

‘Keeping the plates spinning’: a qualitative study of the complexity, barriers, and facilitators to caregiving in heart failure with preserved ejection fraction

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Received 16 December 2021; revised 18 March 2022; accepted 18 March 2022; online publish-ahead-of-print 17 June 2022

Aims

Heart failure with preserved ejection fraction (HFpEF) accounts for 50% of all heart failure cases; yet remains poorly understood, diagnosed, and managed, which adds complexity to the carer role. No study to date has investigated the experiences of informal carers of people with HFpEF. The aim of this study was to explore the role and experiences of informal carers of people with HFpEF.

Methods and results

A qualitative study using semi-structured interviews involving carers alone, patients alone, or carer/patient dyads. The interviews were part of a larger programme of research in HFpEF. Participants were recruited from three regions of England. Interviews were recorded, transcribed verbatim, and analysed thematically. Twenty-two interviews were conducted with 38 participants, 17 were informal carers. Three inter-related themes were identified: Theme 1, the complex nature of informal caregiving ('spinning plates'); Theme 2, the barriers to caregiving ('the spinning falters'); and Theme 3, the facilitators of caregiving ('keeping the plates spinning').

Conclusions

Informal carers play an important role in supporting people with HFpEF. The experience of caregiving in HFpEF is similar to that described for Heart Failure with reduced Ejection Fraction, but complicated by challenges of limited information and support specific to HFpEF, and high burden of multi-morbidity. Healthcare providers should assess the needs of informal carers as part of patient care in HFpEF. Carers and patients would benefit from improved information and co-ordinated management of HFpEF and multi-morbidities. Helping carers 'keep the plates spinning' will require innovative approaches and co-ordination across the care continuum.

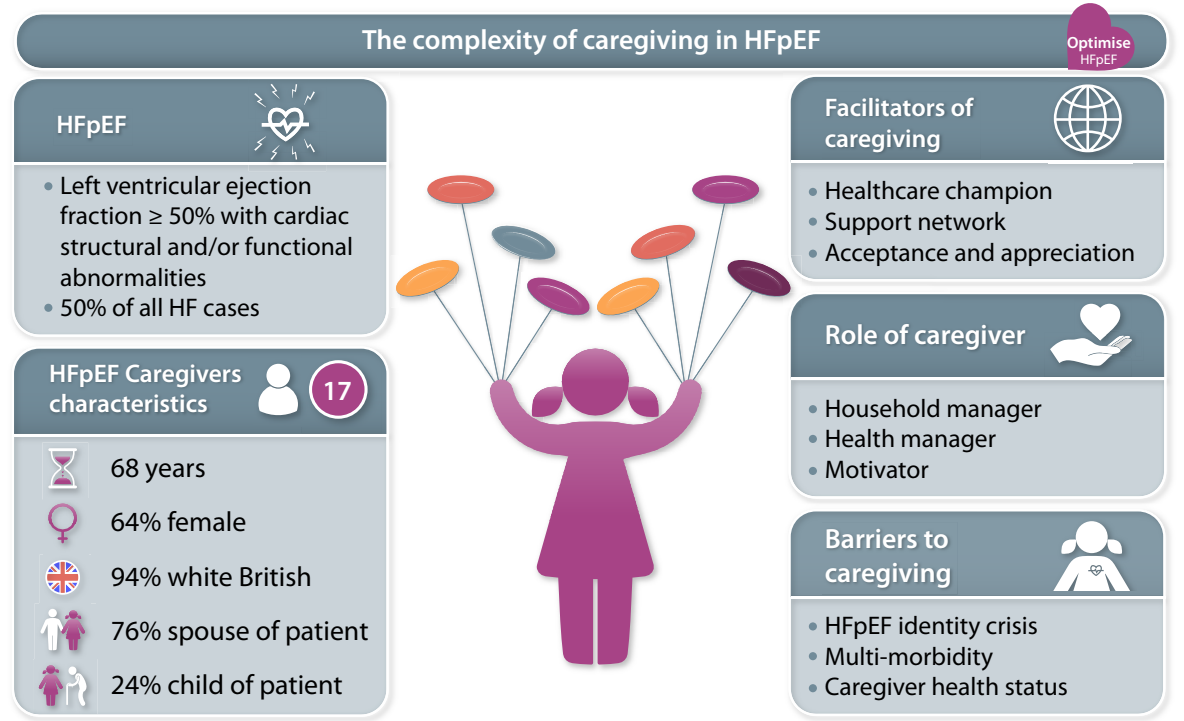
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Graphical abstract



