Cumulative Complexity: A qualitative analysis of patients' experiences of living with heart failure with preserved ejection fraction

Faye Forsyth, Thomas Blakeman, Jenni Burt, Carolyn A. Chew-Graham, Muhammad Hossain, Jonathan Mant, John Sharpley, Emma Sowden & Christi Deaton

Author	Position	Institution & Location
Faye Forsyth	Doctoral Student	Primary Care Unit, Department of Public Health & Primary Care, University of Cambridge, Cambridge UK
Jonathan Mant	Professor of Primary Care Research and Head of the Primary Care Unit	
Christi Deaton	Professor of Nursing	
Emma Sowden	Research Associate	Division of Nursing, Midwifery & Social Work, School of Health Sciences, University of Manchester, Manchester UK
Thomas Blakeman	Clinical Senior Lecturer in Primary Care	Division of Population Health, Health Services Research and Primary Care, School of Health Sciences, University of Manchester, Manchester UK
Muhammad Hossain	Research Fellow	Centre for Research in Public Health and Community Care (CRIPACC),
John Sharpley	Patient	NA
Carolyn A. Chew-Graham	Professor of General Practice Research	Faculty of Medicine and Health Sciences, Keele University, Keele, UK
Jenni Burt	Senior Social Scientist	The Healthcare Improvement Studies Institute, University of Cambridge, Cambridge, UK

Corresponding Author: Faye Forsyth, Clinical Nursing Research Group, Primary Care Unit, Department of Public Health & Primary Care, University of Cambridge, Cambridge UK. fc349@cam.ac.uk

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Abstract:

Aims: To investigate how Heart Failure with preserved Ejection Fraction, within the context of limited clinical services, impacts upon patients' lives.

Methods & Results: Secondary thematic analysis informed by the Cumulative Complexity Model (CCM), of interview transcripts from 77 people diagnosed with HFpEF and their carers. Four themes corresponding to the core concepts of workload, capacity, access and outcome described in the CCM were generated. Theme 1: Shouldering a Heavy Workload, described the many tasks expected of people living with HFpEF. Theme 2: The Multiple Threats to Capacity described how patients and carers strived to engage with this work, but were often faced with multiple threats such as symptoms and mobility limitations. Deficient Illness Identity (Theme 3) reflects how HFpEF either was not recognised or was perceived as a more benign form of HF and therefore afforded less importance or priority. These themes contributed to a range of negative physical, social and psychological outcomes and the perception of loss of control described in Theme 4: Spiraling Complexity.

Conclusions: The constellation of HFpEF, multimorbidity and aging creates many demands that people with HFpEF are expected to manage. Concurrently, the same syndromes threaten their ability to physically enact this work. Patients' recollections of their interactions with health professionals suggest there is widespread misunderstanding of HFpEF, which can prohibit access to care that could potentially reduce or prevent deterioration.

Novelty Box

- A plethora of qualitative research exploring the lived experience of heart failure (HF) exists, however studies have not interrogated whether there are differences by HF phenotype.
- This analysis demonstrates that whilst patients with HFpEF experience significant burdens, similar to those experienced by people with other forms of HF, they face extra challenges as a result of a deficient illness identity.
- Perceptions that HFpEF is a less significant form of HF appear to prohibit access to support that might alleviate burdens experienced and prevent the poor outcomes described by participants.
- Greater effort is needed to raise the profile of HFpEF and to realign services so that people with HFpEF receive support equivalent to those with other types of HF.

1.0 Introduction

Heart Failure with preserved Ejection Fraction (HFpEF) is associated with increased risk of morbidity and mortality, healthcare resource use and reduced quality of life (1). In the United Kingdom (UK), 920,000 people are estimated to have heart failure (HF) (2). Whilst the exact proportion with HFpEF remains unclear, extrapolation from epidemiological data suggests it accounts for 50% of diagnoses. Forecasters predict HFpEF will become the predominant form of HF (3); a recent analysis of real world data from a HF clinic in the UK indicates that in some places, this is already a reality (4).

Within the UK healthcare system, HFpEF poses a challenge due to under recognition (5, 6), diagnostic and management uncertainty (7, 8) and unequal service provision (9-11). Given this context, one might expect a plethora of research exploring the lived experience of HFpEF. However, our analysis of 63 qualitative studies included in five meta reviews if the HF experience (12-16), suggests otherwise (Supplementary Table A). Studies included participants with unspecified HF (n=46, 73%), Heart Failure with reduced Ejection Fraction (HFrEF) exclusively (n=13, 21%) or mixed HF samples with no evidence of data interrogation by HF sub-type (n=3, 5%).

