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Understanding the management of heart failure with preserved ejection fraction:

a qualitative multiperspective study

Abstract

Background

About half of all people with heart failure have heart failure with preserved ejection fraction (HFpEF), in which the heart is stiff. This type of heart failure 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 clinicians' and patients'/carers' perspectives and experiences about the management of HFpEF to inform the development of an improved model of care.

Design and setting

A multiperspective qualitative study involving primary and secondary care settings across the east of England, Greater Manchester, and the West Midlands.

Method

Semi-structured interviews and focus groups were conducted. Transcribed data were analysed using framework analysis and informed by the normalisation process theory (NPT).

Results

In total, 50 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 HFpEF. 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 HFpEF, develop a clear set of accepted practices concerning its management, and ensure that systems of care are accessible and attuned to the needs of patients with this condition.

Keywords

comorbidity; disease management; heart failure; normalisation process theory; qualitative research.

INTRODUCTION

Heart failure (HF) is a complex syndrome that poses an increasing burden on healthcare 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 those with preserved ($\geq 50\%$) left ventricular ejection fraction (HFpEF).^{3,4} Patients with HFpEF are generally older, more frequently female, and have an increased incidence of comorbidities such as hypertension, diabetes mellitus, and obesity.⁵ HFpEF was given the label diastolic HF or 'stiff heart syndrome' over three decades ago and 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 been 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 management of HF 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 In 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

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How this fits in

The type of heart failure called heart failure with preserved ejection fraction (HFpEF) 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 patients with the condition. This 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. The study found there were difficulties surrounding the timely identification of HFpEF and a widespread lack of understanding and awareness of the condition, which had the potential to influence approaches to management. There is a need to raise public and clinical awareness of HFpEF and develop a clear set of accepted practices concerning its management.

optimise management of HFpEF in primary care.²¹

METHOD

Study design and setting

This study used a qualitative multiperspective 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 (that is, by people reflecting and commenting on what others in the group say). A patient advisory group was involved throughout the research process. This study was undertaken and reported in line with the standards for reporting qualitative research.²⁴

Sampling and recruitment

A purposive sampling strategy²⁵ aimed to ensure: variability in age, sex, and comorbidities in patient participants; and a range of organisational practices and

clinicians involved in managing care (GPs, practice nurses, HF specialist nurses, and cardiologists). Patients with diagnosed or suspected HFpEF were eligible for inclusion unless they were identified by the direct care team as having cognitive impairment, being non-English speaking, receiving end-of-life care, or having another life-threatening condition. Caregivers and relatives were interviewed as dyads when accompanying patients at the interview or at a patient's request. Research sites were identified across the east of England, Greater Manchester, and the West Midlands, with the support of the National Institute for Health Research Clinical Research Network. 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

Data collection

Separate topic guides for patients/carers and clinicians based on the aims of the research were used to generate data (Box 1). These guides allowed flexibility for the exploration of participants' understanding and experience of 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 previous 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 two phases: first, framework analysis was used to identify key patterns in the data relating to the research objective,²⁵ and second, normalisation process theory (NPT) was used to provide sensitising constructs to reframe and further interpret the findings and guide recommendations.²⁶ As this was an exploratory study, applying a theoretical framework too early in the formal

Box 1. Summary of interview topic guides^a

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

^aFull versions of topic guides are available from the authors on request. HFpEF = heart failure with preserved ejection fraction.

analytical process could have imposed preconceptions and assumptions on the data.²⁵ Therefore, researchers remained grounded in the data during the first phase of analysis, which involved iterative stages (see Supplementary Table S1 for details).

Table 1. Sample characteristics (patient and clinician participants)

| Demographic | Category | n(%) |
|--------------------------------|----------------------------|---------|
| Patients (N= 50) | | |
| Sex | Female | 23 (46) |
| | Male | 27 (54) |
| Age range, years (mean = 76.5) | 61–70 | 11 (22) |
| | 71–80 | 14 (28) |
| | 81–90 | 15 (30) |
| | 91–100 | 1 (2) |
| | Unknown | 9 (18) |
| Recruitment site | Primary care | 35 (70) |
| | Specialist HF service | 14 (28) |
| | Self-referral ^a | 1 (2) |
| Clinicians (N= 73) | | |
| Sex | Female | 41 (56) |
| | Male | 32 (44) |
| Profession | GP | 35 (48) |
| | Practice nurse | 8 (11) |
| | HF specialist nurse | 14 (19) |
| | Cardiologist | 6 (8) |
| | Other health professional | 10 (14) |

^aOne patient found the authors' website and contacted them directly. HF = heart failure.

