A secondary qualitative analysis to inform understanding of coordination of care for patients with heart failure with preserved ejection fraction

Word count:

<table>
<thead>
<tr>
<th>Section</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>267</td>
</tr>
<tr>
<td>Introduction</td>
<td>501</td>
</tr>
<tr>
<td>Methods</td>
<td>919</td>
</tr>
<tr>
<td>Results</td>
<td>2016</td>
</tr>
<tr>
<td>Discussion</td>
<td>930</td>
</tr>
<tr>
<td>Conclusion</td>
<td>94</td>
</tr>
<tr>
<td>Total</td>
<td>4460  (excl abstract)</td>
</tr>
</tbody>
</table>

ABSTRACT

**Background:** Patients with heart failure with preserved ejection fraction (HFpEF) are a complex and underserved group. They are commonly older patients with multiple comorbidities, who rely on multiple healthcare services. Regional variation in services and resourcing has been highlighted as a problem in heart failure care, with few teams bridging the interface between the community and secondary care. These reports conflict with policy goals to improve coordination of care and dissolve boundaries between specialist services and the community.

**Aim:** To explore how care is coordinated for patients with HFpEF, with a focus on the interface between primary care and specialist services in England.

**Methods:** We applied Systems Thinking methodology to examine the relationship between work-as-imagined and work-as-done for coordination of care for patients with HFpEF. We analysed clinical guidelines in conjunction with a secondary applied thematic analysis of semi-structured interviews.
with healthcare professionals caring for patients with HFP EF including GPs, specialist nurses and cardiologists and HFP EF patients themselves (n = 41). Systems Thinking for Everyday Work (STEW) principles provided a sensitising theoretical framework to facilitate a deeper understanding of how these data illustrate a complex health system and where opportunities for improvement interventions may lie.

**Results:** Three themes (working with complexity, information transfer and working relationships) were identified to explain variability between *work-as-imagined* and *work-as-done*. Participants raised educational needs, challenging work conditions, issues with information transfer systems, and organisational structures poorly aligned with patient needs.

**Conclusions:** There are multiple challenges that affect coordination of care for HFP EF patients. Findings from this study illuminate the complexity in coordination of care practices and have implications for future interventional work.

**SUMMARY**

**What is already known on this topic?**
Heart failure with preserved ejection fraction (HFP EF) is poorly understood. Optimal management for this condition, including how best to coordinate care within health services, remains unclear.

**What this study adds:**
This study identifies variability between the work processes for coordination of care documented in guidelines (work-as-imagined) and working practices described by participants (work-as-done).

**How this study might affect research, practice or policy:**
Findings from this study illustrate the challenges affecting coordination of care for HFP EF, which have implications for future interventional work. Aligned with policy and previous research, our findings illustrate the importance of acknowledging system complexity as we aim to improve the quality of long-term condition care.

**INTRODUCTION**
Approximately 50% of heart failure patients have the subtype ‘heart failure with preserved ejection fraction’ (HFP EF)[1] and this is expected to become the dominant form of heart failure in the future.[2] Despite this, a minority of patients (24%) enrolled in heart failure registries are recorded as having HFP EF, suggesting the condition is under-recognised.[3] Debate remains in the field regarding the best diagnostic criteria for HFP EF. However, patients with symptoms and signs of heart failure, a left ventricular ejection fraction greater than or equal to 50% and evidence of cardiac functional abnormalities are broadly accepted to have the condition.[4] Compared with patients with heart failure with reduced ejection fraction (ejection fraction <50%), HFP EF patients are typically older, with a high burden of comorbidity and frailty, and are an underdiagnosed and underserved group in terms of approved effective pharmacological treatments.[5]
Multidisciplinary heart failure management programmes are the recommended gold standard of care internationally, however, evidence is limited for their effectiveness in HfPEF and no service model has been shown to be optimal.[4] Where these services exist, patients with HfPEF may be excluded due to under-recognition and misdiagnosis.[7] Comorbidities can result in care becoming fragmented between providers and patients can find shared management difficult to navigate.[8]

The phrase ‘coordination of care’ is commonly used but infrequently defined, making its evaluation difficult.[9] Coordination is often discussed alongside ‘continuity of care’ and ‘transitions of care’, between which there is some overlap (Table 1).[9–11] Transitions of care pose a challenge to providing coordinated care.[12,13] They are associated with adverse events and are therefore key improvement targets.[14] Heart failure patients experience multiple transitions including referrals to specialists and discharge to primary care.[15,16] Some argue that a lack of guidance for structuring care provision has resulted in a lack of cohesion between primary care based management and access to specialist involvement when required.[17]