To our knowledge, there are only four reports (7, 8, 17, 18) and two patient letters (19, 20) qualitatively exploring HFpEF. Whilst these studies provide some insight, description of the lived experience was not their intent. This paper reports findings from a secondary analysis of interviews conducted with patients with HFpEF and their carers, that aimed to investigate how HFpEF impacted upon people’s lives.

2.0 Methods

Findings are reported in line with the COREQ checklist (consolidated criteria for reporting qualitative research) (21). Anonymized transcripts from interviews (n=62) conducted with individuals with HFpEF (n=61, denoted a ‘P’) and their informal carers (n=16, denoted as ‘C’), collected as part of two previous studies (7, 18) were collated (Figure 1).

<Figure 1: Consort Style Flow Diagram>

2.1 Sample

Patients with a confirmed diagnosis of HFpEF and their nominated carers were recruited from three geographical areas in England. Four researchers, with experience in qualitative methodology, conducted interviews. Descriptive statistics of the sample are presented in Table 1.

<Table 1: Patient and Carer Characteristics>

2.2 Data Collection

Interviews, conducted either over the phone or face to face, were digitally recorded and transcribed verbatim. Topic guides, which can be viewed on the study website (https://www.optimisehfpef.phpc.cam.ac.uk/), did not change but were informed by concurrent analysis. Mean interview length was 59 minutes and all transcripts were checked against recordings for accuracy.

2.3 Ethical Considerations

Ethical approval was granted by the London–Surrey Research Ethics Committee (REC reference: 17/LO/2136) and Northeast-York Research Ethics Committee (REC reference: 17/NE/0199). All participants provided written informed consent.

2.4 Data Analysis

Regardless of the original study in which patients and carers were enrolled, they were prompted to reflect on their experiences of symptoms, the process of diagnosis and subsequent management. Transcripts were coded in NVivo 12 software by one author (FF). Multiple cycles of sorting and defining, in line with the phases of Thematic Analysis described by Braun and Clarke (22), were performed.

During the mapping phase (22), the relationships and interactions between codes were theorized. This process highlighted similarities with an extant model, the Cumulative Complexity Model (CCM) (23) (see Supplementary Figure 1). The CCM (23) is an evidence grounded model which emphasises the functional mechanisms of complexity at the level of the patient.

Central to the CCM is an interactional process between two concepts: patient workload (day to day tasks and responsibilities) and patient capacity (ability, resource and readiness) to address demands (23). Workload and capacity affect each other and affect healthcare access, use and enaction of treatment (23). The model proposes that imbalances in workload and capacity and barriers and facilitators to healthcare access, influence health outcomes in their own right. However, workload and capacity are further mediated through burden of illness (the effects of diseases including physical, psychological and socio-economic) and burden of treatment (demands placed on patients by healthcare systems) feedback loops (23).

The CCM offered both a lens and a framework through which to view, understand and explain the complex interactional nature of experiences and eventual causal process of deterioration frequently described in interviews. As such, inductively derived themes were deductively mapped to the core concepts described in the CCM.

2.5 Trustworthiness

Codes were verified by another author (CD) via comparison with themes from previous analyses and verification against transcripts. A patient advisor (JS), also contributed to codes, themes, theory application and drafts of the manuscript.

3.0 Results

Four themes corresponding to the core concepts of workload, capacity, access and outcome described in the CCM were generated: shouldering a heavy workload; multiple threats to capacity; deficient illness identity and spiraling complexity (Figure 2). Illustrative quotes are provided throughout, further extracts supporting the analytic points are available in Supplementary Table B.

<Figure 2: Themes framed within the Cumulative Complexity Model>

3.1 Shouldering a heavy workload

For patients with HFpEF and their carers, three sources of work were identified as most important: managing their HFpEF, managing multi-morbidity and syndromes associated with aging and dealing with the challenges of life (lifework). These components were interactional and could be competing or compounding.

3.1.1 Managing HFpEF

The main symptoms of HF, breathlessness, oedema and fatigue, were the manifestations of HFpEF as a condition that required active work. Participants engaged with this work as best as their capacity allowed, primarily by taking prescribed therapies despite significant repercussions on quality of life. Diuretic therapy, the cornerstone in symptomatic management of HFpEF, was associated with significant workload through medical pathways like renal function monitoring and titration, but also through consideration of timing in order to accommodate diuresis within daily routines. Many patients described diuretic therapy as disruptive and few people appeared to have been provided with the skills and knowledge to adapt or sync regimens to daily life, resulting in non-adherence or restricted movement.