Keywords Heart failure with preserved ejection fraction • Carers • Multi-morbidity • Complexity

Implications for practice

- Carers of patients with HFpEF perform many complex roles similar to those of carers for patients with any HF type.
- The role is further challenged by lack of diagnosis, specific information and guidance on HFpEF, patient multimorbidity, less well-defined pathways of care and limited specialist support.
- Patients and carers need not only specific support for HFpEF but a holistic approach encompassing management of multimorbidity and geriatric syndromes common in HFpEF.

Novelty

- This is the first qualitative investigation of informal carers to patients with heart failure with preserved ejection fraction (HFpEF).
- Although there are similarities in the experiences of HFpEF carers to heart failure with reduced ejection fraction, there are also notable differences.
- The experience of carers to people with HFpEF is complicated by challenges of an identity crisis in HFpEF leading to limited information and support, and a high burden of patient multi-morbidity.

Introduction

Heart failure with preserved ejection fraction (HFpEF) accounts for 50% of all heart failure cases and is characterized by typical signs and symptoms of heart failure (HF), a left ventricular ejection fraction of $\geq 50\%$, and evidence of cardiac structural and/or functional abnormalities.¹ Heart failure with preserved ejection fraction is thought to be driven by a comorbidity-induced systemic pro-inflammatory process² and patients are usually older with multi-morbidity and geriatric syndromes.³ Heart failure with preserved ejection fraction is associated with an

increased risk of hospitalization and readmissions, and impaired functional capacity.^{4,5} Despite its prevalence and the associated personal and societal burden of HFpEF, there remains limited awareness and clinical understanding leading to under-diagnosis and variable management.^{6,7} Regardless of HF type, many patients rely upon unpaid support from a wide variety of sources to manage their condition.⁸ Societal definitions of carers vary, however broadly speaking, a carer is anyone who provides unpaid care to a family member or friend who could not cope without their support.⁹ A growing body of literature exploring the roles undertaken by carers of people with HF

demonstrates that carers provide extensive support across a number of domains. The degree of support required varies with periods of deterioration related not only to HF, but also to comorbidities and functional impairments that are associated with aging.⁸

As the patient's condition progresses and care needs become more complex, carers experience an increasing burden that can impact negatively on a number of life domains such as physical and psychosocial health.¹⁰ Qualitative explorations of caregiving consistently demonstrate that carers feel they lack the knowledge and skills required to be effective carers^{8,10} and may have unmet needs.¹¹ Given that the knowledge and understanding of HFpEF is low among healthcare providers and a specialist support is limited,^{6,7,12} we hypothesized that this would accentuate the challenges faced by carers of patients with HFpEF.

Although previous qualitative studies may have captured views of carers of patients with HFpEF, we could find no evidence in the literature of analysis to determine potential agreement and divergence between carers of patients with different HF types. To address this deficit, we aimed to explore the views of patients with HFpEF and their carers participating in two studies within a larger programme of work, Optimising Management of Patients with Heart Failure with Preserved Ejection Fraction in Primary Care (Optimise HFpEF).¹³ We also sought to compare these experiences with the experiences of patients and carers with other forms of HF.

Methods

Findings are reported in line with the Standards for Reporting Qualitative Research.¹⁴ We undertook a thematic analysis using an inductive, realist

approach of transcripts generated from interviews conducted with patients with HFpEF and their carers derived from two separate studies conducted across three geographically dispersed regions in England (Cambridgeshire, the Midlands, and Greater Manchester).

Following an amendment to existing ethical approvals (REC reference: 17/LO/2136), participants were purposively recalled from an established cohort based on documented characteristics relating to carer. Adult carers were purposively sampled and were provided information about the study while they accompanied participants for follow-up or by mail. For inclusion, adult carers had to be >18 years old, able to communicate in English, and self-identify as an informal carer. Interviews from a previous qualitative component (REC reference: 17/NE/0199) that included a carer were also included in this analysis (Figure 1). All participants provided written informed consent, and the study conformed to the Principles of the Declaration of Helsinki. Interviews were stored securely according to University of Cambridge data protection policies, and all transcripts were fully anonymized and labelled with identification number only.

