

# BMJ Open Barriers to accurate diagnosis and effective management of heart failure have not changed in the past 10 years: a qualitative study and national survey

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## ABSTRACT

**Objectives:** To explore changes in healthcare professionals' views about the diagnosis and management of heart failure since a study in 2003.

**Design:** Focus groups and a national online cross-sectional survey.

**Setting and participants:** Focus groups (n=8 with a total of 56 participants) were conducted in the North East of England using a phenomenological framework and purposive sampling, informing a UK online survey (n=514).

**Results:** 4 categories were identified as contributing to variations in the diagnosis and management of heart failure. Three previously known categories included: uncertainty about clinical practice, the value of clinical guidelines and tensions between individual and organisational practice. A new category concerned uncertainty about end-of-life care. Survey responses found that confidence varied among professional groups in diagnosing left ventricular systolic dysfunction (LVSD): 95% of cardiologists, 93% of general physicians, 66% of general practitioners (GPs) and 32% of heart failure nurses. For heart failure with preserved ejection fraction (HFpEF), confidence levels were much lower: 58% of cardiologists, 43% of general physicians, 7% of GPs and 6% of heart failure nurses. Only 5–35% of respondents used natriuretic peptides for LVSD or HFpEF. Confidence in interpreting test findings was fundamental to the use of all diagnostic tests. Clinical guidelines were reported to be helpful when diagnosing LVSD by 33% of nurses and 50–56% of other groups, but fell to 5–28% for HFpEF. Some GPs did not routinely initiate diuretics (23%), ACE-inhibitors (22%) or  $\beta$ -blockers (38%) for LVSD for reasons including historical teaching, perceived side effects and burden of monitoring. For end-of-life care, there was no consensus about responsibility for heart failure management.

**Conclusions:** Reported differences in the way heart failure is diagnosed and managed have changed little in the past decade. Variable access to diagnostic tests, modes of care delivery and non-uniform management approaches persist. The current National Health Service (NHS) context may not be conducive to addressing these issues.

## Strengths and limitations of this study

- Focus groups were held with a wide range of clinical staff to the point of data saturation and validated against historical work.
- The questionnaire response rate was low, although 514 professionals responded.
- Nevertheless, this study provides new understanding of the reasons behind the evidence-practice mismatch for heart failure diagnosis and management in the UK; in particular, the findings highlight the difficulties faced by clinicians in implementing current guidelines.

## INTRODUCTION

Heart failure (HF) is a major health problem in industrialised countries with ageing populations.<sup>1</sup> HF diagnosis and management are complex with variable care provision.<sup>2</sup> Some variability may relate to access to services,<sup>3</sup> regardless of public or private provision.<sup>2–4</sup> The key to reducing mortality, morbidity and costs associated with HF is early, accurate diagnosis and appropriate management.<sup>5–7</sup> Traditionally, HF has been attributed to left ventricular systolic dysfunction (LVSD), generally measured as a reduced ejection fraction. The evidence base for treatment with medication and device therapy relates to LVSD,<sup>8</sup> but over 50% of HF hospitalisations occur in patients with preserved ejection fraction (heart failure with preserved ejection fraction (HFpEF)).<sup>9–12</sup> HFpEF has sometimes been equated with diastolic HF, although the existence of HFpEF per se has been questioned and an evidence base for treatment is lacking.<sup>13–14</sup> HF is difficult to diagnose accurately as symptoms are often non-specific and physical signs can be difficult to elicit<sup>15–16</sup>; there is evidence to suggest that diagnosis is missed in up to two-thirds of cases.<sup>17</sup>

In 2003, we reported reasons why general practitioners (GPs) had not implemented best evidence in the diagnosis and management of HF.<sup>2</sup> Key barriers included a lack of confidence in diagnosis and management, a lack of awareness of the relevant evidence base for care, and variation in GPs' personal preferences and organisational care pathways. Since then, there have been major National Health Service (NHS) reorganisations including dedicated HF services<sup>18</sup> and the introduction of technologies such as cardiac resynchronisation therapy (CRT).<sup>19</sup> Despite, or perhaps because of, ongoing developments, there is variability in the diagnosis and management of HF<sup>20</sup> including service access,<sup>3 4</sup> which includes the availability and use of services. This two-phase study evaluated key barriers and facilitators to the appropriate management of HF in the UK, comparing findings with those reported in 2003,<sup>2</sup> and extending the previous evaluation to include cardiologists, general physicians and HF nurses as well as GPs in a national survey. The previous study<sup>2</sup> employed purely qualitative methods (focus groups) with GPs in the North East of England. The current (national) study sought to replicate and expand this to include focus groups with GPs and other relevant clinicians, and a national survey of specialist and non-specialist clinicians.