> *"If you take them [diuretics] early in the morning you're worried about going out because…once you take them…then you can be peeing for England for up to 5 or 6 hours so if I had to tell what was the main imposition on my life since I got diagnosed it's really been the effect of the diuretics."* P045, female, 80 years

Participants described the self-care work they performed to limit further deterioration or improve the symptoms of HFpEF. This involved trying to remain active, eating healthily, being cognitively engaged and reacting to symptoms. For most, this was achieved through continued performance of routine tasks often articulated as 'keeping going' or 'not giving up'. Other described adaptations like 'pacing' which they employed to manage activity. Notably absent within this category were formal components of HF self-care like fluid restriction, daily weights, and flexible diuretic regimens.

> *"I'd do the washing up and then I'd get tired, so I'd sit down. I'd wait ten or fifteen minutes…and I'd be alright, you see what I mean and now more exertion …But, I do try to recognise the symptoms of when I'm doing too much, and then I stop."* P017, male, 67 years

3.1.2 Managing multimorbidity and aging

Managing comorbid conditions and syndromes associated with aging were identified as a second tier of factors creating work. Comorbidity was extensive and managed through similar concepts of self-care. However, they could be compounding (i.e. urinary incontinence was worsened by diuretic therapy), competing (i.e. acute infection taking priority over active management of HFpEF) or complicating (i.e. attributing symptoms to respiratory conditions). Hospitalisations related to co-morbid conditions were frequent and increased workload, whilst simultaneously reducing capacity through deconditioning.

> *"they say, you've got to keep mobile. I've got two new knees, which is nothing to do with my heart, but my mobility is limited somewhat. So, everything is sort of like, it's all a vicious circle.."* P001, male, 64 years

Multiple comorbid conditions were often accompanied by complex medication regimens that drove workload. The majority described polypharmacy which added to complexity and often resulted in negative effects such as potentially inappropriate medications or therapeutic competition.

> *"[my carer] said to me 'why don't you do a repeat prescription…well I can't because I never know how much insulin I'm going to need and I've got a box up there and I do all my tablets once a week...it takes me about half an hour, you have to be really quiet to make sure you put the right ones in the right thing."* Patient 041, female, 91 years

3.1.3 Lifework

Life's technicalities frequently affected workload or capacity to manage workload. Most participants were older adults who faced events associated with this stage of life like retirement, bereavement and care responsibilities. The majority of life events described affected capacity to perform work (grief causing depression), created new work that had to be accommodated (becoming a carer), affected ability to synchronize workload within daily routines (responsibilities preventing diuretic taking), or took precedence over health problems (prioritisation).

> *"I nursed my husband through Alzheimer's…And I couldn't go taking him to hospitals, and he wouldn't have coped…So I just said to the doctor, forget it [pursuing HFpEF diagnosis], put it on hold."* P006, female, 82 years

3.2 Multiple threats to capacity

Although multiple capacity components that disrupted normal life were identified, the subthemes of HFpEF symptomology, mobility limitations and fear were most prominent.

3.2.1 HFpEF symptomology

To undertake work like self-care, patients require a key resource: physical energy. HFpEF symptoms were described as core threats to this resource. Their presence meant that tasks took longer, were more difficult to achieve and often had repercussions; such as forcing the cessation of activities or compensatory rest days or causing low mood further affecting capacity.

> *"… I do get fed up, yes, because I can't do as much as I want to…its hard work doing my garden, which I do love doing. I can do about half an hour then I have to come in because I can't breathe".* P046, female, 78 years

3.2.2 Mobility limitations

Mobility was frequently highlighted as a regulator of capacity. Limited mobility affected engagement in activities previously enjoyed and complicated routine tasks like shopping and self-care. Mobility demands related to healthcare, often required mobilisation of significant practical, physical or financial resource.

> *"I've got to rely on somebody taking me [to the doctor]. I then have to use my wheelchair because it's on various levels and it's too far for me to walk. So yes, it's a bit of a nuisance."* P009, female, 82 years

3.2.3 Fear

The effects of HFpEF, aging and multi-morbidity jointly conspired to create fear. Fears were multiple including: exacerbation of symptoms, hospitalization, physical deterioration, loss of independence, falling, and fear of what other people might think if unable to control symptoms like breathlessness and urinary urgency. Fears affected capacity by reducing confidence and resilience to perform work (i.e. fear of falling preventing engagement in exercise) and function socially (i.e. reduced social engagement due to incontinence).