Table 1 Definitions of terms

<table>
<thead>
<tr>
<th>Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Coordination of care</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Continuity of Care</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Transition of care</strong></td>
</tr>
</tbody>
</table>

The NHS long term plan aims to address these challenges in the UK, through dissolution of boundaries between health services.[20] However, there are significant challenges in terms of the resourcing, capacity, structure and regional variability of heart failure services.[21]

Systems thinking aids understanding of complex situations when developing and implementing improvement initiatives.[22] One approach has been to explore and attempt to reconcile the difference between work-as-imagined and work-as-done. Work-as-imagined is how work processes may be documented in guidance and protocols. Work-as-done is the way people who do the job adapt working practices based on system conditions they face (such as lack of information, demand
outstripping capacity or suboptimal equipment). The ‘Systems Thinking for Everyday Work’ (STEW) principles can aid understanding of complex processes representing work-as-done in healthcare and develop recommendations for change.[23]

In this study we sought to use the STEW principles to understand the healthcare system experienced by patients with HFpEF with a focus on the interface between primary care and specialist services. Our objectives were to compare how guidelines describe coordination of care (work-as-imagined) with the experience of patients, and healthcare professionals (work-as-done) and to use this insight to generate suggestions for change.

METHODS:

Study design and setting:
This study comprises a secondary thematic analysis of interview data alongside documentary analysis of guidelines.

Interview data were collected as a component of the Optimise HFpEF study, which aimed to explore the perspectives of patients/carers and clinicians across primary and secondary care to develop understanding of how this group can be better managed.[24] Researchers purposively sampled a range of stakeholders, with the intention of gaining adequate information power to form a deep understanding of multidisciplinary HFpEF care.[25] The sampling strategy aimed to ensure variability in age, sex and comorbidities in patient participants; and a range of clinicians involved in HFpEF care.[26] Recruitment took place between October 2017 and July 2019 across three regions (Cambridgeshire, Greater Manchester and the West Midlands). Participants were provided with options regarding the mode of semi-structured interview by five trained qualitative researchers (three clinicians, two non-clinicians), including face-to-face and telephone and were conducted as patient/carer dyads when the patient preferred this. Interviews were performed in accordance with written informed consent, digitally recorded, transcribed verbatim and checked for accuracy. Separate interview topic guides, based on the research aims for patients and clinicians were used to generate data (Table 2) Further detail regarding study procedures are included within the Optimise protocol and outputs.[24,26,27]

<table>
<thead>
<tr>
<th>Table 2 Summary of interview topic guides (full versions available on request)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient topic guide to explore their:</strong></td>
</tr>
<tr>
<td><strong>Experiences of living with HFpEF</strong></td>
</tr>
<tr>
<td>- How did you come to find out about your heart condition?</td>
</tr>
<tr>
<td>- How does your heart problem impact on your day-to-day life?</td>
</tr>
<tr>
<td>- What things make managing your heart condition easier/harder?</td>
</tr>
<tr>
<td><strong>Experiences of managing their heart condition</strong></td>
</tr>
<tr>
<td>- Can you tell me about any things that you do to look after your heart?</td>
</tr>
<tr>
<td><strong>Perceptions of care and the healthcare system</strong></td>
</tr>
<tr>
<td>- Can you tell me about how health professionals are involved in treating/managing your heart condition?</td>
</tr>
<tr>
<td>- What parts of your healthcare, if anything, seemed to work well for you that might be helpful for other people with your heart condition?</td>
</tr>
</tbody>
</table>
Healthcare professional topic guide to explore their:

**Role and experience of caring for HFrEF patients**

- Can you tell me a bit about your experiences of caring for patients with this condition?
- What role do you think guidelines play in managing these patients?
- How do you feel about the information you receive from other professionals involved in the care of patients with HFrEF?
- Have you experienced any challenges when providing services for this patient group?
- What are your experiences of interventions that seem to work in this patient population?

**Perceptions of how this group is managed**

- None of the authors of this paper conducted interviews sampled for this work. The author who led on analysis for this paper (RBW) was not involved in primary analysis of this data set. Two of the authors (TB and CD) were involved in primary analysis and topic guide development. Systems issues across the primary/secondary care interface were identified through primary analysis. As such, this secondary analysis provides a more in-depth analysis of an aspect of the data only partially addressed in the primary study.[28]

**Ethical and Regulatory Considerations:**

Primary data used in this project was anonymized prior to analysis and managed in accordance with agreed standards.[29] The Optimise HFrEF qualitative component received ethical approval from the North East – York Research Ethics Committee (17/NE/0199).