## METHODS

Focus group participants were recruited from health authority registers for the North East of England, including salaried GPs and GP partners, cardiologists, general physicians and HF nurses. Purposive sampling<sup>21</sup> allowed a diverse representation of gender, role, seniority, ethnicity, geographical distribution, employment status (part or full time) and practice size (group or single-handed) and avoided over-representation of individual practices. Specific numbers were guided by data saturation across groups.<sup>22</sup> A qualitative (hermeneutic phenomenological) approach<sup>23 24</sup> was used to explore clinicians' decision-making, as well as experiences of barriers and facilitators to delivering HF care. Thus, the emphasis was on participants describing their experiences and beliefs about 'what can and should be done'. During focus groups, a facilitator presented clinical vignettes covering the diagnosis of LVSD and HFpEF, the use of B-type natriuretic peptide and N-terminal pro-B-type natriuretic peptide (BNP and NT-proBNP) and ECGs, the use of ACE-inhibitors (ACEi),  $\beta$ -blockade and spironolactone therapy, cardiac resynchronisation therapy, rehabilitation and end-of-life care. Sessions were audio taped, transcribed verbatim and verified by the facilitator (AF or JJM) and moderator (HCH or HC).

Themes derived from the focus groups informed the development of a UK survey which sought to assess views about care provision from diagnosis to the end of life. An initial pilot survey involved 14 healthcare professionals drawn from the groups of interest. Piloting promoted a survey language and format that was acceptable

and meaningful to participants. The survey presented a series of neutral multiple-choice and open questions about the diagnosis and management of HF (LVSD and HFpEF), as well as facilitators and barriers to care (the survey can be viewed here: [https://www.survey.bris.ac.uk/durham/hf\\_survey](https://www.survey.bris.ac.uk/durham/hf_survey)). The survey was anonymised by code and an invitation to participate was sent by email to the complete sample of each of the five professional groups held by Binley's (<http://www.binleys.com/>); to maximise response, a reminder email was sent after 3 weeks. Binley's hold healthcare and public sector data, mailing lists, directories and maps covering NHS and local government; figures indicate that they hold contact details for 16 442 staff in the relevant groups (comprising: 2619 for cardiology and general medicine, 319 for specialist nurses and 13 504 for salaried GPs and GP partners). We estimated that a sample size of about 2100 would permit population rate precisions for binary values of about 2% (eg, rate 25%, deviation 2%, confidence 95%, N=1798). Subgroup sizes would permit differences between groups of about 10% (eg, 20% vs 30%, 90% power, 5%  $\alpha$ , N=412 per group, Fisher's exact test).

## Data analysis

Thematic data analysis<sup>23 24</sup> conducted by two phenomenologists (HCH and HC) produced a textural description of experiences of diagnostic and care provision for HF from the focus groups<sup>25</sup>; neither analyst was involved in the 2003 study. Preliminary codes were identified by each analyst, refined as coding progressed, and grouped into categories. From these, a set of themes emerged which were tested using diverse accounts within and between cases to challenge and define the integrity of the theme boundaries. Findings were subsequently discussed by the whole team.

Descriptive data analysis, using SPSS V.19, was used to summarise survey findings and explore subgroup patterns. The key subgroups were salaried (permanent, locum and out-of-hours) GPs, GP partners, cardiologists, general physicians and HF nurses. A lower than expected response rate was achieved and prevented a meaningful analysis of differences between groups.

## Results

### Study population

Eight focus groups with salaried and partner GPs, cardiologists, general physicians and HF nurse participants (39 GPs, 4 cardiologists, 6 general physicians and 7 HF nurses) were conducted between December 2010 and March 2011 in affluent and deprived locations in the North East of England.

For the national survey, of eligible staff from the professional groups included, 514 (3.1%) responses were received from staff working in 40 strategic health authorities (SHAs) across the UK. Of these, 10 were duplicate responses and a further 10 declined to indicate their occupational group; thus, a total of 494 unique responses were included in the analysis. Reasons for

non-participation are unknown. Not all respondents answered all questions; thus, denominators for each group and question are tabulated.

The majority of survey participants (69.4%) were aged between 41 and 60 years of age, were male (54.5%) and worked within an English SHA (85.3%). Baseline characteristics of participants are shown in table 1. Similar demographic trends were apparent in each professional group with the exception of salaried GPs and nurses who were predominantly female. Focus group themes and survey responses are reported together.

### Study findings

From the focus groups, four categories were identified which contribute to variations in the diagnosis and management of HF: uncertainty about clinical practice, the value of clinical guidelines, tensions between individual and organisational practice, and, uncertainty about end-of-life care. The first three categories virtually replicated 2003<sup>2</sup> findings, and the fourth was new.

### The diagnostic process

The majority of survey respondents had responsibility for diagnosing HF due to LVSD with the exception of nurses of whom 23% reported doing so. Comorbidities and non-specific symptoms and signs were the most challenging aspect of making a diagnosis. Cardiologists, general physicians and nurses rated comorbidities highest while GPs rated non-specific signs and symptoms as most highly challenging. A lower proportion of HF

nurses (32%) were confident in their ability to diagnose LVSD than any other group, followed by GPs (66%) when compared with 95% and 92% of cardiologists and general physicians.

