

**Understanding the management of Heart Failure with
Preserved Ejection Fraction: a qualitative multi-perspective
study**

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Understanding the management of Heart Failure with Preserved Ejection Fraction: a qualitative multi-perspective study

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About half of all people with Heart Failure have a type called Heart Failure with Preserved Ejection Fraction (HFpEF), in which the heart is stiff. This type is more common in older people with a history of hypertension, obesity, and diabetes mellitus. Patients with HFpEF are often managed in primary care, sometimes in collaboration with specialists. Knowledge about how best to manage this growing population is limited, and there is a pressing need to improve care for these patients.

Aim

To explore clinician and patient/carer perspectives and experiences surrounding the management of HFpEF to inform the development of an improved model of care.

Design & Setting

A multi-perspective qualitative study involving primary and secondary care settings across the East of England, Greater Manchester, and the West Midlands.

Methods

Semi-structured interviews and focus groups were conducted. Transcribed data were analysed using Framework analysis and informed by the Normalisation Process Theory (NPT).

Results

Fifty patients, nine carers/relatives and 73 clinicians were recruited. Difficulties with diagnosis, unclear illness perceptions, and management disparity were identified as important factors that may influence management of this condition. The NPT construct of coherence reflected what participants expressed about the need to improve the identification, understanding, and awareness of this condition in order to improve care.

Conclusion

There is a pressing need to raise the public and clinical profile of this condition, develop a clear set of accepted practices concerning its management and ensure systems of care are accessible and attuned to the needs of patients with HFpEF.

How this fits in

A type of Heart Failure called Heart Failure with Preserved Ejection Fraction is more common in older people with multiple long-term conditions. Although it is increasing in prevalence, it lacks evidence-based treatments. Research is needed to understand how to improve the management of this patient population. Our study aimed to develop a detailed understanding of the perspectives of patients (including some relatives/carers) as well as primary and secondary care clinicians to inform the development of an improved model of care. This study found there were difficulties surrounding the timely identification of HFpEF and a widespread lack of understanding and awareness of this condition, which had the potential to influence approaches to management. This study makes recommendations about the need to raise public and clinical awareness of HFpEF and develop a clear set of accepted practices concerning management.

INTRODUCTION

Heart failure (HF) is a complex syndrome that poses an increasing burden on health care resources and has a significant impact on individuals’ quality of life (1, 2). The current clinical classification system used to determine management options for HF involves a distinction between patients with reduced ($\leq 40\%$) left ventricular ejection fraction (HFrEF) and preserved ($\geq 50\%$) left ventricular ejection fraction (HFpEF) (3, 4). Patients with HFpEF are generally older, more frequently female, and have increased incidence of comorbidities such as hypertension, diabetes mellitus, and obesity (5). Defining HFpEF has been controversial, emerging over three decades ago with the label diastolic HF or ‘stiff heart syndrome’; only recently has it been convincingly demonstrated to exist as a condition in its own right (6, 7).

Despite therapeutic advances in treating patients with reduced ejection fraction, evidence-based pharmacological approaches for HFpEF remain minimal; diuretics are linked to an improvement in quality of life, but no drug treatments have shown to reduce mortality and morbidity (8). Although management of underlying comorbid conditions, such as hypertension, diabetes and obesity, benefit patients with HFpEF, there are few data specifically related to programmes of management for this condition (9).

In line with the focus on how care can be better integrated and centred on the needs of people living with long-term conditions (10, 11), it is recommended that HF management should provide ‘seamless’ care encompassing self-management strategies, supported by a multidisciplinary team of professionals across primary and specialist care (4, 12-14). However, the optimal structure of integrated care remains unclear, and a persistent gap between guidelines and current practice exists (15-18). Within this growing and complex population, in which multimorbidity and older age are the norm, primary care might undertake a pivotal role in addressing the unmet clinical need for new strategies to improve quality of life and outcomes (19, 20). This study aimed to explore the perspectives of patients/carers and clinicians from primary and secondary care settings to provide an understanding of how this group can be better managed. It will inform a larger programme of work to optimise management of HFpEF in primary care (21).