**Philosophical paradigm, methodology and reflexivity**

This project was developed and undertaken in keeping with soft systems methodology within the critical realist paradigm. Soft systems methodology was developed in engineering to define and tackle problematical situations.[30] Healthcare systems, such as the one around heart failure patients, involve people, processes, technology, a physical environment and other interconnected systems depending on where artificial boundaries are drawn. When considering improvement initiatives, we must consider these components and their interactions to determine how to better ‘engineer’ it.[22] The STEW principles (Figure 1) consider multiple perspectives of real life, everyday work. The STEW principles are used in this study as a sensitizing framework for thematic analysis of the data to explore how and why everyday work differs from work as imagined in guidelines. STEW principles direct the exploration of how work conditions (such as demand/capacity issues, availability of resources, and constraints), interactions and flow of work and competing goals result in people adapting the way they work. These adaptations manifest as trade-offs, work arounds and result in variability of care which may or may not be beneficial in the care of HFrEF patients.[23] Through exploration they provide a framework for considering practical resolutions to problems.

A reflexive journal was kept by the coding researcher throughout analysis.

**Sampling:**
**Guideline Data:**

A search was performed in the NHS evidence and NICE guidance search databases (Supplementary information). Guidelines were included where they advised on coordinating healthcare for heart failure patients. Non-guideline documents, guidelines pertaining to specific treatments only or non-NHS care were excluded.

Guidelines identified by searching reference lists of included documents and those that interview participants reported using were also included. Heart Failure Specialist Nurses across research sites were contacted directly to obtain available, relevant local guidance (Figure 2).

A full list of included guidelines is included in Supplementary Information.

**Interview Data:**

Interview transcripts for secondary analysis were purposively sampled from within the Optimise HfPEF data corpus, which comprises interviews with 50 patients, 9 carers/relatives and 73 clinicians. An initial 25 interview sample included a range of stakeholders identified from guideline review (General Practitioners (GPs), Heart Failure Specialist Nurses (HFSNs), Cardiologists, Practice Nurses and Patients/Patient and carer dyads). Further interviews were sampled, after determining initial themes, to seek multiple perspectives (as required by the STEW principles), obtain adequate information power and examine referential adequacy.\[23,25\]

In total, 41 interviews were sampled from the Optimise HfPEF data corpus (Table 3).

**Table 3 Sample Characteristics**

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Category</th>
<th>n(% of patients or % of clinicians) range (mean) for age</th>
<th>Descriptor within results (Identifier alongside quotes – if different)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patients (N=13)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>Female</td>
<td>5 (39)</td>
<td>Patients (P)</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>8 (62)</td>
<td></td>
</tr>
<tr>
<td>Age range (years)</td>
<td></td>
<td>64-85 (74)</td>
<td></td>
</tr>
<tr>
<td>Carer</td>
<td>Carer included in interview</td>
<td>3 (23)</td>
<td>Carer (Carer)</td>
</tr>
<tr>
<td><strong>Clinicians (N=28)</strong></td>
<td></td>
<td></td>
<td>Clinicians</td>
</tr>
<tr>
<td>Sex</td>
<td>Female</td>
<td>17 (61)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>11 (39)</td>
<td></td>
</tr>
<tr>
<td>Profession</td>
<td>General Practitioner</td>
<td>11 (39)</td>
<td>GP*</td>
</tr>
<tr>
<td></td>
<td>Practice Nurse</td>
<td>4 (14)</td>
<td>Practice Nurse* (PN)</td>
</tr>
</tbody>
</table>
| Heart Failure Specialist Nurse | 5 (18) | HFSN
| Cardiologist | 4 (14) | Cardiologist
| Other HCP | 3 (11) | As per role - Geriatrician, GP Commissioner, Cardiac Physiologist |

**Total** |
41 (100)

When GPs and PN opinions are reported together, they are referred to as ‘primary care clinicians’

When cardiologist, geriatrician and HFSN opinions are reported together, they are referred to as ‘secondary care clinicians’

When primary and secondary care clinicians shared opinions they are referred to as ‘clinicians’

Mean patient interview length was 65 minutes (range 21-130, data missing for 3 patients) Mean clinician interview length was 37 minutes (range 16-75, data missing for 5 clinicians).

