Conference.

- 2019: “Specialist Research Nursing to Nurse Researcher” Clinical Research Network Wessex Conference
- 2019: “Is it really the patient’s fault” Portsmouth Hospitals NHS Trust, Grand round, co-presented with Dr Elena Cowan
- 2019: “Specialist Research Nurse to Nurse Researcher” presented to Health Sciences Faculty at University of Stavanger
- 2019: “Symptoms and Burden of Treatment” presented to PROHEALTH group at University of Stavanger
- 2019: “CDRF PhD in the UK presented to PhD students at University of Stavanger and faculty at Stord campus Western Norway University of Applied Sciences
- 2019: “UoS to UiS” Experience of PhD internship presented at University of Southampton Clinical Academic Conference
- 2019: “PPI in PhD” Portsmouth Hospitals NHS Trust, Research Festival
- 2018: “Thinking about Burden of Treatment in the context of Symptom Burden”, Burden of Treatment Seminar (#BIGBOT18), Southampton, UK.

Invited Lectures

- 2021: “I’m a clinical researcher… Ask me anything!” Online panel discussion hosted by Healthcare Professionals in Research Facebook group.
- 2021: “Building Clinical Academic Careers: lessons from a CDRF PhD, Wessex ARC Stakeholder Event
- 2018: “PPI in a PhD” Invited lecture at “Building Research Partnerships” a collaborative event between Portsmouth Health Trust and the NIHR (October)

Awards / Achievements

- 2021: British Society for Heart Failure Early Investigator award (First nurse to win, £100)
- 2021: British Association for Nurses in Cardiovascular Care (professional development award £250)
- 2020-2019: SYMPACT is the third highest recruiting study in cardiology in Wessex CRN
- 2019: Travel scholarship to University of Stavanger £3000
- 2018: Portsmouth Hospitals NHS Trust “Pride of Portsmouth” CEO award for involvement and leadership of patient research ambassador group

Peer review work

- "The GENICA Project: a prospective cohort of heart failure patients with a comprehensive ambulatory approach aiming better outcomes" for Therapeutic Advances in Cardiovascular Disease – *decision by journal unknown.*

- “Quality of life and disease experience in patient with heart failure with reduced ejection fraction in Spain: and Ethnographic study” for BMJ open – *final decision by journal accepted pending minor revisions.*
- “Deriving and validating a brief measure of treatment burden to assess person-centre healthcare quality in primary care: a multi-method study” for BMC Family Practice – *paper published*
- “Measuring body weight in the clinical setting – Important lesson for the clinician” ESC Heart failure – *decision by journal unknown*

Blogs

- “How I overcame my fears to win recognition for nurse research” (2022) Guest blog on NIHR Applied Research Collaboration Wessex. Available: https://www.arc-wx.nihr.ac.uk/news/how-i-overcame-my-fears-to-win-recognition-for-nurse-research/

- “Specialist Research Nurse and Clinical Doctoral Research Fellow.” (2020) Guest blog on NHS England and NHS Improvement SouthEast. Available: https://www.england.nhs.uk/south-east/2020/02/10/rosalynns-blog-specialist-research-nurse-and-clinical-doctoral-research-fellow/

Video Podcasts

- **“**PHU reviewing the evidence series: Clinical Academic” (2022) YouTube. Available: https://www.youtube.com/watch?v=x_ZUlsR7EF0&t=17s

- “PHU reviewing the evidence series: Medicine management” (2022) YouTube. Available: https://www.youtube.com/watch?v=NFcF3VklCYs

- “PHU reviewing the evidence series: Dementia” (2022) YouTube. Available: https://www.youtube.com/watch?v=e3YWXGVE6Ho

- “PHU reviewing the evidence series: Deconditioning” (2021) YouTube. Available: https://www.youtube.com/watch?v=GweR0Z6ze_k

Research council/forum memberships

- Chief Nurses Office Professional Shared Decision-Making Research Council (2020-present)
- British Association for Nurses in Cardiovascular Care Research Council (2021-present)

Mentorship outputs

- Poster: Hardy, H., Green, M., Morton, G., Kalra, P. R., Austin, R.C., Guha, K. Introduction of novel ambulatory heart failure service during the COVID-19 pandemic. *Submitted to BSH autumn conference 2021*.
- Paper: Green, M. A novel heart failure care pathway developed during the pandemic. *British Journal of Nursing (online)*, in press. Assisted with the editing of this paper.
- Poster: Green, M.G., Kalra, P.R., Morton, G., Guha, K., Austin, R.C. The introduction and delivery of a novel HF ambulatory clinic: During the first wave of the COVID pandemic. British Society of Heart Failure autumn meeting, 2020.

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