Interviews were guided by a semi-structured interview schedule that developed from the literature review, expert input, and discussion with a patient and public panel. Interviews were audio-recorded with digital devices. Most interviews were performed face to face ($n = 20$), two were telephone interviews. Most interviews with carers were performed as dyads with patients contributing. Interview schedules did not change over time but were informed by previous responses and familiarization in an iterative process. Interview schedules are available on the study website (<https://www.optimisehfpef.phpc.cam.ac.uk/study-documents/>). All interviews were transcribed verbatim, anonymized, and checked against interview recordings.

Interviews conducted as part of the earlier qualitative component were not specifically targeted at carers and the caring experience, but more broadly explored the HFpEF experience. Therefore, beyond consent, minimal data about these carers were obtained and descriptions of time spent caring and demographic data were drawn from interview

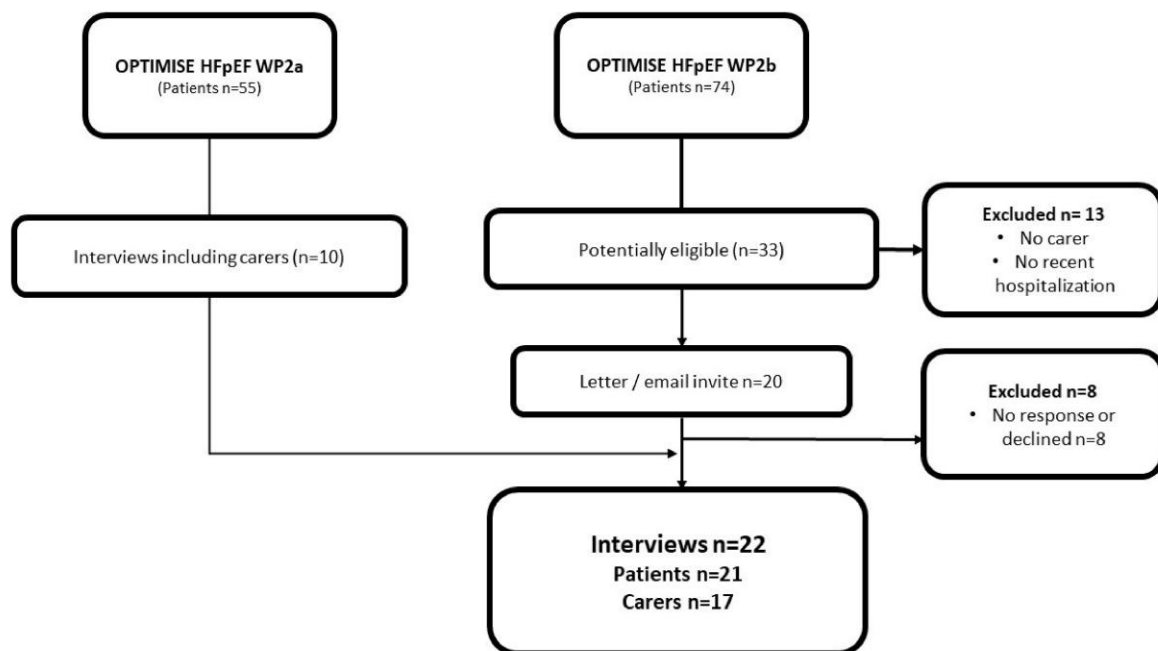


Figure 1 Flow diagram of patients with heart failure with preserved ejection fraction and their carers.

narratives. Those purposively sampled from the cohort study ($n=12$) provided more extensive quantitative data including estimated time spent providing care and detailed demographic information. All interviews were conducted by experienced healthcare researchers, two of whom (F.F. and C.D.) are clinically qualified with a specialist interest in HFpEF. Participants recruited from the cohort study had attended previously for clinical assessment, therefore there was an established rapport.