**Analysis**

Data were analysed in two concurrent and interrelated processes.

**Documentary Analysis:**

Guidelines were analysed through an iterative process, combining aspects of content analysis (excluding quantification) and thematic analysis.[31] Documents were coded to identify passages relating to coordination of care. These were annotated with descriptions of processes and practices imagined to be required for coordinated care delivery. Data were categorised using principles of thematic analysis to define a cohesive aim for guideline-imagined work of coordination of care (work-as-imagined).

**Interview Analysis:**

Interview data were analysed through applied thematic analysis.[32] NVivo 12 facilitated organisation of codes and linked memo writing.[33] Coding was undertaken by a single researcher (RBW), who regularly peer debriefed with the Optimise study qualitative team.[26] First cycle coding was completed inductively. Further cycles transitioned to deductive coding using the STEW principles (Figure 1) as a sensitising theoretical framework to identify work conditions, interactions and flow enabling and constraining the everyday working practices of coordination of care and to understand reports of performance variability within the healthcare system for HfPEF (work-as-done).[23]

**Synthesis of findings:**

Themes were constructed through constant comparison between findings from documentary and interview analysis.[34]
RESULTS:

Work-as-Imagined:

The imagined aim of coordination of care for heart failure synthesized from thematic analysis of the 12 included guidelines is detailed in Table 4. No guidelines offered different recommendations for coordination of care for HFrEF compared with heart failure with reduced ejection fraction (HFrEF). Therefore, work-as-imagined was assumed to be similar for both groups. All guidelines relayed minimal depth as to how work should be performed.

Table 4 Work-as-imagined of coordination of care for HFrEF

<table>
<thead>
<tr>
<th>What is the aim of work-as-imagined?</th>
<th>To deliver seamless, joined-up care through effective information sharing and discussion between the patient and their carer, primary care and specialist services with the aim of delivering continuous optimal management of heart failure, that centres on the patient’s individual needs, preferences and context.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example Guideline</td>
<td>Imagines the multidisciplinary team (MDT) to work collaboratively with primary care but does not inherently include primary care within this MDT. Defines roles and responsibilities clearly in some areas and envisages linear referral pathway from primary care to specialist heart failure service for diagnosis:</td>
</tr>
<tr>
<td>Chronic heart failure in adults:</td>
<td>“The specialist heart failure MDT should: diagnose heart failure...” p7</td>
</tr>
<tr>
<td>diagnosis and management. NICE</td>
<td>“The primary care team should carry out... at all times, including periods when the person is also receiving specialist... care... ensure effective communication links between different care settings and clinical services... arrange access to specialist... services if needed.” p7</td>
</tr>
<tr>
<td>Guideline 106 [45]</td>
<td>Imagines accurate, timely and seamless transfer of clinical information and patient preferences in the form of a clinical record and care plan:</td>
</tr>
<tr>
<td>Published: 12 September 2018</td>
<td>“The primary care team [should]... recall the person at least every 6 months and update the clinical record; ensure that changes to the clinical record are... shared with the specialist heart failure MDT” p7</td>
</tr>
<tr>
<td><a href="http://www.nice.org.uk/guidance/ng106">www.nice.org.uk/guidance/ng106</a></td>
<td>“The specialist heart failure MDT should write a summary for each person with heart failure..... Give a copy of the care plan to the person with heart failure... and all health and social care professionals involved in their care.” p8</td>
</tr>
</tbody>
</table>

Variability between Work-as-Imagined and Work-as-Done

We identified variability between how work is imagined by guidelines and reported to be done in practice by participants. This could be understood through three interrelated themes: working with complexity; information transfer; and working relationships.

Working with Complexity

Guidelines imagine a multidisciplinary team (MDT) holding a shared perspective on the best medical management of patients’ conditions aligned with patient preferences. In contrast, frontline clinicians described that the day-to-day work of managing HFrEF as a poorly understood condition, typically alongside medical and social comorbidity, did not reflect the clarity of medical decision-making and care delivery imagined in guidance.

“When there are housing issues... other factors causing breathlessness... When there’s an element of mental illness or dementia, when there’s immobility... the list goes on really... it’s almost always a complex problem.” GP7
Variation between participant reports compared with guideline ideals could be understood through three subthemes.