METHOD

Study Design and Setting

This study used a qualitative multi-perspective design in which viewpoints of patients with HFpEF (including carers/relatives) and clinicians involved in managing their care were collected separately and triangulated using Framework analysis. This approach was chosen to capture the multidisciplinary nature of HF care (4), generating a deeper understanding of needs and experiences than can be achieved through a single perspective approach (22, 23). All participants were given the option to participate in semi-structured, face-to-face or telephone interviews, to explore individual perspectives. Focus groups were also offered as an efficient means of collecting data from busy clinicians that, despite being more complex to interpret, can stimulate new insights through interaction (i.e. people reflecting and commenting on what others in the group say). A Patient Advisory Group (PAG) was involved throughout the research process. This study was undertaken and reported in line with the Standards for Reporting Qualitative Research (SRQR) (24).

Sampling and Recruitment

A purposive sampling strategy (25) aimed to ensure i) variability in age, gender, comorbidities in patient participants (depicted as P in data extracts) and ii) a range of organisational practices and clinicians involved in managing care (e.g., General Practitioners, Practice Nurses, HF Specialist Nurses and Cardiologists, depicted as GP, PN, HFSN, and C respectively in data extracts) (Table 2). Patients with diagnosed or suspected HFpEF were eligible for inclusion unless they were identified by the direct care team as having cognitive impairment, were non-English speaking, receiving end of life care, or had another life-threatening condition. Caregivers and relatives were interviewed as dyads when accompanying patients at the interview or at a patient's request (depicted as 'Carer of P' in data extracts). Research sites were identified across the East of England, Greater Manchester and West Midlands, with the support of the NIHR Clinical Research Network (LCRN). Recruitment was conducted between October 2017 and July 2019. Potential patient participants were recruited via participating GP practices and secondary care settings. They were invited to take part by a personalised GP letter or by their direct care team. Clinicians were invited via personalised email. Each participant received a recruitment pack. Recruitment concluded when increasing the sample size no longer contributed new evidence and the data collected sufficiently addressed the research aim (25).

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Data Collection

Separate topic guides for patients/carers and clinicians based on the aims of the research were used to generate data (Table 1). These guides allowed flexibility for the exploration of participants’ understanding and experience managing HFpEF to help identify potential barriers to care.

Interviews and focus groups were conducted by five of the authors, all of whom have training and experience in qualitative methods; two were non-clinicians and none had a prior relationship with participants. Written consent was obtained from all participants. Conversations were digitally recorded, transcribed verbatim, and checked for accuracy of transcription by a researcher before analysis. Reflexive notes were recorded by researchers throughout the process.

Data analysis

The analytical approach occurred in to two phases: first, framework analysis (25) was used to identify key patterns in the data relating to the research objective, and second, Normalisation Process Theory (NPT) was used to provide sensitising constructs to reframe and further interpret our findings and guide our recommendations (26). As this was an exploratory study, we recognised that applying a theoretical framework too early in the formal analytical process may impose preconceptions and assumptions on the data (25). Therefore, we stayed grounded in the data during the first phase of analysis, which involved iterative stages (see Supplementary Table S1). At regular team meetings (face-to-face and by telephone), joint coding and discussions about the coding and interpretations took place. Analytical themes were also reviewed by investigators from the wider research programme and a PAG to ensure findings were credible and confirmable. Patient and clinician frameworks were initially developed separately, but as the data were analysed iteratively during the charting and interpretation process, the coding frame was expanded, refined, and combined to identify key overarching barriers to the optimal care of patients with HFpEF (Table 3).

In the second phase, the explanatory model, NPT informed an evaluative view of the themes identified through framework analysis (Table 4). NPT has been used to review and evaluate the social organisation of healthcare from patients’ and clinicians’ perspectives (26). It comprises four interrelated generative mechanisms that correspond to work or implementation processes, which can influence how and why health care practices become embedded and sustained (i.e., normalised into everyday practice) (26, 27) (see Supplementary Table S2).

RESULTS

We recruited fifty patients, nine carers, and 73 clinicians (from 26 GP practices and 9 Hospitals from across 5 NHS Trusts) (Table 2). Mean patient interview length was 56 minutes. Interviews were conducted either face-to-face at the patient's home address (n= 38) or via telephone (n=12). All carers/relatives (n=9) took part in a joint face-to-face interview with the patient. Clinicians took part in either a face-to-face (n=42) or telephone interview (n=16) or one of two focus groups (n=15). Mean clinician interview length was 38 minutes, and the mean focus group length was 55 minutes.