I'd leave it to specialists (Out-of-hours GP)

The majority of cardiologists (87%) identified that they had responsibility for diagnosing HFpEF, followed by general physicians (59%). Of the 13 cardiologists who did not diagnose HFpEF, 9 were not convinced that HFpEF exists. Most GPs (84%) and nurses (87%) did not diagnose HFpEF. A lower proportion of GPs (7%) were more confident in their ability to diagnose HFpEF than any other group. One cardiologist commented that they would like access to "A crystal ball" to inform HFpEF diagnosis, while a GP partner asked "What is HFpEF?"

A cardiologist highlighted the complex nature of diagnosis:

I've rescued a few people with heart failure from asthma clinics...But we all know it's very hard to do sometimes, isn't it, in someone who's breathless and they've got crackles and they've got a funny looking x-ray, and distinguishing between fibrosis and chronic lung disease and heart failure, just on that first visit isn't always very easy. (Cardiologist)

### Diagnostic tests

The majority of survey respondents who diagnosed LVSD used ECGs, chest X-rays and clinical assessment, the exception being nurses. Around a quarter of the nurses (23%) and half of the GPs (49%) were confident in interpreting the results of an ECG while most cardiologists and general physicians (both: 87%) were confident. One-third of nurses (33%) and two-thirds of GPs (65%) were confident in interpreting the results of an echocardiogram while the majority of cardiologists and general physicians (98% and 85%, respectively) were confident. Cardiologists were more likely to use ECGs and chest X-rays (64% and 63%, respectively) to diagnose HFpEF than other groups; clinical assessment was almost never used by any group. This was reflected in the confidence levels in interpreting these results (see table 2).

### Availability and use of echocardiography services

For LVSD, echocardiographic findings were used by 97% of cardiologists, 91% of general physicians, 52% of salaried GPs, 35% of GP partners and 31% of nurses. Even though availability was generally high, some GPs and general physicians were reluctant to use open access echocardiography because of a lack of knowledge about interpreting results; many preferred to refer the patient to a cardiologist or to a specialist HF clinic.

...I don't understand a lot of the [echocardiograms]... (GP partner)

**Table 1** Baseline characteristics of survey respondents

Characteristics	Participants
Age (years)*	
20–40	125 (26%)
41–60	333 (69%)
61+	22 (5%)
Gender†	
Male	263 (55%)
Female	220 (45%)
UK region‡	
England	422 (85%)
Scotland	24 (5%)
Wales	32 (7%)
Northern Ireland	12 (2%)
Professional group§	
Salaried GP	84 (17%)
Partner GP	167 (33%)
Cardiologist	103 (20%)
General physician	54 (11%)
Heart failure nurse	78 (16%)
Other	8 (2%)

Denominator for each variable:

\*n=480.

†n=483.

‡n=490.

§n=494.

GP, general practitioner.

**Table 2** Beliefs about current practice, facilitators and barriers to the diagnosis of LVSD and HFpEF

Diagnostic issue	GP N=251	Cardiologist N=103	General physician N=54	HF nurse N=78	Total N=494
Currently diagnose					
LVSD	189 (75.3%)	99 (96.1%)	51 (94.4%)	18 (23.1%)	357 (72.3%)
HFpEF	40 (15.9%)	90 (87.4%)	32 (59.3%)	10 (12.8%)	172 (34.8%)
Confident to diagnose					
LVSD	166 (66.1%)	98 (95.1%)	50 (92.6%)	25 (32.1%)	339 (68.6%)
HFpEF	17 (6.8%)	60 (58.3%)	23 (42.6%)	5 (6.4%)	105 (21.3%)
Use echocardiography to diagnose					
LVSD	103 (41%)	100 (97.1%)	49 (90.7%)	24 (30.8%)	276 (55.9%)
HFpEF	54 (21.5%)	94 (91.3%)	36 (66.7%)	16 (20.5%)	200 (40.5%)
Would use echo but no access for					
LVSD	4 (1.6%)	0 (0%)	1 (1.9%)	0 (0%)	5 (1%)
HFpEF	7 (2.8%)	1 (1%)	2 (3.7%)	0 (0%)	10 (2%)
Use BNP to diagnose					
LVSD	69 (27.5%)	16 (15.5%)	7 (13.0%)	7 (9.0%)	99 (20.0%)
HFpEF	23 (9.2%)	19 (18.4%)	10 (18.5%)	2 (2.6%)	54 (10.9%)
Would use BNP but no access for					
LVSD	82 (32.7%)	24 (23.3%)	27 (50.0%)	8 (10.3%)	141 (28.5%)
HFpEF	30 (12.0%)	22 (21.4%)	19 (35.2%)	4 (5.1%)	75 (15.2%)
Use NT-proBNP to diagnose					
LVSD	45 (17.9%)	26 (25.2%)	6 (11.1%)	6 (7.7%)	83 (16.8%)
HFpEF	14 (5.6%)	25 (24.3%)	4 (7.4%)	4 (5.1%)	47 (9.5%)
Would use NT-proBNP but no access for					
LVSD	57 (22.7%)	30 (29.1%)	17 (31.5%)	9 (11.5%)	113 (22.9%)
HFpEF	20 (8.0%)	26 (25.2%)	10 (18.5%)	5 (6.4%)	61 (12.3%)
Use ECGs to diagnose					
LVSD	172 (68.5%)	84 (81.6%)	40 (74.1%)	15 (19.2%)	311 (63.0%)
HFpEF	43 (17.1%)	66 (64.1%)	27 (50.0%)	12 (15.4%)	148 (30.0%)
Would use ECGs but no access for					
LVSD	1 (0.4%)	0 (0%)	0 (0%)	1 (1.3%)	2 (0.4%)
HFpEF	2 (0.8%)	0 (0%)	1 (1.9%)	0 (0%)	3 (0.6%)
Use chest X-rays to diagnose					
LVSD	156 (62.2%)	67 (65.0%)	42 (77.8%)	9 (11.5%)	274 (55.5%)
HFpEF	44 (17.5%)	65 (63.1%)	28 (51.9%)	6 (7.7%)	143 (28.9%)
Would use chest X-rays but no access for					
LVSD	3 (1.2%)	0 (0%)	0 (0%)	0 (0%)	3 (0.6%)
HFpEF	5 (2.0%)	0 (0%)	1 (1.9%)	0 (0%)	6 (1.2%)
Use clinical assessment to diagnose					
LVSD	200 (79.7%)	92 (89.3%)	49 (90.7%)	21 (26.9%)	362 (73.3%)
HFpEF	1 (0.4%)	3 (2.9%)	1 (1.3%)	0 (0%)	5 (1.0%)