> *"sometimes I can get very anxious and then it takes my breath, that's what worries me more than anything because I've got nobody here if I collapsed… if I'm on the floor, how do I get to my phone. It's frightening.."* Patient 029, female, 80 years

3.3 Deficient illness identity

Whilst established barriers to healthcare access, utilisation and self-care were described (24-26); these were often secondary to a more important barrier: deficient illness identity. The term illness identity is varyingly defined and applied within medical literature. In this analysis, we drew on the definition coined by MacDonald *et al.* (27) whereby illness identity means "our shared understanding of the significance of an illness category". Our analysis would suggest that HFpEF carries less importance, significance and priority than other life-limiting conditions and even other forms of HF. Evidence that HFpEF lacks a coherent illness identity were organized under three sub-themes; misattribution, misconceptions and missed opportunities.

3.3.1 Misattribution

Participants described typical HF symptoms which were often misattributed by both themselves and clinicians to age or co-existing disease. Misattribution combined with a low index of clinical suspicion for HFpEF often resulted in repeat consulting, prolonged diagnostic processes and/or diagnosis post decompensation. Such processes would drive patient work and sometimes result in dilution of capacity (e.g. hospital associated deconditioning, worsening heart function) which was not always recovered.

> *"what's wrong with me? Why can't I get my breath? Because you're fat…So, I lose weight. I can't get my breath. It's multi-factorial. But I can't get my breath.*

> *You drink too much…So I cut down my drinking. I still can't get my breath. Do you want another tablet?"* P001, male, 64 years

3.3.2 Misconceptions

Once diagnosed, participants reported receiving information about HFpEF that was inaccurate. Clinical information provided in consultations affected patients' belief about HFpEF, often leading to two misinterpretations. The first, 'HFpEF is not that bad' signalled to patients that there is no need to worry or make changes. The second, 'nothing can be done' related to the perceived lack of treatment options in HFpEF. Non-treatment was often understood as lack of empathy, or lack of importance and sometimes undermined participants' legitimacy as a patient with a need for treatment.

> *"He [heart failure specialist nurse] said to me …you don't know how lucky you are because … normally your heart condition, although you do have heart failure… is not to such a degree that you would normally merit a heart failure nurse".* P051, male, 81 years

3.3.3 Missed opportunities

Participants provided rich descriptions of their health history which highlighted risk factors for HFpEF (e.g. hypertension, inactivity, obesity, diabetes). Early identification and aggressive management of risk factors could have prevented or delayed progression of HFpEF. Very few participants received specialist input from a multi-disciplinary HF service or referral to rehabilitation in line with guidelines (28, 29). Lack of access affected empowerment in terms of treatment, lifestyle change, self-care and access to other supportive services like social care, which could have improved outcomes. Many also reported needless work and limitations that could have been alleviated with appropriate support.

> *"I enquired was I eligible for it [cardiac rehabilitation] and somebody, and I don't know who, said they didn't think so…I didn't fit the criteria".* P059, female, 76 years

3.4 Spiralling complexity

The combination of a heavy workload and multiple capacity restraints driven by HFpEF, multi-morbidity and aging led to progressive dilution of quality of life and independence. Whilst patients articulated this loss of ability in a number of ways, it was categorized into two sub themes: physical, social and psychological decline; and loss of control. Interaction with healthcare services rarely resulted in improvement in either capacity or workload, and the lack of significance afforded to HFpEF meant that participants were unable to elicit and affect change which contributed to loss of ability.

3.4.1 Physical, social and psychological decline

When capacity and workload became imbalanced and there was limited support from clinical services, many patients reached what the CCM describes as a 'situational tipping point' (23). Once reached, capacity to perform work was so eroded it precipitated or exacerbated more vulnerabilities like depression, isolation, frailty, loss of engagement with friends, hobbies and the outdoor world.

> *"It's [HFpEF] affected everything...He was a man who had loads of hobbies… he had a workshop...and played golf and went away fishing for weekends. All that's gone."* C006, female, 72 years

3.4.2 Loss of control

Many patients described feeling ill-equipped or robbed of the power to make decisions about maintaining health. The majority did not recall being explicitly told of their HFpEF, what it meant to have HFpEF, how they can take responsibility or influence the trajectory of their HFpEF and what it might mean going forward. Conversely, those describing greater knowledge, self-care skills and agency reported a greater sense of control.