**Seeking a Unicorn – The Accessible Time-Rich Specialist Generalist**

Most clinicians felt that these patients were best managed by an expert generalist in the community who could navigate comorbidity. However, many reported that primary care clinicians could lack specialist knowledge needed to diagnose and optimally manage HFrEF. This resulted in inconsistent referral and prescribing practices requiring variable amounts of coordination. Specialists reported discomfort managing the messiness of comorbidities. Whereas, primary care clinicians found the remit of heart failure services too narrow. Several raised single specialty care as an inefficient use of resources in the context of a growing multimorbid population, for which all professionals require an awareness of patients’ holistic needs.

“[heart failure nurses] are very one dimensional… we need more frailty nurses who are trained in the broad spectrum of chronic diseases, all of which interact” GP9

Work conditions such as appointment length, clinician workload, regional variability in commissioning and a lack of budgetary incentives for HFrEF exacerbated perceptions that specialist and generalist services functioned largely separately of one another.

“nobody can agree on who sees them, when they see them, what resources they've got for it” GP11

In theory accessible, aligned specialist and generalist care should be deliverable via a team of professionals with different professional boundaries. However, this illusive combination may be somewhat of a ‘unicorn’ within current time and resource poor services.

**Navigating Inconsistent Advice**

Clinicians described conflicts between single condition guidelines and the patient in front of them and the performance variability inherent to individualising decisions.

“I suppose we can all read the NICE guidance... but patients don’t always fit into a guidance do they” PN1

Patients sometimes found individualised clinician decisions disconcerting. Several attributed personalised management to inequitable treatment provision or poor clinician knowledge, particularly when the rationale for decisions was unclear or clinicians had conflicting opinions.

“You go and see them about your heart, and they say... we’ll just tweak this, oh we’ll just try this... says to me, you don’t really know what you’re doing, do you?” P1

**Linear pathways, circuitous journeys**

Many clinicians described referral pathways, in keeping with guidelines, as linear single disease pathways. However, patient descriptions of their route to diagnosis were often circuitous, for example, following several different speciality appointments. HFSNs described diagnosis being complicated by comorbidities, suggesting medical complexity may explain some of this discrepancy.

“you will get a patient that is significantly breathless, but they may have underlying COPD, and it’s trying to differentiate... it’s a real challenge” HFSN3
Patients described managing multiple, diverse appointments, frequently in the context of poor mobility, frailty and limited transportation options. Clinicians raised that the location of care delivery was a constraint affecting their ability to optimize care, but that resourcing implications of home care were significant. Descriptions suggested there could be unseen bottlenecks to patients accessing coordinated care, compared with the linear routes imagined. Several suggested heart failure specialist care delivered in primary care settings could offer some resolution.

“If they’re well and can get a lift from my town to the hospital, and then it’s a two-hour round trip... with poor link-up of notes... people are actually happily enacting as part of their jobs things which just don’t work for the patient” GP5

**Information Transfer**

Guidelines envisage seamless transfer of accurate, complete information between stakeholders via interoperable IT interfaces facilitating coordinated care. Variability between imagined and reported informational continuity could be understood through three subthemes.

**Clinical record Information Technology (IT) systems**

Participants offered few examples of clinical record IT systems already functioning with a shared interface and that this limited sharing of investigation results and management advice. Obtaining reports or repeating tests was felt to increase demand in a system with limited capacity. Medication changes and diagnoses made in primary care could go unrecognised at specialty appointments due to lack of contemporaneous record sharing, resulting in recommendations that were either impossible or inappropriate to act upon and which could result in extra work to ensure safety.

“often secondary care... they can send us through... I want you to start this... Actually they’re already on it... or they’ve actually got asthma, so I can’t start a beta-blocker. Secondary care never had that information, we had that information all along... So it causes a lot of inefficiency and delay.” GP7

Clinicians perceived IT systems to lack adequate codes to identify HFrEF patients within the heart failure group. This was exacerbated by a lack of diagnostic clarity, a perception of poor clinician coding practices and a lack of financial incentives for HFrEF care.

“GPs dare I say it, are notoriously useless at coding... So therefore, firstly A, we’re missing on the income for it, B, the patient’s not getting the recalls, flu jabs, all these other things” GP11

**The challenge of clear multifunctional correspondence**

Most clinicians reported written correspondence between healthcare professionals varied in quality, in conflict with guideline-imagined processes of uniform information sharing meeting all stakeholder needs. Time pressure and the clinical experience level of writers were proposed as factors affecting quality.