Anonymized transcripts were uploaded and managed in NVivo12[®]. The six phases of thematic analysis as described by Braun and Clarke¹⁵ were followed. Familiarization (Phase 1) was performed by all researchers. Initial data-driven coding (Phase 2) of five interviews was performed independently by three researchers (C.R.P., F.F., and E.K.) and checked for consistency/variance. Codes and code descriptions based on the first pass coding were agreed and the remainder of the transcripts was coded to this frame by C.R.P. with additional codes being added as needed. The final codebook was reviewed independently by two researchers (C.P. and F.F.) who separately sorted the codes into potential themes which were visualized as thematic maps (Phase 3: searching for themes). All authors reviewed the thematic maps, agreed the candidate themes through discussion, and checked theme coherence at code and data corpus level (Phase 4: reviewing themes and Phase 5: defining and naming). During coding, no new themes were generated beyond the first 10 interviews and the additional interviews added confirmation and detail.

Each narrative was interrogated to establish the type of care provided and care relationships were categorized according to a broad descriptive typology: supportive [general support excluding activities of daily living (ADLs)], instrumental (general support plus assistance with one or more ADLs), reciprocal (where both parties experience morbidity and care is reciprocal dependent on health status/need), or derived from multiple sources (a person who draws on multiple sources such as family, friends, and the wider community, where no single source was identified as providing the most assistance).

Results

In total, 22 interviews were conducted with 21 patients and 17 carers. Patient and carer characteristics are described in Table 1. Interviews totalled 1390 min in length with a median interview time of 63 min. All patients were elderly, and most were males of white British ethnicity. Carers were younger, pre-dominantly female spouses and of white British ethnicity. The pre-dominant care relationship described was instrumental whereby a carer provided general support plus assistance with one or more ADLs.

Thematic analysis resulted in the generation of the analogy of a performer keeping multiple plates spinning. Three key descriptive themes characterized the dataset: Theme 1, the complex nature of informal caregiving ('spinning plates'); Theme 2, the barriers to caregiving ('the spinning falters'); Theme 3, the facilitators of caregiving ('keeping the plates spinning').

Theme 1: Spinning plates: the complex nature of caring

Informal carers reported juggling many different responsibilities which were categorized into three subthemes: household manager, health manager, and motivator. Responsibilities within these categories were variable from light touch support to total management and influenced by many factors. Experiences described were akin to the spinning plates analogy, whereby each spinning plate is demanding

Table 1 Characteristics of patients with heart failure with preserved ejection fraction and their carers

Patient characteristics		Carer characteristics	
Mean age (years)	83	Mean age (years)	68
Female, n (%)	9 (43)	Female, n (%)	11 (64)
Ethnicity white British, n (%)	19 (90)	Ethnicity white British, n (%)	16 (94)
Marital status—married, n (%)	11 (52)	Marital status—married, n (%)	14 (82)
Marital status—widowed, n (%)	7 (33)	Carer relationship to patient—spouse, n (%)	13 (76)
Previous clinical HFpEF diagnosis, n (%)	10 (48)	Carer relationship to patient—adult child, n (%)	4 (24)
Study HFpEF diagnosis	11 (52)	Type of care provided	
		Supportive care, n (%)	5 (23)
		Instrumental care, n (%)	7 (32)
		Reciprocal care, n (%)	4 (18)
		Multiple sources, n (%)	6 (27)

HFpEF, heart failure with preserved ejection fraction.

attention at different times, without which it is liable to topple. Responsibilities waxed and waned according to both patient and carer factors and the type of care provided. For example, care provided by those in reciprocal care relationships was often inter-dependent and shared based on their respective health status. All care relationships were dynamic and constantly negotiated based on need, however, typically became more burdensome as ill health and functional impairment progressed.

Household manager

Carers commonly took on responsibility for many household tasks and assisted the patient with ADLs, such as cleaning, cooking, shopping, and managing finances, although many patients continued to do as much as they could.

Housework, [husband] has taken over more of the [housework] always doing the hoovering downstairs. Patient 8

She [wife] does all my accounts, and organises all sorts of things, anything to do with finances, various things. Patient 3

Health manager

Carers frequently had a very active role in co-managing the health of the person they cared for. They often took responsibility for or provided practical assistance with organizing and attending medical appointments, managing medications, and supporting lifestyle changes like dietary adjustments.