> *"Well, you can kind of plan or kind of adapt your life to know, or what's going to happen in the future, or how to avoid making things worse, or... Any information like that, surely it's going to help you adjust your life or not adjust your life to your condition."* P019, female, 61 years

4.0 Discussion

The overarching story of this group of participants and their carers is that of a constant struggle to negotiate the heavy workload imposed by HFpEF, co-morbidity and gerontological conditions in the context of multiple capacity restraints and systems of care not supportive of their condition. If burdens associated with patient work and capacity restraints were not ameliorated through active management or support, they carried a heavy cost, often resulting in loss of confidence, resilience or capacity to perform activities. In many cases, there were opportunities to intervene earlier, for example supporting access to cardiac rehabilitation or enabling flexible diuretic regimens, that could have potentially prevented a decline in function becoming a lost capacity. Misconceptions that HFpEF is a benign condition lacking evidence-based treatment meant that participants experienced inequality in accessing services, or received inaccurate messages on severity and potential management.

4.1 Comparison with previous research

Five meta-reviews have synthesized the literature on the HF experience (12-16). The search strategies included in these reviews focussed on the terms chronic HF and none parsed nor interrogated the impact of HF phenotype. However, as the characteristics of HF as a syndrome are similar across the phenotypes, these reviews offer the most relevant comparisons within existing literature.

Many concepts identified here are similar to those reported in previous reviews (12-16): the problems caused directly by HF symptoms and through management of symptoms (distress, reduced physical and social function); the downstream effects of changes driven by patient work (loss of identity, social isolation) and the requirement for support to cope with these changes. However, our analysis yields two novel insights. Firstly, HFpEF lacks a coherent illness identity which results in patients experiencing greater inequalities in care, over and above those reported by people with other forms of HF. Secondly, by applying an extent model, we are able to move beyond description to hypothesise how experiences translate to outcomes.

4.2 Implications for research and practice

Current healthcare provision, which should support patients by either improving capacity through active treatment or reducing treatment burden through self-care support, did not meet needs. As a result, outcomes reported tended to be poor, and patients felt powerless to affect change. Without escalated efforts to: 1) change misconceptions around the severity of HFpEF and 2) address management complacency so as to improve illness and treatment burden; outcomes will undoubtedly remain poor.

4.3 Changing misconceptions about HFpEF

HF in the context of a preserved ejection fraction should not be understood as a less severe, age-related condition, with a better prognosis as was described here and by others (7, 8, 26, 30-32). Prevailing evidence overwhelmingly suggests otherwise. Mortality risk, including sudden cardiac death (33) and (re)hospitalisation is high and quality of life is low (1, 3, 34), resulting in substantial healthcare cost (35).

The overall picture is that of a life-limiting disease with significant individual and societal ramifications, comparable to other forms of HF and thus deserving equal concern. It is unclear how and why misinformation has arisen although changing terminology and diagnostic criteria, professional scepticism and perceived lack of therapies may have contributed (7, 26, 36, 37). Focusing on barriers to diagnosis and management can help identify structural issues and Hancock *et al.* (26) and Sowden *et al.* (10), have highlighted pertinent targets. Given that much of clinical practice is driven by guidelines, reframing and giving equal weight to HFpEF within these would be a useful start that may prompt re-organisation of care so that it is more inclusive of HFpEF. Current systems appear to be organised around HFrEF, often unfairly excluding patients with HFpEF (38, 39).

4.4 Improving capacity and workload burdens

It is unlikely a clinician would advise a patient with clinically manifest HF and an ejection fraction <40% that there is ‘nothing we can do’. Equally this statement should not be made in HFpEF for there are therapeutic interventions with proven efficacy. Physical activity interventions are highly efficacious; successive systematic reviews (40-43) describe important improvements in physical capacity and quality of life (43-45). A recent rehabilitation focussed intervention demonstrates that even in the most physically compromised, capacity gains are possible (46).