“you get people who say this particular person is breathless, they’ve responded to diuretics, please continue. Well okay, but it doesn’t tell me the diagnosis.” GP11

Clinicians described situations where lack of clarity in correspondence resulted in performance variability. A cardiac physiologist described how limited referral information could result in untargeted echocardiogram reports and missed diagnoses. HFSNs raised that insufficient information within referrals could affect workflow.
“we sometimes get referrals from GPs which are not detailed at all... We then have to ring and say, ‘What do you want us to do?’” HFSN1

Many clinicians identified that one piece of correspondence struggled to balance multiple stakeholder needs, given variable HFpEF knowledge and a lack of consensus regarding professional role boundaries. Echocardiogram reports were frequently raised as an example.

“the system of echocardiograms is not in my view designed in any way to help clinicians or patients, lots of technical measurements are provided and no clear guidance is provided on what this means for the clinician...” GP5

Patients generally valued being copied into letters. However, some felt that these lacked understandable information, particularly regarding medications and diagnoses, which could cause distress.

“It’s just the terminology they use really. I mean, if [patient1] received this letter on his own, he would think, what’s that? That sounds horrible. What does that mean?” P1 Carer

The inertia of the letter

Guidelines highlight the importance of timely, shared, written correspondence for providing cohesion in patient management plans. Patients and clinicians were generally accepting of system reliance on letters, but suggested that this could limit coordination of care across the interface.

Some HFSNs described confusion when written advice to primary care had not been acted on, suggesting a lack of feedback in the letter system acts as a barrier to coordinated care.

“It was my third letter that I wrote to the GP asking to review hypertensive but they never did” HFSN4

Clinicians were aware of the potential for delays or inaction in response to letters and reported adjusting modes of communication to telephone, fax or more rarely email to enhance patient safety. They described efficiency/thoroughness trade-offs affecting their decisions to perform this work.

“So I can pick up the phone to <<HFSN>>... then we can physically have a discussion... if you speak to the cardiologists at the hospital, you would typically be writing a letter, there’s no direct access email, they’re far harder to contact on the phone via their secretaries... there are so many more barriers to communication” GP7

Several GPs raised potential benefits of direct access email communication and more face-to-face interactions with specialists. They reflected that system reliance on letters resulted in lost opportunities to upskill and build working relationships.

Working relationships

Guidelines envisage seamless, multi-professional collaboration of clinicians working in partnership across the interface and with patients. While relational continuity is not explicitly recommended in guidance, it is implied to exist with the GP, or with a team. This description sits in tension with reported experiences of inter-professional and patient-clinician working relationships. Variation could be understood through two subthemes.
The GP as ‘the intermediary’ or ‘the partner’?

One area described successful partnership working across the interface, where GPs attended MDT meetings in person. However, most participants described a relational disconnect between primary care and specialist services. It was rare for GPs to be described as active partners within the MDT. This was in tension with their almost universal recognition by participants and in guidance as key stakeholders.

“There is that lack of face to face interaction [with HFSNs]… it’s still very much working in silos.” GP10

This issue was coupled with service design and commissioning arrangements resulting in work being passed across the interface without shared understanding of work conditions. Requests perceived to be simple by secondary care, were reported by GPs to be time and resource consuming. Clinicians felt that, in these circumstances, GPs functioned as an intermediary, providing logistical support rather than clinical expertise to patient care. However, the location of specialist services and patient mobility could limit alternative arrangements.

“They’re really being used as a technical point, if you like, to get the blood tests done… because the GP is not necessarily involved in that episode of care…. So it kind of becomes fragmented” C3

Most clinicians felt that heart failure care would benefit from better integration into the community, with mentoring in difficult cases from specialists. Virtual ward rounds and enhanced primary care involvement in MDTs were proposed as improvement initiatives.

The patient coordinator – managing variable relational continuity

Guidelines emphasise the importance of patients having a key contact who can facilitate care coordination, typically their GP or a HFSN. Interview data suggested experience of this was variable. Engaged patients and carers worked hard to coordinate their own care. However, while they could work to arrange appointments, monitor their health, and take their medications, they identified a need for health services to respond to their requests for support. Many felt responsiveness was variable and described experiences of fragmented care and loss of trust.

“And you go to the GP, and you don’t see the same GP… First you’ve got to get through the wall of the receptionists… I don’t feel confident… and to be honest, if I’m feeling that ill, I’m going to the hospital.” P4

Clinicians echoed this, suggesting self-care needed to be properly supported by services and that poor resourcing and regional variation could limit this.