My role in the family is to help him with his doctor's appointments, hospital appointments and to make sure his tablets are fine, etc. You know, just that side of his life, to make sure the medical side is

in order and that he's keeping to his plan and what the doctor tells him to do. Carer 6

You're also lucky in a way, that I buy into this, and I do the diet, so if I wouldn't do the diet for you or I still sat in front of you drinking glasses of wine every night... It wouldn't be [easy].... whereas if you had somebody who wasn't interested or it was too inconvenient, because it isn't convenient, it'd be very different. Carer 4

When you're given the information at the end, I think it's always helpful if someone else is there to hear it, because you don't always hear it, especially if they've said something that you go, oh, and it shocks you a little bit, and you don't then always pick up the rest of it. Patient 19

Motivator

Living with HFpEF is difficult for both the patient and the carer as both the illness and treatment burden are high. One of the spinning plates was the role of the carer as a psychosocial and self-care motivator to the patient. Psychosocial support offered and accepted was varied and dependent on contextual factors like mood and capacity. Carers supported and motivated engagement with monitoring HF and comorbid symptoms, and often adopted the role of advocate, encouraging health service access.

If I was alone now ... If I'd not got [my wife] to sort things out for me, I'd be in a council flat somewhere, doing absolutely nothing. Even with heart failure, thinking to yourself, well this won't get any better, you might as well just carry on and live life as it is. Patient 12

I think part of it was me nagging you to go to the doctors. [patient] doesn't like going to the GP unless it's really really vital. Carer 3

Theme 2: When the spinning falters: barriers to caregiving

Significant barriers were identified in providing 'optimal' care in HFpEF. Key barriers were grouped under three sub-themes, namely HFpEF identity crisis, burden of multi-morbidity, and caregiver health status. Similar to Theme 1, these barriers to care were also dynamic and dependent on the health status of both patient and carer and their interaction with health services and health professionals.

Heart failure with preserved ejection fraction identity crisis

Lack of awareness, information, and support to manage HFpEF often meant patients and their caregivers were uncertain of their diagnosis, what this meant for them, and what they could do in terms of self-management. Patients reported receiving mixed messages from health providers and they struggled to reconcile the finality of a diagnosis of 'heart failure' when it was coupled with the message 'nothing to worry about'.

"Oh, we've found one thing, you've got heart failure". And I said, "Can you expand on it?", and he said, "It's nothing to worry about". And that was about all he said. He didn't explain it at all. Patient 9

but I think the more you know about a condition, you know how to handle it better. Carer 11

Burden of multi-morbidity

Patients and carers reported a significant burden relating to multi-morbidity that complicated many aspects of life. In terms of their HFpEF, it resulted in protracted diagnostic processes, misattribution of symptoms, and complicated management, particularly when patients were managed by separate specialist teams.

They concluded that, on the occasion, that [his breathlessness] wasn't to do with COPD but it was to do with his heart tablets causing him to be out of breath. As a result they [respiratory physicians]... they actually took him off, completely, this particular drug, which we found out that he shouldn't have been taken off this drug straight away, it should have been reduced by certain levels. So he went from taking the maximum to zero, which obviously made him fall over, he basically couldn't function. Carer 6

... it would have been really helpful if somebody, knowing that all the conditions he's got, would sit down with me and say, right, now this is what you can get. You can have support from there, support from there, support from there, and support from there. Carer 14

Caregiver health status and stress

Many caregivers struggled with their own health and oftentimes caregiving was reciprocal. When both parties were struggling with their health, managing simple ADLs could be difficult and self-management activities like engaging in physical activity were often abandoned as capacity to address these diminished. As HFpEF progressed, carers reported increasing levels of stress as the complexities of care escalated and the patient's capacity to manage them independently deteriorated.

It's been horrendous, because I'm his carer, and over the years he's become quite frail...he doesn't remember much, so I have to be there all the time. Carer 14

Theme 3: Keeping the plates spinning: facilitators of caregiving

There were facilitating factors that helped carers to 'keep the plates spinning'. In this study, carers identified the following three important sub-themes: (i) having a healthcare champion, (ii) ability to engage a wider support network, and (iii) acceptance and/or appreciation of the role. Not everyone was able to access these facilitators and most participants referred to lack of information to enable them to access formal, non-family/friend-related support networks in their community. Some attributed this lack of access to the lack of identity that HFpEF has as a diagnosis.

Having a healthcare champion

Healthcare champions ranged from HF specialist nurses to consultants or general practitioners (GPs). Regardless of the person or role, they supported patients and their carers similarly through being empathetic, listening, active communication, and trouble shooting. For carers, these champions ensured they were involved in all aspects of care. Those who did not have a healthcare champion often

described feeling lost or left to their own devices, uncertain where to get advice, or what to do in the face of deterioration.