Joint coding and discussions about the coding and interpretations took place at regular team meetings (face-to-face and by telephone). Analytical themes were also reviewed by investigators from the wider research programme and a patient advisory group to ensure that 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.

In the second phase, the explanatory model, NPT informed an evaluative view of the themes identified through framework analysis. NPT has been used to review and evaluate the social organisation of health care 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 healthcare practices become embedded and sustained (that is, normalised into everyday practice) (see Supplementary Table S2 for details).^{26,27}

RESULTS

A total of 50 patients, nine carers/relatives, and 73 clinicians (see Table 1 for sample characteristics) were recruited from 26 GP practices and nine hospitals from across five NHS trusts. The 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 ($n = 15$). The mean clinician interview length was 38 minutes, and the mean focus group length was 55 minutes (data not shown).

The identifiers given alongside quotes in this section are P (patients), GP (GPs), PN (practice nurses), HFSN (HF specialist nurses), C (cardiologists), and other HP (other health professionals).

Key themes

Framework analysis highlighted overarching tensions across patient/carer and clinician accounts in terms of how HFpEF is identified and understood. These corresponded to three main themes: diagnostic difficulty, unclear illness perceptions, and management disparity (Box 2). These themes were examined in

Box 2. 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 |

HFpEF = heart failure with preserved ejection fraction.

relation to NPT processes, as summarised in Box 3, which together provide an evaluative view of the 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 for details). Three main factors were influential in preventing timely differentiation of HFpEF that had the potential to delay appropriate care: the challenge of the normal echocardiogram (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.' [C1]

Box 3. Factors influencing the achievement of Normalisation Process Theory (NPT) constructs^a

| NPT construct | Description | Barriers to achievement |
|---|--|---|
| Coherence (Sense-making work) | The work of understanding ways of working or new practices | Lack of clear understanding and differentiation of HFpEF Professional scepticism Lack of visibility of HFpEF Variability in referral pathways and specialist input Diagnostic process not attuned to identifying HFpEF Lack of shared knowledge of specific tasks for HFpEF management, for example, clinical inertia/lack of evidence-based practice Uncertain roles and responsibilities in HFpEF care Lack of clear understanding of the implications of practices involved in HFpEF care |
| Cognitive participation (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 coherence Uncertainty about what constitutes the right set of practices and the validity of these practices for HFpEF Lack of collective definition of the procedures required for optimal HFpEF care |
| Collective action (Operational work) | The work of implementing ways of working or new practices and providing the necessary resources and training to operationalise these | Failure to initiate work around managing HFpEF owing to lack of coherence Unclear undifferentiated treatment due to lack of coherence 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, for example, QOF, referral pathways, and echocardiogram reports Inequitable and variable division of resources for HFpEF |
| Reflexive monitoring (Appraisal work) | The work of evaluating and monitoring ways of working or new practices | Variability/uncertainty about best practice and roles/responsibilities in long-term follow-up due to lack of coherence and inequitable HF provision Communication problems across primary and secondary interface Access and capacity limitations Systems more attuned to monitoring HFrEF or associated comorbid conditions |

^aNPT framework by May et al. has been used to inform findings.²⁶ HF = heart failure. HFpEF = heart failure with preserved ejection fraction. HFrEF = heart failure with reduced ejection fraction. QOF = Quality and Outcomes Framework.

GPs conveyed uncertainty about making sense of results, reporting a 'normal echo' (that is, 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".' (GP1)

Many GPs emphasised that they were not trained to evaluate echo reports; they often relied on summaries or conclusions provided within them, 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.' (HFSN1)

Referral practices varied; some involved routine specialist review, while others included triaging within a tier 2 community cardiology service (an intermediate service led by a GP with a special interest in cardiology) or a community direct access echo. Findings showed the expedience of the direct access echo might be countered by delays caused by duplication in secondary care as a result of 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.' (GP7)

A convoluted pathway to diagnosis: 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 to the other, and one was saying it was the lungs, and the other one was saying, "no, it's definitely the heart".' (P13)

Clinicians also acknowledged that a patient's quest to reach a correct diagnosis could be lengthy, involving the navigation of a complex system with numerous visits to multiple clinics:

'Often people have been batted from, they've gone through a lot of different clinics, and no-one's really given them a diagnosis.' (C1)

Patient and clinician accounts illustrated the incidental nature wherein heart problems became visible when individuals underwent interventions for other health complaints, such as elective surgery or hospital admission with pneumonia. Analysis suggested that comorbidities, non-specific symptoms (including no pain), and multifactorial breathlessness often resulted in a prolonged diagnostic process.