Key themes

Framework analysis highlighted overarching tensions across patient/carers and clinician accounts in terms of how HFpEF is identified and understood. **These corresponded** to three main themes – diagnostic difficulty, **unclear** illness perceptions, management disparity (Table 3). **These themes were examined in relation to NPT processes, as summarised in Table 4, which together provide an evaluative view of our analysis.**

Diagnostic difficulty

For any practice to be 'normalised' into routine practice, there needs to be a clear understanding and differentiation between aspects of the illness, tests and treatments that are integral to 'sense-making work' - a key mechanism of NPT (see Supplementary Table S2). Three main factors were influential in preventing timely differentiation of HFpEF that had the potential to delay appropriate care: the challenge of the normal echo, variability in referral pathways and specialist input, and a convoluted pathway to diagnosis- the HFpEF maze

The challenge of the 'normal echo'

Some clinicians expressed concern that HFpEF may be overlooked in a system attuned to identifying patients with the more easily recognisable and understood HFrEF.

We seem to have a fixation on ejection fraction in this country, and if it's not abnormal then everything is happy doolally... (C-1)

GPs conveyed uncertainty about making sense of results, reporting a 'normal echo' (i.e., an echocardiogram showing a normal or near-normal ejection fraction), which could hinder a timely diagnosis.

I feel like the diagnosis probably comes later down the line because patients or clinicians are a bit thrown by 'oh they have a normal echo', or this doesn't quite fit... (GP-1)

Many GPs emphasised they were not trained to evaluate echo reports; they often relied on summaries or conclusions provided within it, which were viewed as variable in quality.

Variability in referral pathways and specialist input

A key challenge was getting the diagnosis correct; many clinicians indicated a need for specialist opinion.

...diagnosing reduced ejection fraction is hard; so then, diagnosing preserved ejection fraction is even harder, and I think that should be done by a specialist. (HFSN-1)

Referral practices varied; some involved routine specialist review, while others included triaging within a tier 2 community cardiology service or included a community direct access echocardiogram (echo). Findings showed the expedience of the direct access echo might be countered by delays caused by duplication within secondary care due to access and quality issues with community echos. Some specialists expressed concern over potential missed or inaccurate diagnoses with direct access echos without specialist review. GPs, in this situation, wanted more guidance about referral practices.

I think the HFpEF is hard because there just seems to be a lack of guidance about, I think particularly about who to refer (GP-7)

A convoluted pathway: the HFpEF maze

Patients' descriptions of their diagnoses frequently contrasted with the linear referral pathway of protocols and guidelines, instead conveying a convoluted, protracted series of hospital admissions or specialist visits. Patients reported feeling frustrated or concerned during delays in which their health typically deteriorated and required hospital admission.

...Well I kept going back to the doctor's and he kept sending me back to the clinics, and they all kept saying, no it's not me, and no it's not me... I was going from one

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3 *to the other, and one was saying it was the lungs, and the other one was saying, no*
4 *it's definitely the heart (P-13)*
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7 Clinicians also acknowledged that a patient's quest to reach a correct diagnosis could be lengthy,
8 involving the navigation of a complex system with numerous visits to multiple clinics.
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11 *...often people have been batted from, they've gone through a lot of different*
12 *clinics, and no-one's really given them a diagnosis... (C-1)*
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15 Patient and clinician accounts illustrated the incidental nature wherein heart problems became
16 visible, while individuals underwent interventions for other health complaints (e.g., elective surgery,
17 hospital admission with pneumonia). Analysis suggested that comorbidities, non-specific symptoms
18 (including no pain), and multifactorial breathlessness often resulted in a prolonged diagnostic
19 process.
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25 **Unclear illness perceptions**

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27 NPT suggests that communal and individual understanding about an illness is necessary to facilitate
28 optimal management. In this context, we viewed a lack of application or shared understanding of
29 the label of HFpEF across patient and clinician accounts as a potential barrier and one closely
30 interrelated with differentiation of this condition. Furthermore, the seeming complexity and lack of
31 clarity surrounding the condition appeared to hinder clinicians and patients acquiring an in-depth or
32 shared understanding of the condition.
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38 ***What's in a name?***