BNP, B-type natriuretic peptide; GP, general practitioner; HF, heart failure; HFpEF, heart failure with preserved ejection fraction; LVSD, left ventricular systolic dysfunction; NT-proBNP, N-terminal pro-B-type natriuretic peptide.

Cardiologists and nurses were more confident in using and interpreting echocardiography reports than GPs but expressed frustration about patients not routinely referred for echocardiography testing and the poor quality of referral information:

...we go onto the ward, we read the notes, and it's screaming heart failure at you, screaming it. And nobody's considered doing an echo. And...you want to just say, will you please echo this patient! (HF nurse)

To diagnose HFpEF, most cardiologists used echocardiography (91%) followed by physicians (67%), salaried GPs (30%), nurses (21%) and GP partners (17%).

Again, confidence in using results reflected this pattern of usage (table 2).

#### *Availability and use of BNP and NT-proBNP*

GPs were more likely to use BNP (28%) than other groups; similarly, NT-proBNP was used in low proportions. Between 10% and 50% of all respondents expressed a need for access to natriuretic peptides. However, a general physician commented:

We have tried BNP and found that it added no value (General Physician).

Between 10% and 61% of all respondents expressed confidence in interpreting the results of natriuretic peptides in LVSD diagnosis (table 2). Few practitioners use natriuretic peptides to diagnose HFpEF.

### *Communicating a diagnosis*

All cardiologists (100%) and most physicians (94%) and nurses (95%) took responsibility for informing patients of a HF diagnosis; a minority of GPs felt that this was not their responsibility (16%) but a cardiologist's. One cardiologist commented:

In some patients it is very easy and in some very difficult. Communicating difficult information well requires training and experience. (Cardiologist)

And another:

I think it's something we haven't been trained to do. (Cardiologist)

Most participants felt it was important to educate patients about their illness but some expressed concerns about informing patients of their diagnosis as this might lead to anxiety.

I don't tend to tell them that their prognosis is pretty lousy if they've got a bad heart, which it is, isn't it. (Cardiologist)

### *The value of clinical guidelines*

When diagnosing LVSD, a third of nurses (33%) and about a half (50–56%) of other groups found clinical guidelines helpful (table 3). All groups identified the National Institute for Health and Care Excellence (NICE) guidelines as the most helpful for the management of LVSD (50–89%). Information overload was seen as a common cause of anxiety among salaried and partnered GPs. Some participants felt that it was 'too late' for them to be educated.

The problem with being a GP is there's so many; if you read all of the bloody NICE guidelines that were relevant to us, and there're all big weighty documents, and we're meant to all look at them, and sign them off for the PCT. (GP partner)

I mean things like pacing and ventricular pacing and synchronised pacing. Those are things which are way beyond me, I say, it's too late for me to be educated in that. I like the heart failure team to make that decision. (General physician)

When managing LVSD, nearly all nurses (95%) and the majority of other groups (57–73%) found clinical guidelines helpful. All groups identified NICE guidelines as the most helpful (53–80%). A GP partner stated:

...guidelines rarely cover options in poly-pharmacy and are written by academics. (GP Partner)

Only a minority of respondents in any group found clinical guidelines helpful when diagnosing and managing HFpEF.

Some GPs and HF nurses felt duty bound to follow guidelines but expressed frustration that they did not offer enough scope for individualised care:

I try and use them but I think a lot of people don't fit into them, the little boxes. (GP partner)

Some salaried and locum GPs valued guidelines and expressed the view that they led to more confident decision-making:

...it gives you confidence if you've got some guidelines, sitting with the patient, you can follow, you know, follow instructions a little bit, which does make you feel a bit more confident. (Locum GP)

In contrast, cardiologists appeared more confident in using their clinical judgement and discretion in preference to following guidelines and described decision-making in more complex, multilevel and nuanced ways than GPs.