“Health care isn’t really self-care, it’s self-care supported by the health service.”
Commissioner

Patients with accessible, relational continuity with a clinician reported a feeling of cohesion around their care, compared with patients who struggled to obtain this.

“So even a nurse practitioner at the practice, whose keeping an overall view of what’s going on and what’s happening would help… there isn’t anybody… it just all seems very random” P2
DISCUSSION:

System complexity has been proposed to exist in the coordination of care for people with chronic conditions both horizontally in terms of interactions between patients and providers and vertically in terms of interactions between organisations, organisational processes and funding.[10] This analysis, using the STEW principles,[23] illustrates the system factors posing challenges to optimally managing complex HfPEF patients within the convoluted, resource-limited system of multiple-provider care provision in England.

Currently, specific clinics and models of care for HfPEF are rare across health systems,[6,7,35] and the condition is poorly recognized and understood.[36,37] This must be addressed given recent therapeutic advances to ensure effective and equitable care provision.[2,38] While this study focused on heart failure care in England, a wide variety of approaches to improve heart failure care have been evaluated internationally.[6,39,40] The challenges identified in this study are relevant to the development and improvement of multi-professional care programmes for HfPEF in any healthcare setting.

Comparison with existing literature

The continued development and implementation of clinical practice guidelines contributes to improvements in patient care.[41] However, this study, consistent with existing concerns, highlights challenges to their practical implementation and raises questions as to the appropriateness of single condition guidelines for patients with multimorbidity.[42,43]

Heart failure guidelines and evidence to date recommend a multidisciplinary approach.[39,40,44,45] Artificial professional boundaries have been previously recognized as a constraint on the inter-professional and inter-organisational work required to deliver multidisciplinary coordinated care.[10,46] Reports from this study, identifying the need for both specialist and generalist skills for HfPEF management, highlight a false dichotomy between these skills within services. While specialist input is undoubtedly required for HfPEF given its diagnostic challenges,[47] recently international medical leaders have called for a focus on generalism across all services given rising levels of multimorbidity and frailty.[48–50]

Continuity of care is associated with reduced mortality and is a facilitator of effective coordination of care.[19,51] Both concepts have been highlighted by patients, clinicians and policy makers as a key priority for improving the management of chronic conditions across the world.[52–54] Patients in this study valued relational continuity, but identified limited access, resources and time as barriers to this, consistent with previous literature.[55] As we navigate increasing clinical complexity, system conditions, such as workload and appointment length, need to be addressed to support the advantages of the patient-clinician relationship.[56]

Participants also identified previously documented challenges to informational continuity.[57–59] Information transfer underpins how knowledge and professional boundaries are navigated in practice[18] and, when inadequate, can be a factor in adverse events at transitions of care.[12] In addition, a lack of feedback in communication systems can result in lost learning opportunities and affect care coordination quality.[60,61]

Guidelines analysed for this study did not provide practical advice on how the work of coordination of care should be performed. Moving forward, defining this work for complex patients and how this should be distributed is important. However, a lack of internationally accepted tools and metrics for assessing and monitoring the effectiveness of care coordination models remains an ongoing challenge.[62] This study’s findings, aligned with previous literature, highlight that organisational processes and work conditions can limit partnership working and impact patient care.[63–65] Where
care is delivered across services, historic divisions between providers, coupled with capacity and resourcing pressures, can allow clinicians to distance themselves from aspects of patient need.[66] Balint described this as a ‘collusion of anonymity’ resulting in gaps in care.[56] Participants described advantages of including primary care in the MDT, reflecting calls in the literature for interventions to bring clinicians together.[53,67,68]

The work of coordination of care is not limited to professionals. Patients in this study described working to coordinate their own care. Indeed, encouraging patient self-management is promoted in policy and guidance,[4,48,65] and has been associated with reduced health care utilization.[69] Our results confirmed primary analysis findings that self-care capacity is dependent on knowledge and access to health-service support.[26] Recent literature suggests patient work may be a helpful and necessary source of system resilience.[10,70]

Implications for policy and research

Addressing issues in HFpEF care may provide transferable learning relevant to other patients with complex and/or multiple long-term conditions. There is a compelling need for interventional research to determine optimal practice for poorly understood and costly conditions like HFpEF.

Our participants raised a tension between resourcing and patient demand, in keeping with documented concerns regarding the economic burden of heart failure care.[21,71] There is limited evidence regarding the cost-effectiveness of improving quality, and even less regarding care coordination quality.[62,72] This deficiency must be addressed to enable justification for spending on improvement initiatives in resource-scarce healthcare systems.