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40 Few patients were aware of the label of HFpEF (prior to participating in the study). Those that were
41 aware had been introduced to the term in secondary care or by HF specialists; these individuals were
42 often proactive in the process.
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46 *Well, I mostly did stuff myself and then asked some questions after my*
47 *pacemaker...it's only recent that I've understood it properly and it's something*
48 *which is called, well you know this- it's preserved ejection fraction isn't it? (P-14)*
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52 Many primary care clinicians were unfamiliar with the term HFpEF; it was not readily visible in
53 correspondence or patient records and was not viewed as being applied consistently. Some
54 expressed uncertainty whether this label represented a new classification.
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I understand it's slightly synonymous with diastolic dysfunction, isn't it?...I think it's an up and coming term but I don't think we really know very much about it at the moment... (GP-18)

Several clinicians indicated an awareness of professional scepticism with the label of HFpEF, and most expressed a need for more knowledge and understanding of this syndrome.

There are people in the heart failure world that don't believe in it as a diagnosis...
(C-5)

Many patients had partial or incomplete knowledge, which often related to existing cardiac comorbidities; few patients provided a clear understanding of their HF.

No they didn't say, they said I'd got coronary heart disease, and that was as far as it went, and I'd got the atrial fibrillation, and that was it ...I've never heard anybody refer to me as having heart failure. (P-21)

Some clinicians viewed the emotive term 'heart failure' as a barrier to full disclosure of diagnosis, leading to the use of euphemisms. Others felt HFpEF was more difficult to explain compared to HFrEF.

[It's] a challenge to try and explain [HFpEF] to patients, treatment feels a bit, sort of less clearly understood, less clearly targeted... (GP-9)

Specialists emphasised the importance of diagnostic awareness but highlighted this could be difficult, requiring significant time and relational investment.

...we will allow up to sort of 90 minutes to spend with the patient, so particularly those patients that have got a new diagnosis... (HFSN-Focus group)

While some patients accepted 'failure' was a negative term, they emphasised the importance of understanding and making sense of their diagnosis, and many expressed a desire to know more.

...one of the things which I find a big problem with the services you get from the hospital and the doctor, they don't tell you enough... (P-34)

Management Disparity

Findings from this study corresponded with the interrelated nature of the four generative mechanisms and constructs of NPT and suggest that optimal management of HEpEF presupposes a

high degree of coherence or sense-making work (Table 4). If clinicians and patients/carers are unclear about the differentiation of HFpEF or what the work around managing HFpEF involves, then deciding who does the work, how it is done and how the work is monitored becomes problematic.

Widespread management disparity represented by variability in service provision, uncertain roles and responsibilities and gaps in care could be understood in this context. In contrast, systems were more established and clinicians were more confident in the context of HFrEF, which was conveyed by some primary care clinicians as routine practice.

Ongoing communication problems across the primary-secondary interface and issues relating to continuity of care appeared to be heightened due to uncertainties surrounding the identification and management of HFpEF.

Variability in service provision

The analysis revealed a differential service by ejection fraction in terms of the allocation of resources and access to services, which was complicated further by the problem of a variable HF provision overall. HFpEF patients did not necessarily receive the same resources or opportunities as those with HFrEF, which was viewed as inequitable. Similarly, access to cardiac rehabilitation or exercise programmes was variable; other cardiac or pulmonary conditions appeared to be prioritised. This disparity was noted by primary care clinicians, who focused their responsibility on the incentivised identification and clinical management of patients with reduced ejection fraction.

...they [GPs] don't receive QOF [Quality Outcomes Framework] points or payments for that particular group of patients [patient with HFpEF] so I don't think we actively seek them out... (PN-4)

Some of these clinicians conveyed confidence in understanding, identifying, and treating patients with reduced ejection fraction. However, in the context of HFpEF, a sense of clinical inertia was conveyed within some patient and clinician accounts due to a lack of evidence-based practice and a feeling there was little that could be done.