...trying to keep abreast of what the literature's suggesting you do, but also the fact that you're a little bit constrained by guidelines that are seemingly quite behind the literature. (Cardiologist)

### *HF management*

Of those who managed LVSD, all groups cited comorbidities as the most challenging aspect of management. GPs and general physicians cited polypharmacy as being the second most challenging aspect, while cardiologists and nurses cited unpredictable disease progression. Some GPs felt that the organisation of care, with an emphasis on specialist HF services, led to deskilling in primary care.

The thing that concerns me most is being deskilled because as I'm doing much less management of heart failure than, the heart failure nurses are probably doing a lot more. (GP Partner)

A particular concern among GPs, regardless of the level of experience, was anxiety about the delicate risk-benefit balance where management required investigations, initiation and titration of evidence-based medication and monitoring:

Things like titrating the beta blockers as well, and ACE inhibitors, diuretics. It's all a challenge really. (Salaried GP)

And the other thing, it's a necessary evil, all the monitoring you have to do when you're titrating the medications. You just have to see people every bloody two weeks. (GP partner)

Cardiologists most commonly initiated medication for the treatment of LVSD, although the majority of all

**Table 3** Beliefs about the use of clinical guidelines in the diagnosis and management of HF

Management issue	GP N=251	Cardiologist N=103	General physician N=54	HF nurse N=78	All respondents N=494
Helpful for diagnosing LVSD	139 (55.4%)	58 (56.3%)	27 (50.0%)	26 (33.3%)	250 (50.6%)
Helpful for diagnosing HFpEF	28 (11.2%)	29 (28.2%)	15 (27.8%)	4 (5.1%)	76 (15.4%)
Helpful for managing LVSD	166 (66.1%)	75 (72.8%)	31 (57.4%)	74 (94.9%)	346 (70.0%)
Helpful for managing HFpEF	33 (13.1%)	28 (27.2%)	15 (27.8%)	14 (17.9%)	90 (18.2%)

GP, general practitioner; HF, heart failure; HFpEF, heart failure with preserved ejection fraction; LVSD, left ventricular systolic dysfunction.

groups reported initiating medication (table 4). Some GPs did not routinely initiate diuretics (23%), ACEi (22%) or  $\beta$ -blockers (38%). All respondents reported titrating medication for the treatment of LVSD. Concerns surrounding the initiation and titration of ACEi and  $\beta$ -blockers seemed to arise as a result of previous teaching, a fear of side effects and the burden of monitoring.

The danger of impaired renal function with high doses of not only the diuretics but the ACE inhibitors as well juggling doses of ACE inhibitors against diuretics, up and down, checking potassium. I do find some of those conflicts difficult to resolve. (GP partner)

There was a reluctance to prescribe additional medications to a group characterised by polypharmacy and comorbidities; this was seen as a particular problem in the elderly:

Particularly in more frail/elderly people for example, particularly if the blood pressure is hovering around 100–110 anyway, because of their age and you crank their ACE inhibitor as far as it can go, maybe a little bit dry as well, I think a  $\beta$ -blocker on top of that is always a bit of a

concern. Relatively easy to do, maybe, when the patient's already in hospital, and is going to be in for another day or so and they can see probably what's going to happen but it's more difficult out in the community. (GP partner)

All professional groups shared a reluctance to increase dosage if the patient was asymptomatic or stable:

I must say I'm inclined to do it when the patient's struggling a wee bit rather than when they're well. You know if you've got a perfectly, someone who's feeling great, and you put them on an ACE inhibitor and their kidney goes pear shaped, I tend to just not do anything I must admit. (Cardiologist)

Most GPs admitted to being unaware of the place for other agents including spironolactone and angiotensin II antagonists in treating HF:

What I'm not clear about is spironolactone, do we adjust the dose of that? It seems 25 mg is the recommended dose and yet when we used to use it 30 odd years ago it was always 100 mg of spironolactone. Is it more dangerous to use a higher dose, is there a titration schedule? I don't know. (GP partner)