Unclear illness perceptions

NPT suggests that communal and individual understanding about an illness is necessary to facilitate optimal management. In this context, a lack of application or shared understanding of the label of HFpEF across patient and clinician accounts was viewed as a potential barrier and one closely interrelated with differentiation of this condition. Furthermore, the seeming complexity and lack of clarity surrounding the condition appeared to hinder clinicians and patients acquiring an in-depth or shared understanding of the condition.

What's in a name? Few patients were aware of the label of HFpEF before participating in the study. Those that were aware had been introduced to the term in secondary care or by HF specialists; these individuals were often proactive in the process:

'Well, I mostly did stuff myself and then asked some questions after my pacemaker ... it's only recent that I've understood it properly and it's something which is called, well you know this, it's preserved ejection fraction isn't it?' (P14)

Many primary care clinicians were unfamiliar with the term HFpEF; it was not readily visible in correspondence or patient records, and was not viewed as being applied consistently. Some expressed uncertainty about whether this label represented a new classification:

'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.' (GP18)

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.' (C5)

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.' (P21)

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

'[It's] a challenge to try and explain [HFpEF] to patients, treatment feels a bit, sort of less clearly understood, less clearly targeted.' (GP9)

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.' (HFSN1, 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.' (P34)

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 HFpEF presupposes a high degree of coherence or sense-making work (Box 3). 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 because of 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 provision for HF overall. Patients with HFpEF 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 [patients with HFpEF] so I don't think we actively seek them out.' (PN4)

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 in some patient and clinician accounts because of a lack of evidence-based practice and a feeling that there was little that could be done:

'Why bother to have a label when you can't do something about it?' (GP7)

'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.' (P13)

Uncertain roles and responsibilities. Primary care clinicians without a cardiology background were unclear how a diagnosis of HFpEF influenced their clinical management of the patient's condition, stating they would treat these patients the same as those with left ventricular diastolic dysfunction. 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.' (GP3)

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.' (P11)

The data suggest patients with an incomplete understanding of their illness and treatment were more likely to misattribute HF symptoms to other causes, 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.' (P35)

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.' (HFSN2, 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.' (P44)

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 in 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.' (HFSN7)

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.' (P24)

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 in primary care were likely to bypass it in favour of other services, such as 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 [appointment] 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 [accident & emergency] ... and before you've got to the GP, you're already back in the hospital anyway.' (P17)

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.' (GP19)

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 specialties 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.' (Other HP1)

Clinicians acknowledged that 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.' (GP21)

DISCUSSION

Summary

This study drew on the perspectives of a range of clinicians and patients/carers from primary and secondary care settings in three regions of England 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. NPT enabled the findings to be examined within a robust generalisable theoretical framework to inform future intervention work (Box 3).²¹

Systems of care were not developed consistently or systematically to differentiate this condition compared with 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 dataset promotes trustworthiness and transferability of the findings.^{24,28} However, there would be potential benefits in drawing from wider stakeholder input beyond patients/carers and clinicians, such as managers, commissioners, charity representatives, and public health scientists. Consequently, the authors are using wider stakeholder analysis for ongoing 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 patient advisory group to help ensure that assumptions were continually examined and that an applied focus was maintained.^{24,29} Clinicians were recruited via the National Institute for Health Research Clinical Research Network, 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 the type of HF is important for management options.³⁰ Resonating with other studies, the current study's findings indicate that HFpEF is not widely visible, understood, or diagnosed in primary care.^{16,31} Variability in routes to a

HF diagnosis has been noted previously;³² the current 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} This study echoed this by focusing on the views and experiences of patients with HFpEF. 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 were found to be variable. The current study's findings 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 concerns about the balance between the 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 concerns about expanding definitions of diseases by specialists and the need to ensure these definitions show a strong evidence of benefit.^{36,37} It has been recommended 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 health care.^{13,39}

Implications for research and practice

This study illustrates the uncertainty and variability surrounding the management of HFpEF. The NPT construct of coherence may 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 (Box 3). 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, as is 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 the growing population of patients with HFpEF. Continued collaboration of key stakeholders will be essential in the development and design of future interventions.

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Ethical approval

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

Provenance

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Competing interests

The authors have declared no competing interests.

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