...why bother to have a label when you can't do something about it? (GP-7)

I've never called him [GP] out or anything because to be honest with you. I don't think there's anything that he can do, there's nothing anybody can do, that's what they've told me. So that's what I've accepted. (P-13)

Uncertain roles and responsibilities

Primary care clinicians without a cardiology background were unclear how a HFpEF diagnosis influenced their clinical management of the patient's condition, stating they would treat these patients the same as those with left ventricular diastolic dysfunction (LVSD). Many lacked confidence and personal experience in managing this patient group and expressed a need for more education, clearer guidelines, and support from specialists.

I suppose it's new for a lot of us, it's new and there's lots of unknowns in terms of what we do and then how and what we communicate and not much official guidance or even support from secondary care. (GP-3)

Details of specific HF self-management support strategies were infrequent in patients' accounts. They were typically described as being provided by a specialist, yet were instrumental in ensuring individuals had some individual control over the day-to-day management of their HF in an increasingly stretched NHS.

...I think you need to have the ability to self-care, you can't rely on your GP for everything, and I think they're pretty overworked, to be honest with you... (P-11)

The data suggest patients with an incomplete understanding of their illness and treatment were more likely to misattribute HF symptoms to other causes or describe poor concordance with diuretics or delay seeking help.

One thing, I've got one medicine [diuretic] I don't understand why they give it to me. Because they've given me one of, for the urine, but I don't know, so this morning I never took it because I go all the time. (P-35)

GPs recognised the need to upskill but wanted to remain generalists who took a holistic view of the patient. Specialists were unclear how far their role should extend to other disciplines.

...it's very, it's time consuming because you basically are doing the work for I feel, tell me if I'm wrong, for some of the general medical consultants, and your GPs because they don't know what's going on... (HFSN-Focus group)

Limited capacity was conveyed as a barrier to the roles and responsibilities of generalists, specialists, and patients.

Gaps in care

Concerns about the **availability and access** of ongoing community management were expressed across patient and clinician accounts.

I think if I had to say my observation of the health service is lack of continuity of care... (P-44)

Several patients said they had not seen a specialist, and only a few spoke of direct access to HF services typically in the form of HFSN support. Without the addition of more resources or improved collaboration with specialist services, clinicians were uncertain of the feasibility of ongoing monitoring for these patients within primary care.

...you feel like when you're discharging them, you're discharging them into the unknown, whether the GP can manage to keep an eye on these people. (HFSN-7)

Analysis indicated the nature of follow-up in primary care was, in part, dependent on HFpEF being identified and understood as a diagnosis; otherwise, these individuals may only be seen in long-term reviews where HFpEF may not be visible or actively managed.

Every time I've been to the doctor since, nobody's spoken a word about my heart at all. It's either been about my knee or about my diabetes. (P-24)

Gaining timely access to GPs was often viewed as problematic; patients emphasised the value of relational continuity, something they felt was increasingly challenging to attain with resource constraints, larger practices, and transient GPs/locums. Patients who reported inadequate access to or poor relationships within primary care were likely to bypass it in favour of other services (e.g., Accident & Emergency Departments).

First, you've got to get through the wall of the receptionists you know, and then you've got if you're lucky you get one a fortnight in advance. Unless you sort of go there and collapse on the floor, and say, I think I better see a GP... what I did was, I took myself to the A&E... and before you've got to the GP, you're already back in the hospital anyway. (P-17)

GP access to specialist services was variable, yet viewed by clinicians as necessary to help avoid hospital admissions, ensure optimal **clinical** management, and incentivise primary care to take on more responsibility for long-term follow-up.

...it's just having that access really, that rapid access that's available and sadly, you know when things go wrong, I think, or potentially if they got an intervention by a specialist or got some advice from a specialist early, you can often avoid these kinds of sometimes very extreme outcomes... (GP-19)

Ongoing communication problems across the primary-secondary interface were reported, with a continuing need for more coordination, improved relationships, and an investment in unified IT systems. Patient and clinician accounts suggested communication problems were heightened in the management of HFpEF, often involving multiple specialities and lacking visibility, understanding, or consistent labelling of the condition. Reports conveyed a reliance on patients and family members to coordinate care, which was problematic when a clear understanding of their heart problem was lacking.