Whenever I feel I need to talk to him [GP], I always can and he's always very good. Patient 11

But you've got no-one to talk to. [...] but I can't ask them [heart failure team] because they don't know exactly what's wrong. Nobody does I suppose really. Carer 1

Engaging a wider support network

Most participants referred to a network of friends, neighbours, family members, and community services they engaged to support them. This often required complex organization, particularly when attending healthcare appointments which was challenging due to limitations imposed by HFpEF, multi-morbidity, and age-related conditions. These networks were vital for both patients and carers to maintain their independence and interests outside of the carer role. Support described was predominantly practical, but was often informational, social, or emotional.

We've got good friends, we've got good family. We've got a daughter and husband and grandchildren, and they'll all help. Carer 14

Acceptance and appreciation

For most patients and their carers, a diagnosis of HFpEF was associated with accepting and adapting to a new role as a patient with a life-limiting condition and debilitating symptoms. For carers, it often meant accepting new responsibilities requiring time and energy. Accepting this situation could be a source of tension, particularly when either patient or carer, or both, had different responsibilities previously (e.g. outside work) and it often altered the established dynamic. Most reconciled to their new roles, doing as much as they could within the context of their abilities or making alterations to established life patterns and hobbies to maintain as much 'normality' as possible. For some carers, ability to adapt to and offer support was a source of satisfaction; others reported feeling overwhelmed, particularly as physical conditions deteriorated.

As we now have a diagnosis of heart failure, with preserved ejection fraction, we can therefore begin to come to terms with it. Carer 8

We just accept what's happening and try to make the best of a bad job you know, that's just the way we are, we talk about it between ourselves erm and what we, what to do... Patient 20

But we enjoy it that he's [patient] still with us... we feel very lucky that we are in a position that we can help dad. Carer 6

Yeah, it just gets to me sometimes I think, I just can't cope anymore. Carer 14

Discussion

To our knowledge, this is the first qualitative investigation of informal carers of patients with HFpEF. Previous studies exploring the experiences of carers of people with HF have either included heart failure with reduced ejection fraction (HFrEF)-only samples¹⁶ or they lacked

detailed descriptions of the study population to ascertain the inclusion or proportion of those with HFpEF.¹⁰

This study confirms that carers of patients with HFpEF perform many complex roles and experience both barriers and facilitators that affect their ability to provide quality care. There are many similarities in the experiences described here to those detailed in previous studies conducted with carers of patients with HFrEF or unspecified HF phenotypes, for example, the complexity of care and roles of carers as seen in Theme 1.^{10,11,16,17} Equally, the support networks and patient/carer dynamics that facilitate or disrupt provision of care (Themes 2 and 3) have also been well-described in HFrEF.^{18,19}

However, there were differences in the ways in which informal carers were able to support the disease management process in people with HFpEF. This analysis and our previous work have highlighted the lack of information (and sometimes definitive diagnosis) and clinical nihilism surrounding HFpEF.^{6,20} We would argue that this crisis of identity acts as a unique structural barrier for patients with HFpEF and their carers that is not observed in other chronic conditions where illness perceptions or identities are stronger. For example, a diagnosis of HFrEF usually sets off a cascade of pharmacological treatments, consideration of possible device options, self-management information/support, and cardiac rehabilitation. A diagnosis of HFpEF did not appear to trigger equivalent pathways, and patients and their carers were effectively stymied from accessing supportive services and care. In effect, the type of HF diagnosis appeared to inappropriately moderate the care received.

Barriers to care optimization driven by an identity crisis in HFpEF is further evidenced by the minimal reference to HF multi-disciplinary teams (HFMDTs) in the theme healthcare champions. Most guidelines now recommend HF care is delivered by a multi-disciplinary team (HFMDT)^{1,21} and should include information and advice on lifestyle change and self-management strategies including symptom recognition, potential limitation of fluid and sodium intake, nutrition and weight management, smoking and alcohol cessation, physical activity, immunizations, sexual and mental health promotion, remote monitoring, sleep, and travel advice.^{1,22} Many participants reported not having anyone to talk to or champion their cause; a role typically filled by HF specialist nurses.