**Table 4** Beliefs about current practice, facilitators and barriers to the pharmaceutical management of LVSD and HFpEF

Management issue	GP N=251	Cardiologist N=103	General physician N=54	HF nurse N=78	All respondents N=494
Role in management of LVSD	203 (80.9%)	100 (97.1%)	44 (81.5%)	74 (94.9%)	421 (85.2%)
Role in management of HFpEF	69 (27.5%)	87 (84.5%)	29 (53.7%)	51 (65.4%)	236 (47.8%)
Initiate medication for LVSD	202 (80.5%)	102 (99.0%)	50 (92.6%)	73 (93.6%)	427 (86.4%)
Titrate medication for LVSD	225 (89.6%)	101 (98.1%)	50 (92.6%)	77 (98.7%)	453 (91.7%)
Initiate diuretics for LVSD	193 (76.9%)	97 (94.2%)	46 (85.2%)	70 (89.7%)	406 (82.2%)
Titrate diuretics for LVSD	165 (65.7%)	61 (59.2%)	30 (55.6%)	70 (89.7%)	326 (66.0%)
Initiate ACEi for LVSD	196 (78.1%)	101 (98.1%)	49 (90.7%)	71 (91.0%)	417 (84.4%)
Titrate ACEi for LVSD	204 (81.3%)	92 (89.3%)	33 (61.1%)	76 (97.4%)	405 (82.0%)
Initiate ARB for LVSD	128 (51.0%)	80 (77.7%)	21 (38.9%)	64 (82.1%)	293 (59.3%)
Titrate ARB for LVSD	113 (45.0%)	65 (63.1%)	11 (20.4%)	73 (93.6%)	262 (53.0%)
Initiate $\beta$ -blockers for LVSD	155 (61.8%)	101 (98.1%)	41 (75.9%)	69 (88.5%)	366 (74.1%)
Titrate $\beta$ -blockers for LVSD	181 (72.1%)	91 (88.3%)	30 (55.6%)	76 (97.4%)	378 (76.5%)
Initiate spironolactone for LVSD	95 (37.8%)	98 (95.1%)	40 (74.1%)	67 (85.9%)	300 (60.7%)
Titrate spironolactone for LVSD	79 (31.5%)	48 (46.6%)	19 (35.2%)	63 (80.8%)	209 (42.3%)
Initiate digoxin for LVSD	55 (21.9%)	63 (61.2%)	24 (44.4%)	41 (52.6%)	183 (37.0%)
Titrate digoxin for LVSD	47 (18.7%)	29 (28.2%)	10 (18.5%)	39 (50.0%)	125 (25.3%)

ACEi, ACE-inhibition; ARB, angiotensin receptor blockers; GP, general practitioner; HF, heart failure; HFpEF, heart failure with preserved ejection fraction; LVSD, left ventricular systolic dysfunction.

Several respondents reflected on the lack of effective symptomatic treatment for HFpEF, leading to “an inability to do anything useful” (GP partner), while another GP partner stated:

I remember when I was doing my medical training, actually on a hospital basis, it (HFpEF) was semi-mythical and... it was apparently very difficult to diagnose and no one was quite sure what medications were best for it. So it was just assumed that everybody had systolic heart failure or cor pulmonale and then there were a few odd people who might have diastolic, we didn't know what to do about them. Well I still don't know what to do about them. (GP Partner)

A nurse stated:

I'm not comfortable in titrating people with that diagnosis (HFpEF) because there's very little evidence out there to say what drugs we should be using.

### Non-pharmaceutical management of HF

Around half of the respondents in all groups reported that they had access to rehabilitation for HF (table 5). HF nurses and cardiologists highlighted the importance of rehabilitation and frustration at the limitations on service provision in this area.

We had a support group running for our patients for about 4 years successfully, and now the commissioners have just pulled it because they won't fund it anymore. It was an exercise support group, rehab, and they won't fund it now, so we can't run it. (HF Nurse)

It's patients who've had heart failure and previous coronary disease...patients with heart failure secondary to cardiomyopathy. Then it's sometimes difficult to find a rehab program for them. (Cardiologist)

Few GPs (18%) understood the indications for electrical therapies in the management of HF compared with nearly all cardiologists (98%).

...you think 'crikey', particularly with the younger heart failure patients maybe they ought to go and talk to somebody who knows a bit more than me. Because maybe

there are things that can be done for them that I wouldn't even dream about. (GP Partner)

### Priorities for care in HF management

Views varied about priorities for investment to improve HF services. Cardiologists, general physicians, salaried GPs and nurses emphasised improved access to HF clinics and HF nursing teams; salaried GPs cited education for GPs.

If you look at heart failure admissions since we introduced specialist heart failure nurses and the heart failure clinic in 2002, they've actually gone down year on year. (General Physician)

...the clinic is every two weeks, so if you do the echo and then a clinic, that's 4 weeks you know, and 4 weeks without  $\beta$ -blockers, 4 weeks perhaps without ACE inhibitors...certainly we are dragging the whole process out. (GP partner)

### Tensions between individual and organisational practice

In addition to specialist medical training (or lack thereof) and clinical experience, another important theme influencing clinicians' diagnosing behaviour arose from the provisions made by outside organisations (health authorities, secondary care trusts and primary care trusts). For example, cardiologists and general physicians expressed concern about the organisation of specialist care by primary care trusts, which meant that services were unavailable at weekends:

The worst is the weekends because on the weekends you send a request out, this is logistics, it's nothing to do with the individual, because by the time they get the referral it's Tuesday, and you want the patient to be out by that time. (General Physician)

Time constraints and generally increasing clinical and administrative workload were highlighted by all GPs as being a barrier to effective HF management:

To look after patients properly they are very time consuming consultations, they take a large portion of GPs time...and the number of regular reviews that are clearly needed to manage the patients properly. There aren't that many conditions that we treat with that degree of

**Table 5** Beliefs about current practice, facilitators and barriers to the non-pharmaceutical management of LVSD and HFpEF (selected questions)