Clinical trials of therapies which have returned significant morbidity and mortality benefits in HFrEF, have not delivered convincing results in HFpEF. A perceived lack of therapies is postulated as an explanation for clinical inertia (36). However, a recent trial of Sodium–glucose cotransporter 2 inhibitors reported a significantly reduced combined risk of cardiovascular death or hospitalization for HFpEF (47). A growing body of secondary analyses have demonstrated the potential benefit of 'failed' drugs. Post-hoc (48), meta-analyses (49, 50) and cohort studies (51) consistently show that aldosterone antagonists can reverse adverse cardiac remodelling and reduce mortality and hospitalisation in some patients with HFpEF. New analyses of the effects of the angiotensin receptor–neprilysin inhibitor, sacubitril–valsartan, which narrowly missed the primary endpoint in the principle trial (52), have also shown potential benefit, particularly in women (53, 54).

Previous reviews of the HF experience (13-16) highlight patients' engagement in coping and self-care strategies as a means to manage and/or reduce the impacts of HF. Types of coping strategies included sharing experiences and burden, being flexible to changing circumstances, engaging in self-care, and adjusting, accepting or making sense of HF (13-16). Whilst some of these strategies, particularly generic strategies like slowing down, were echoed in the accounts of HFpEF participants, many were absent. Patients often could not share their experiences due to deficiencies in illness identity that surround the condition. Moreover, there were multiple examples of unnecessary tolls on life which could have been alleviated through appropriate guidance in self-care (55).

This study involved a large sample of patients with HFpEF and presents a new, theoretically underpinned, understanding of the patient experience that moves beyond description. Previous qualitative explorations have openly acknowledged interpretative constraints through limited integration of theory (16).

However, it is important to acknowledge that only a small number of carers were included in the study and that the sample is limited geographically to one country within the UK (England), which operates a system of free universal healthcare. Findings may not be transferable to other settings operating different systems of care.

Some have argued secondary analyses are inherently less valid as the analysis is removed from its original context (56). However, the studies from which the sample was drawn explored experiences and the analysis included researchers involved in the original research, minimizing this shortcoming.

Lastly, whilst we believe that applying the CCM (23) as an analytic lens and framework has strengthened this analysis, it could have constrained findings by forcing data into already established constructs.

5.0 Conclusions

Exploring the HFpEF experience through the lens of the CCM enables generation of an explanatory model of decline in HFpEF whereby a heavy workload and multiple threats to capacity beget a poor outcome, with neither potential targets (workload or capacity) being ameliorated though presentation at healthcare services. Whilst many similarities exist between the experiences of people with HFpEF and HFrEF, particularly around burdens relating to self-care and treatment, people with HFpEF appear to experience additional barriers to comprehensive care through deficient illness identity.

The visibility of HFpEF must be elevated so that it is perceived as an illness carrying importance and understood as a condition worth diagnosing and actively treating. Clinicians must also work with patients to ensure that workload-capacity difficulties are identified and improved, so that patients have the physical and psychological capacity they need to prevent the cycle of decline described.

Conflicts of Interest: JM has done consultancy work for BMS/Pfizer and Omron. CD has consulted for Astra Zeneca. All other authors declare no conflicts of interest.

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Data Sharing Agreement: Much of the data has been included with the supplementary material, additional data will be made available upon reasonable request.

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Figures & Tables:

Table 1: Patient characteristics

Patient Characteristics (n=61)	
Age (mean)	66.6 years
Female Gender n(%)	29 (47)
Ethnicity White British n(%)	59 (97)
Carer Characteristics (n=16)	
Age (mean)	53.5 years
Female Gender n(%)	12 (70)
Ethnicity White British n(%)	16 (94)