The literature on carer involvement in HF self-care is well developed and there are multiple primary studies and reviews exploring the many factors that affect patient and carer ability to engage in and provide self-care.^{23–25} However, patients and carers in this cohort were infrequently supported by a HFMDT which may explain the absence of references to self-care strategies within interviews. This finding is consistent with previous studies that also found limited specialist support for management primarily due to lack of capacity.^{6,12,20,26}

Within the UK, not all specialist HF services accept patients with HFpEF and there are significant variations in the provision and structure of services for people with HFpEF.^{12,26} Moreover, there is a lack of awareness of HFpEF among many primary care clinicians, scepticism over the value of a HFpEF diagnosis, and practical barriers to diagnosis and services.^{12,27,28} In the context of these disparities, it is perhaps unsurprising that many patients and carers were not provided the information and skills to engage in the types of self-management strategies outlined in guidelines. For example, in the Optimise HFpEF cohort study (including some of these interviewees), scores on a self-care questionnaire were low, and many patients reported not engaging in self-management or symptom monitoring activities.⁵

A further significant barrier for patients and carers was managing their HFpEF in the context of multi-morbidity and age-related conditions. Previous studies have found that multi-morbidity can complicate HF management, particularly as it can lead to polypharmacy with complex medication regimens, therapeutic competition among medications, and adverse drug reactions.²⁹ Patients in the Optimise HFpEF cohort study were taking an average of eight medications, and more than one-third were taking 10 or more.⁵ Multi-morbidity is thought to drive HFpEF and due to the limited therapeutic options, optimization of co-morbid conditions is a core management strategy.^{1–3} Holistic management of multiple co-morbid conditions and geriatric syndromes is a substantial challenge. Outside of primary care and geriatric services most healthcare is organized by specialties with limited co-ordination across services. Patients and carers are often left to make sense of what may seem to be conflicting advice from different specialists, a problem exacerbated if they lack diagnosis and information about HFpEF.

Limitations and strengths

Although the sample in this study was geographically diverse enhancing the generalizability of the findings, it was relatively small. Patients and carers were mostly interviewed together which may have prevented carers from speaking freely. One set of dyadic interviews was conducted within a qualitative study more broadly focused on diagnosis and management of HFpEF, rather than carers' roles. Nonetheless, the interviews provided valuable information about carers' roles and responsibilities, and the interdependence between patients and carers within the context of frequently protracted diagnostic processes, limited guidance and support for HFpEF, and frequent multi-morbidity (additional interview content is available in the [supplementary material](#)). Although there will be commonalities regarding caring for patients with any type of HF, there were unique challenges for carers within the context of a less well-defined system of care for HFpEF. The study was strengthened by being nested within a broader programme of research in patients with HFpEF and using a robust analytical approach.

Conclusion

Carers of people with HFpEF supported their loved ones to manage many of the health and day-to-day responsibilities faced by patients living with chronic conditions. The care role described was complex and dynamic with both patients and carers exhibiting tremendous resource to maintain independence. Roles and responsibilities were complicated by structural (organizational) barriers to care, driven by an identity crisis in HFpEF (lack of recognition and understanding), which appeared to moderate access to important support resources such as a HFMDT.

Authors' contributions

All authors have been involved in the conduct of the study and/or analysis of the data, approved the manuscript, and agreed to be accountable for all aspects of the work. C.D. is the senior and corresponding author.

Supplementary material

[Supplementary material](#) is available at *European Journal of Cardiovascular Nursing* online.

Acknowledgements

We thank the patients and carers who shared their thoughts and stories with us. We also acknowledge the invaluable advice provided by experts in carer support, Dr Gail Ewing (Cambridge) and Prof. Gunn Grande (Manchester).

Funding

This work was supported by the National Institute for Health Research School for Primary Care Research (grant number 384), the NIHR Cambridge Biomedical Research Centre (BRC-1215-20014), Addenbrooke's Charitable Trust, and the British Heart Foundation Centre of Research Excellence. The views expressed are those of the authors and not necessarily those of the NIHR, the NHS, or the Department of Health and Social Care. The study sponsors were not involved in any aspect of the study including study design, data collection, data analysis, and interpretation of data.

Conflict of interest: none declared.

Data availability

The data underlying this article cannot be shared publicly to protect the privacy of the participants who were interviewed. Some data may be shared on reasonable request to the corresponding author.

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