Our findings can be extrapolated to recommendations aligned with other studies that might improve coordination of care for HFpEF (Table 5). Evidence for complexity-informed interventions thus far has been inconsistent, perhaps due to inherent heterogeneity.[62,73] Further work should establish how best to build interventions that accommodate local work conditions, while supporting the comparability to build an evidence base.
Table 5 Recommendations for practice

**Recommendations for practice with potential to improve coordination of care for HFrEF**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Intervention &amp; supporting reference(s)</th>
</tr>
</thead>
</table>
| **Working with complexity** | • Support development of generalist skills within specialist services[48,74]  
                               • Support development of HFrEF specific knowledge in primary care[26,47]  
                               • Support development of nursing roles and education to support complexity and multimorbidity[75]  
                               • Consider workload and accessibility of professionals when determining roles and responsibilities in care for HFrEF[55]  
                               • Consider multimorbidity and mobility issues when designing and commissioning services e.g. ‘cluster medicine’ clinics, community specialist clinics, home care delivery[76]  
                               • Align financial incentives e.g. QOF with best practice for HFrEF and integrated working[26,77]  
                               • Support patient education to enable understanding of individualised decisions in complex LTCs such as HFrEF[78] |
| **Information transfer**    | • Develop and implement interoperability of IT systems to facilitate consistent sharing of records and care plans between primary care and specialist services[79]  
                               • Consider further training regarding appropriate coding practice for heart failure[57]  
                               • Develop and implement timely modes for advice e.g. Econsult[80]  
                               • Develop mechanisms of feedback to improve correspondence quality[81]  
                               • Consider a degree of standardisation of correspondence to facilitate clarity of diagnosis and management while retaining flexibility to accommodate personalised recommendations[82]  
                               • Develop goals for correspondence in accordance with needs of the recipient[83] |
| **Working Relationships**   | • Agree work distribution and resourcing across the interface when implementing HFrEF services[84]  
                               • Develop systems to support multidisciplinary working that embeds primary care centrally e.g. virtual MDT, community clinics in GP practices[85]  
                               • Support face-to-face or equivalent e.g. virtual working between professionals to support collaborative working[86,87]  
                               • Develop services to support relational continuity for patients with LTCs[51]  
                               • Enable patient engagement through provision of accessible support e.g. a key contact[65,70] |

**Strengths and Limitations:**

This multi-perspective, multi-sited dataset promotes transferability of findings and trustworthiness.[88] However, there would be benefits in seeking further stakeholder perspectives, such as administrative staff, other healthcare professionals and third sector workers.

As a supplementary analysis, this study deepens understanding of themes identified in primary analysis[26] somewhat mitigating potential concerns regarding data fit.[28] Continued reflexivity and regular discussion with the data collecting team during analysis as a form of researcher triangulation aimed to minimize loss of context and enhance rigour.[89] However, interview data only assess ‘work-as-reported’ which may differ from ‘work-as-done’. Observational studies would illuminate discrepancies between these.[90] This is particularly important given changes in working practices and services since the COVID-19 pandemic.[91,92]
CONCLUSION:
This project aimed to explore, through a systems thinking lens, how care is coordinated for patients with HFpEF with a focus on the interface between primary care and specialist services.

Variability between work-as-imagined and work-as-done could be understood through three interrelated themes: working with complexity, information transfer and working relationships.

Our findings have implications, which could affect the design of interventions to improve coordination of care. More widely, aligned with policy and research, they reflect the importance of acknowledging system complexity as we strive to improve care quality alongside increasing medical and social multimorbidity.
Figure Legends

Figure 1 Systems Thinking for Everyday Work Principles - image taken and adapted with explanation from McNab et al 2020 [23]

Figure 1 Prisma Flow Chart for Guidelines Related to Coordination of Care for HfP EF

BIBLIOGRAPHY


12. Redwood S, Brant H, Maluf A, Combes G, Neubauer K, Thomas C, et al. How latent patterns of interprofessional working may lead to delays in discharge from hospital of older people living...


43. Carol Sinnott, Sheena Mc Hugh, John Browne, Colin Bradley. GPs’ perspectives on the management of patients with multimorbidity: systematic review and synthesis of qualitative research. BMJ Open. 2013 Sep 1;3(9):e003610.


56. Edgcumbe D. But there are no QOF points for Balint work!: its place in modern practice. Br J Gen Pract. 2010 Nov;60(580):858–9.