Figure 1 – Consort Style flow Diagram

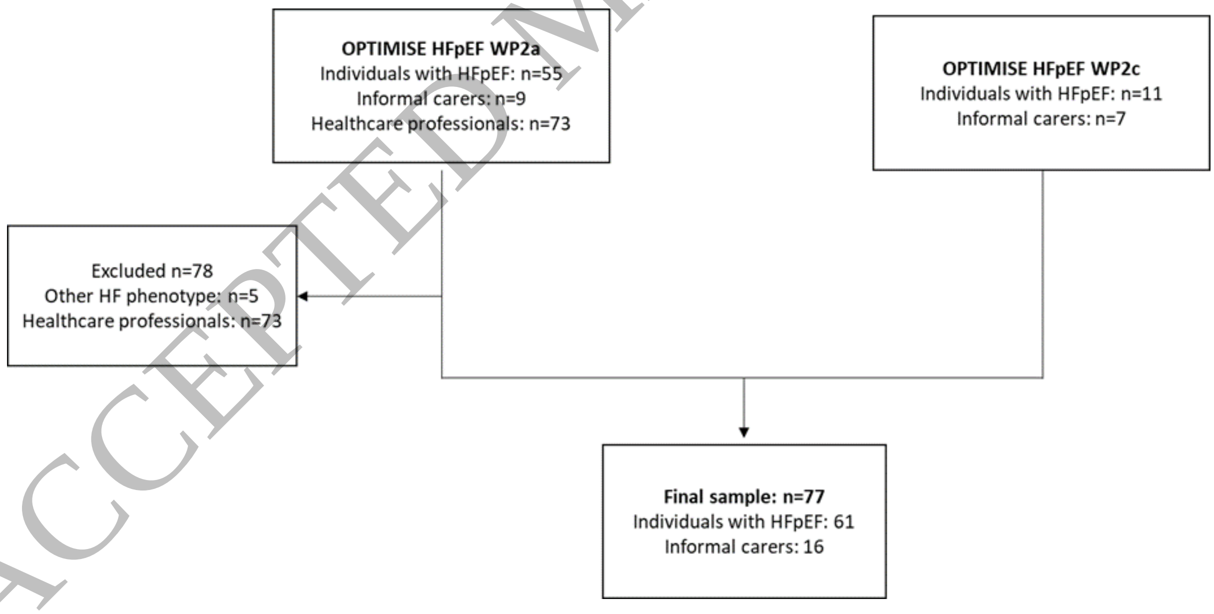
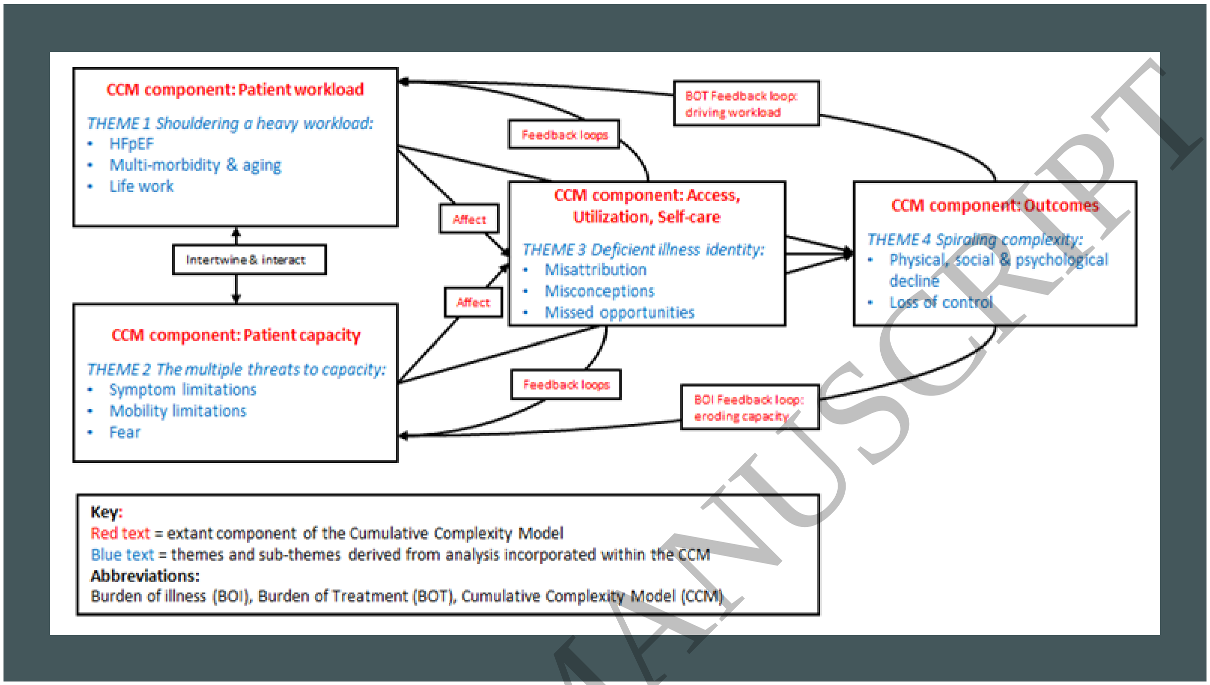
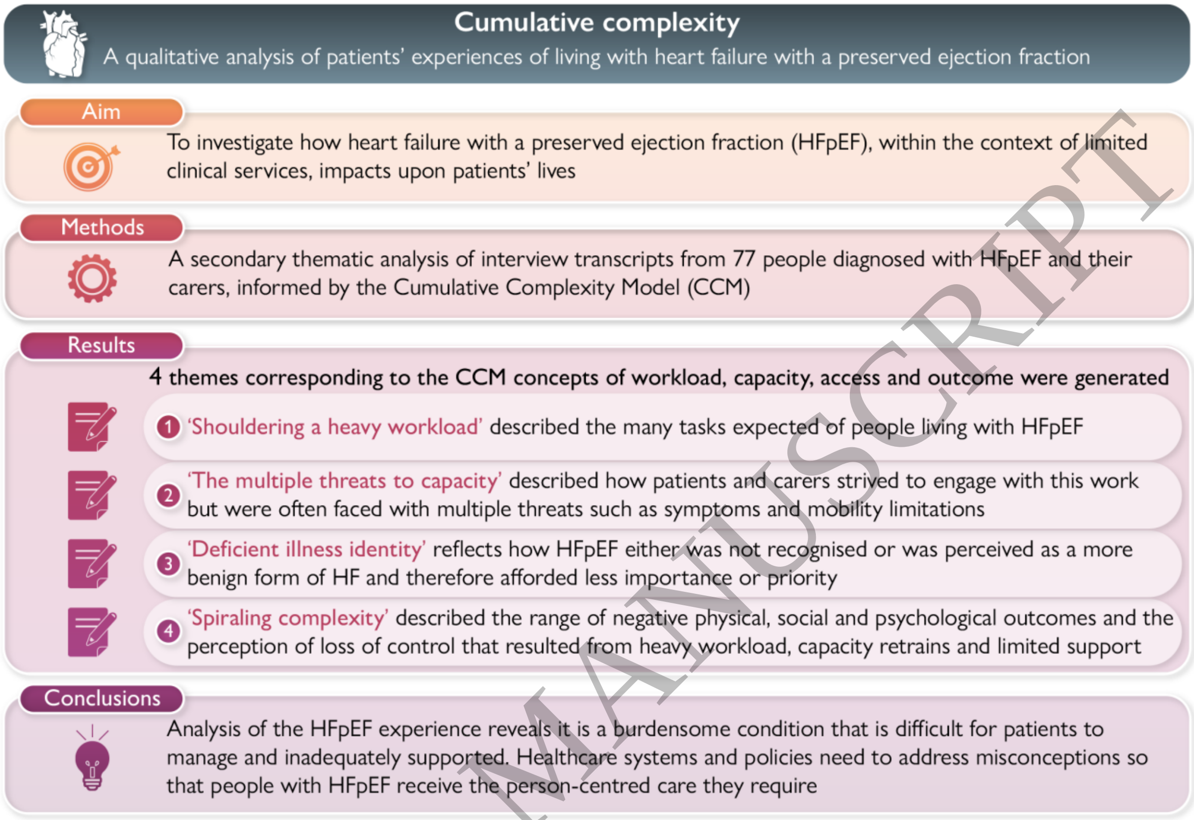