I think most of the time; the patient is quite happy being the coordinator in a way ...because often it's only the patient who knows who's involved. I mean we're terrible at communicating with each other. (Geriatrician-1)

Clinicians acknowledged this approach was not ideal and was increasingly problematic in an ageing population.

I think particularly in the elderly population you can't necessarily rely on, you know, that they've definitely picked up that they need their blood test and when or whatever... (GP-21)

DISCUSSION

Summary

This study drew on the perspectives of a range of clinicians and patients/carers from primary and secondary settings to understand how HFpEF can be better managed. Three interrelated themes were identified from the data as factors that may need to be considered to improve care for this patient group: diagnostic difficulty; unclear illness perceptions; and management disparity. The use of NPT enabled us to examine our findings within a robust generalizable theoretical framework to inform future intervention work (21) (Table 4).

Systems of care were not developed consistently or systematically to differentiate this condition compared to HFrEF. Clinicians and patients often portrayed the diagnostic process as problematic, complicated by non-specific symptoms, comorbidities and variability in service provision. Many

patients expressed limited understanding and awareness of the condition, and clinicians acknowledged professional scepticism and an educational need in this area. Unclear roles and responsibilities, and uncertainty about best practice could lead to a failure to initiate work around managing HFpEF. Integration of services and continuity of care were also more problematic in a context of uncertainty.

Strengths and limitations

The use of a large multi-sited triangulated data set promotes trustworthiness and transferability of the findings (24, 28). However, we recognise the potential benefits of drawing from wider stakeholder input beyond patients/carers and clinicians, such as managers, commissioners, charity representatives and public health scientists. Consequently, we are using wider stakeholder analysis for on-going consensus work informed by this study and linked to future intervention development (21). In terms of reflexivity, the research team was multidisciplinary, involving wider expert opinions and a PAG to help ensure assumptions were continually examined and that an applied focus was maintained (24, 29). Clinicians were recruited via the NIHR LCRN, which is likely to have access to more research-active individuals particularly interested in HFpEF research. This was potentially captured by the in-depth knowledge conveyed by participating specialists, despite acknowledging ongoing scepticism within the cardiology community.

Comparison with existing literature

Determining HF type is important for management options (30). Resonating with other studies, findings indicate HFpEF is not widely visible, understood, or diagnosed within primary care (16, 31). Variability in routes to a HF diagnosis has been noted previously (32); our study provides further insights into contributing factors. An incomplete patient understanding of the nature of their HF has been shown in other qualitative studies (33, 34). Our study focusing on the views and experiences of patients with HFpEF echoed this. An individual's ability to self-manage and play an active role in the coordination of their care is central to prevailing policies (10, 11, 13). However, being a 'self-manager' is dependent on having knowledge of the condition and access to appropriate services, both of which we found to be variable. Our research suggested patients with HFpEF want to receive a diagnosis, and many conveyed a desire for more information, a view supported by HF patient advocacy literature (35).

Some clinicians expressed concern about the balance between harms and benefits of diagnostic disclosure of a condition they lacked knowledge about and for which there is no HFpEF-specific pharmacological therapy. Working groups have likewise expressed concern about expanding

definitions of diseases by specialists and the need to ensure these definitions show a strong evidence of benefit (36, 37). A current opinion is that disease definitions need to be primary care-led and people-centred (38). Nonetheless, systematic identification of HFpEF is integral to improving the management of this population, and a patient’s awareness and understanding of their HF diagnosis is part of effective healthcare (13, 39).

Implications for research and practice

This study illustrates the uncertainty and variability surrounding the management of HFpEF. We suggest the NPT construct of coherence can help explain how a lack of shared understanding and identification of this condition had the potential to influence how care was enacted, coordinated, and appraised (Table 4). More work is required to raise the public and clinical profile of HFpEF, to ensure widespread differentiation and awareness of this condition. The development of a clear set of accepted practices that assimilate well-defined roles and responsibilities in its management also has the potential to improve care. Furthermore, equitable provision of services is required and the development of systems that improve access and integration across primary and secondary care settings. Consequently, there is a pressing need for the development of interventional research aimed at ensuring optimal practice underpinned by coherence, thus legitimising approaches to primary care management of this growing population. Continued collaboration of key stakeholders will be essential in the development and design of future interventions.