Management issue	GP N=251	Cardiologist N=103	General physician N=54	HF nurse N=78	All respondents N=494
Access to an HF clinic	150 (59.8%)	83 (80.6%)	36 (66.7%)	69 (88.5%)	338 (68.4%)
Routinely refer to an HF clinic	103 (41.0%)	65 (63.1%)	35 (64.8%)	66 (84.5%)	269 (54.5%)
Access to HF rehabilitation	126 (50.2%)	63 (61.2%)	24 (44.4%)	57 (73.1%)	270 (54.7%)
Access to electrical therapies for HF	172 (68.5%)	103 (100%)	42 (77.8%)	78 (100%)	395 (80.0%)
Access to end-of-life care pathway for HF	181 (72.1%)	84 (81.6%)	31 (57.4%)	69 (88.5%)	365 (73.9%)
Responsible for end-of-life care for HF	194 (77.3%)	35 (34.0%)	17 (31.5%)	61 (78.2%)	307 (62.1%)

GP, general practitioner; HF, heart failure; HFpEF, heart failure with preserved ejection fraction; LVSD, left ventricular systolic dysfunction.

intensity or regular review I don't think. Perhaps cancer care in the later stages. So a lot of doctor time. (GP partner)

The majority of respondents in all groups had access to a dedicated HF clinic provided by a multidisciplinary team, though not all routinely referred patients to this service. One GP partner stated: "...the mammoth wait makes using this service impractical" while a cardiologist commented "...selected patients are referred according to where they live—patients are not referred routinely."

All groups referred to the lack of integrated systems of care, disease registers and compatible computer systems across primary and secondary care as a barrier to communication in HF care.

My major frustration is regarding patients who have recurrent admissions with heart failure. And the frustration there basically is that I feel that there's no joined up care for these patients to be followed up by a professional with an interest in heart failure, whether that is a primary care physician with an interest in heart failure or a secondary care cardiologist with an interest in heart failure. (General Physician)

...even trying to get blood results if you titrate the medication and you take bloods, getting the results I have to ask the GPs to fax the results back to me. If we were linked to the same system as the hospital, well even if we're on System One then we could get it. (HF nurse)

### Uncertainty about end-of-life care

Most respondents stated that their patients had access to an end-of-life pathway for HF, although these were used only occasionally by any group other than nurses, 45% of whom stated that they used care pathways frequently. Most cardiologists and general physicians did not see themselves as being responsible for end-of-life care for HF, while around 80% of GPs and nurses felt that they had responsibility within a team. There was a lack of consensus about who held final responsibility for end-of-life care, with most respondents identifying some or all members of the multidisciplinary team as being responsible.

Within most of the professional groups studied, 'defining end-of-life' was the most challenging aspect of end-of-life care; 'coordination of care' was the second most challenging aspect. A cardiologist stated that the most challenging aspect was:

persuading overzealous colleagues that palliation is appropriate."

Another cardiologist highlighted the:

sometimes false expectations of patients and their families—sometimes fuelled by other health care professionals—sometimes fuelled by success of previous treatment for heart failure. (Cardiologist)

The majority of participants, regardless of role, identified doubts about their ability to identify the end-of-life stage and expressed fear about withdrawing active treatment. Participants expressed frustration at trying to balance the competing requirements of palliative planning, against a cultural emphasis on the use of invasive technologies for end-stage HF. A cardiologist stated:

I have this overwhelming feeling that we're almost sort of being encouraged to put ICDs (Implantable Cardioverter Defibrillators) into everybody. (Cardiologist)

Some GPs reported improvements in the care of patients towards the end of life as a result of the introduction of new care pathways, and the willingness of palliative care service providers to treat patients with non-cancer diagnoses:

We recently had a couple of heart failure patients go through palliative care, end of life pathways, and it's been absolutely fantastic, the hospice and Macmillan, whatever, and I think it's a really new string to our bow, and a really sophisticated sensible thing to have as well. (GP Partner)

There was some acknowledgement that these pathways could only be implemented for a minority of HF patients. The remainder had difficulties in identifying and communicating the end-of-life stage to patients and their families, partly because of the unpredictable nature of the disease progression.

From not knowing how long people have got left and sort of declining and you don't know whether it's weeks or months, do you, it's very difficult to know at what point, how quickly they're going to go down. (Salaried GP)

So it can be difficult sometimes I think, to broach it with the patient, broach it with the carer, decide within a team and then the issue of out of hours, sometimes you decide this is it, and then you find that they're admitted to hospital overnight. (GP Partner)

### Discussion

Among the five health professional groups studied, variable opinions and practices persist in the diagnosis and management of HF. Uncertainty about appropriate clinical practice (including the diagnostic process and medical management), utility of clinical guidelines and individual practice preferences with local organisational influences were similar to themes identified a decade ago.<sup>2</sup> Uncertainties around end-of-life care emerged as a new theme.