Figure 2: Themes framed within the Cumulative Complexity Model





Cumulative complexity

A qualitative analysis of patients' experiences of living with heart failure with a preserved ejection fraction

Aim

To investigate how heart failure with a preserved ejection fraction (HFpEF), within the context of limited clinical services, impacts upon patients' lives

Methods

A secondary thematic analysis of interview transcripts from 77 people diagnosed with HFpEF and their carers, informed by the Cumulative Complexity Model (CCM)

Results

4 themes corresponding to the CCM concepts of workload, capacity, access and outcome were generated

① 'Shouldering a heavy workload' described the many tasks expected of people living with HFpEF

② 'The multiple threats to capacity' described how patients and carers strived to engage with this work but were often faced with multiple threats such as symptoms and mobility limitations

③ 'Deficient illness identity' reflects how HFpEF either was not recognised or was perceived as a more benign form of HF and therefore afforded less importance or priority

④ 'Spiraling complexity' described the range of negative physical, social and psychological outcomes and the perception of loss of control that resulted from heavy workload, capacity retrains and limited support

Conclusions

Analysis of the HFpEF experience reveals it is a burdensome condition that is difficult for patients to manage and inadequately supported. Healthcare systems and policies need to address misconceptions so that people with HFpEF receive the person-centred care they require

Graphical Absract
159x111 mm (x DPI)