In summary, our analysis of multiple perspectives across three regions of England emphasises the importance of ensuring that systems of care are accessible and attuned to the needs of HFpEF patients, which must begin with clear differentiation, understanding and awareness of this condition and the development of interventional work to ensure optimised integrated management across healthcare settings.

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Ethical Approval

The study was approved by the Northeast York Research Ethics Committee (Reference 17/NE/0199).

Provenance

Freely submitted; externally peer-reviewed

Competing Interests

None declared

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Table 1 .Summary of interview topic guides

Patient topic guide	Sample questions
Aim - to explore patients'	
Understanding and experiences of living with HFpEF	<i>It would be helpful if you could talk me through how you came to find out you had a heart condition</i> <i>How would you describe your heart condition</i>
Views and experiences of managing their heart condition	<i>What things make managing your heart condition easier/harder?</i> <i>Can you tell me about any things that you do to look after your heart?</i>
Perceptions on care	<i>Can you tell me about how health professionals are involved in treating/managing your heart condition?</i>
Clinician topic guide	Sample questions
Aim - to explore clinicians'	
Understanding of their role and experience of supporting patients with HFpEF	<i>Can you tell me about patients with HFpEF in your service/practice</i> <i>Can you tell me about your role in the care of patients with HFpEF?</i>
Perceptions on how this patient group is managed	<i>Can you tell me about any challenges you have experienced (or anticipate) when providing services for this patient group?</i> <i>What are your experiences of interventions that seem to work in this patient population?</i>

[Full versions of topic guides available from the authors on request]

Table 2. Sample characteristics (patient and clinician participants)

Demographic	Category	n (%)
Patients (n=50)		
Gender	Female	23 (46)
	Male	27 (54)
Age (mean =76.5)	61-70 years	11 (22)
	71-80 years	14 (28)
	81-90	15 (30)
	90-100	1 (2)
	NK	9 (18)
Recruitment site	Primary Care	35 (70)
	Specialist HF Service	14 (28)
	Self-referral*	1 (2)
Clinicians (n=73)		
Gender	Female	41 (56)
	Male	32 (44)
Profession	GP (GP)	35 (48)
	Practice Nurse (PN)	8 (11)
	HF Specialist Nurse (HFSN)	14 (19)
	Cardiologist (C)	6 (8)
	Other Health professional (HP)	10 (14)

* Found our website and contacted us

Table 3. Barriers to the optimal care of patients with HFpEF

How is HFpEF:	Theme	Sub-themes
Identified	Diagnostic difficulty	The challenge of the 'normal echo.' Variability in referral pathways and specialist input A convoluted pathway - the HFpEF maze
Understood	Unclear illness perceptions:	What's in a name?
Managed	Management disparity	Variability in service provision Uncertain roles and responsibilities Gaps in care

Table 4. Factors influencing the achievement of Normalisation Process Theory (NPT)

Constructs

NPT Construct	Description	Barriers to achievement
<i>Coherence:</i> (Sense-making work)	The work of understanding ways of working or new practices	Lack of clear understanding & differentiation of HFpEF Professional scepticism Lack of visibility of HFpEF Variability in referral pathways & specialist input Diagnostic process not attuned to identifying HFpEF Lack of shared knowledge of specific tasks for HFpEF management e.g., clinical inertia/ lack of evidence-based practice. Uncertain roles & responsibilities in HFpEF care Lack of clear understanding of the implications of practices involved in HFpEF care
<i>Cognitive participation</i> (Relational work)	The work of engaging individuals/groups to engage in ways of working or new practices	Uncertainty about who to engage in HFpEF work stemming from a lack of <i>coherence</i> Uncertainty about what constitutes the right set of practices & the validity of these practices for HFpEF Lack of collective definition of the procedures required for optimal HFpEF care
<i>Collective action</i> (Operational work)	The work of implementing ways of working or new practices and providing the necessary resources and training to operationalize these	Failure to initiate work around managing HFpEF owing to lack of <i>coherence</i> Unclear undifferentiated treatment due to lack of <i>coherence</i> Educational need around HFpEF Missed opportunities for self-management, specialist review, or cardiac rehabilitation/activity programmes Unclear division of labour for HFpEF work Systems more attuned to practices for HFrEF, e.g., QOF, referral pathways, echo reports Inequitable & variable division of resources for HFpEF
<i>Reflexive monitoring</i> (Appraisal work)	The work of evaluating and monitoring ways of working or new practices	Variability/uncertainty about best practice & roles/responsibilities in long-term follow-up due to lack of <i>coherence</i> & inequitable HF provision Communication problems across primary & secondary interface Access & capacity limitations Systems more attuned to monitoring HFrEF or associated comorbid conditions