The difficulty of achieving an accurate diagnosis of HF has changed little in the past 10 years despite improved access to diagnostics including natriuretic peptides and echocardiography. Non-specific symptoms and signs, and significant comorbidities in increasingly elderly patients, continue to contribute to the complexity of



diagnosis. Despite NICE guidance recommending natriuretic peptide testing when diagnosing HF, availability and use remains variable. Although the vast majority of survey respondents now have open access echocardiography, NICE guidelines now discourage this and suggest referral for specialist assessment for diagnosis and management.<sup>26</sup> Comments from focus group respondents highlighted the lack of awareness among some clinicians about the existence or content of relevant guidelines. Thus, it is possible to suggest that while the guidelines themselves may have utility, variations in perceptions and awareness of their content may have been a barrier to optimum care.

A lack of knowledge about diagnosis and management of HFpEF was evident across all professional groups, including many cardiologists. Issues around communicating the diagnosis of HF to patients and carers were highlighted. Generally, the lack of an evidence base for diagnosis and management of HFpEF meant that the guidelines for this condition were deemed to be less useful than those for LVSD. Of note was the fact that 9% of cardiologists remained unconvinced about the existence of HFpEF, which may have influenced the confidence of other clinicians when considering a diagnosis of HFpEF.

Despite a decade of availability and clear guidance, clinicians still vocalise concerns about initiating  $\beta$ -blockers or digoxin, although survey findings suggest that most clinicians initiate and titrate evidence-based drugs for HF. The previous study identified ageism as a potential source of variability, although in this study ageism per se was not seen as a problem; rather, the comorbidities associated with age.

Availability of diagnostics (including natriuretic peptides), access to HF specialist services and rehabilitation were variable and thus subject to geographical locality. Cardiologists felt that lack of continuity of care and service availability at weekends increased hospital admissions and delayed hospital discharge. Lack of integrated disease registers and joined up computer systems across primary and secondary care were seen as a barrier to communication in HF care.

In the previous study,<sup>2</sup> participants were given the opportunity during each focus group to identify and discuss any sources of variation or difficulty in diagnosing and managing HF. End-of-life care for HF was not identified during these focus groups, perhaps reflecting a lack of focus on this issue within the NHS. In the current study, end-of-life was a preagreed topic for discussion but most participants highlighted the issue without prompting from the facilitator, thus demonstrating its increasing relevance and importance to clinicians today. Many participants felt that the main barrier to a coordinated end-of-life management plan was the inability to predict when the palliative phase should start in patients with HF. There was a difficult balance to strike between increasingly invasive technologies (including CRT and International Classification of Diseases (ICD))

and palliative care planning underpinned by quality of life considerations. All groups highlighted the difficulty in communicating the end-of-life phase to patients and carers, especially if high expectations for survival had been raised by colleagues.

There appeared to be a lack of consensus about who is responsible for HF care, from diagnosis through management to palliative care. This is despite the fact that NICE guidelines recommend specialist care by multidisciplinary HF teams for patients with suspected HF and in patients with HF. Potential solutions to the difficulties highlighted by this paper lie in improved service availability, access, coordination of care and education. Previous national and international research has demonstrated the value of a coordinated, multidisciplinary approach to care in reducing hospital admissions, reducing treatment variability and improving quality of life for people with HF.<sup>27–30</sup> Thus, specialist HF clinics are available in many centres across the UK. However, these services may not provide end-of-life care or address some of the other issues raised by this study, such as the education needs of GPs. One innovative solution to the variability of HF care, recently implemented by study team members, demonstrated the acceptability and feasibility of an on-site specialist HF service for people in UK care homes.<sup>31–34</sup> Other research has evaluated cardiology-palliative care teams, demonstrating their potential to address some of the uncertainty around care for these patients.<sup>35</sup> Given the ageing population and the increasing burden of HF, implementing more innovative solutions is key to addressing the challenges of HF care.

### Strengths and limitations of the study

The mixed methods approach used in this study permitted the key themes and issues experienced by clinicians to be identified and a questionnaire to be developed to quantify current beliefs and behaviours. Focus groups were conducted to the point of data saturation and can be validated to some extent against historical work, although it would be useful for independent research to confirm these themes. The response rate to the questionnaire appears low at 3.1%; however, this was an electronic survey with a substantial total number of responses. Electronic surveys, as unsolicited emails, typically feature low responses. This style of technology has been commonly used in market surveys and in clinical and epidemiological research. Despite their relative popularity and ease, they frequently do not reach all patients. Qualitative and survey research, by necessity, reports what respondents wish to say, which may differ in some circumstances from their actual behaviour.<sup>36 37</sup> It is possible that the respondents agreed to participate in the survey as a result of shared frustration with the issues raised, and that the findings are not representative of the current clinical view. Although bias as a result of self-selection is a possibility, findings from this research mirror themes from other research nationally and

internationally, suggesting that the challenges and problems are universal. Thus, this study provides further understanding of the reasons behind the evidence-practice mismatch for HF in the UK.

## Conclusions

The reported reasons for variability in HF diagnosis and management have changed little in the past decade. Issues of service availability, access, delivery of care and a lack of coordination persist. The current working environment appears not to be conducive to promoting ownership or engagement with such difficulties. Rather than interventions targeted at clinicians to improve care, the primary need may be for a health service, which enables coordinated care, responsibility and training.

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