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Adapted from: May C, Rapley, T., Mair, F.S, et al. *Normalization Process Theory On-line Users’ Manual, Toolkit and NoMAD instrument*
2015 <http://www.normalizationprocess.org> NPT: 2020

For Review Only

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SUPPLEMENTARY MATERIAL

Supplementary Table 1. The analytic process

Definition	Purpose	Process
Stage 1 Familiarisation	To become fully acquainted with the data To identify what people are saying that is relevant to the research objective	Reading and re-reading transcripts & listening to audio files & checking accuracy & ambiguities Making handwritten notes on transcripts Reading field notes and making case summaries Identifying key ideas within individual accounts
Stage 2 Development of thematic framework	A formal system to manage and organise the data and to allow systematic and comprehensive coverage and comparison of the data-set	To compare and contrast data between and across cases Uploading of transcripts to qualitative data analysis software QSR NVivo 12 Grouping of data according to descriptive codes Analytical memo writing of key ideas Returning to stage 1 where necessary
Stage 3 Indexing and sorting the data	To identify dominant recurrent unifying ideas/concepts occurring across the data concerning the research objective	Applying thematic framework to the data Recode or refine dimensions of existing framework according to developing analytical insights Returning to stage 1 and 2 where necessary
Stage 4 Charting data	To summarize and display the data and to begin to distill overarching themes.	To create an excel spreadsheet based on the thematic framework To summarize the data within the spreadsheets maintaining links to original data Continue cross-examination of the data Returning to stage 1 and 2 where necessary
Stage 5 Describing and interpreting the data	To actively look for meaning in the data to explain key features and patterns found across the data set concerning the research objective To introduce theoretical concepts or theories in as far as they actually match the data	To identify overarching themes and sub-themes which convey across the data which relating to the research objective To draw on the wider literature to theoretically inform our findings our indings to inform our recommendations and conclusion

Adapted from: Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (2013). Qualitative research practice: A guide for social science students and researchers: sage.

Supplementary Table 2. Four generative mechanisms of Normalisation Process Theory

Construct	Description of construct	Sub-component	Description of sub-component
Coherence: sense-making work	The work of understanding new practices or ways of working	Differentiation	Understanding how a set of practices and their objects are different from each other
		Communal specification	Building a shared understanding of the aims, objectives, and expected benefits of a set of practices
		Individual specification	Understanding specific tasks and responsibilities around a set of practices
		Internalization	Understanding the value, benefits, and importance of a set of practices
Cognitive Participation: Relational work	The work of engaging individuals/groups to engage in ways of working or new practices	Initiation	Whether or not key participants are working to drive a set of practice forward
		Enrolment	Strategies used to engage sustained engagement in practices
		Legitimation	Believing involvement in a set of practices is right, and that they can make a valid contribution
		Activation	Collectively define the actions and procedures to sustain a practice
Collective action: Operational work	The work of implementing practices and providing the necessary resources and training to operationalize these	Interactional workability	Interactional work needed to operationalize a set of practices
		Relational Integration	Knowledge work needed to build accountability and maintain a set of practices
		Skillset workability	Allocation of work that underpins the division of labour around a set of practices
		Contextual integration	Management of a set of practices through the allocation of different resources and the execution of protocols and procedures
Reflexive Monitoring: Appraisal work	The work of evaluating and monitoring or ways of working or new practices	Systematization	Determine the effectiveness of a set of practices
		Communal appraisal	Evaluation of the worth of a set of practices
		Individual appraisal	Working experientially as individuals to appraise the effects of a set of practices
		Reconfiguration	Redefining procedures or modifying practices

Adapted from: 2015 Normalisation Process Theory Online Users' Manual, toolkit and NoMAD [<http://www.normalizationprocess.org>]