

## Barriers to accurate diagnosis and effective management of heart failure in primary care: qualitative study

Ahmet Fuat, A Pali S Hungin, Jeremy James Murphy

### Abstract

**Objective** To ascertain the beliefs, current practices, and decision making of general practitioners in the diagnosis and management of suspected heart failure in primary care, with a view to identifying barriers to good care.

**Design** A qualitative approach using focus groups with 30 general practitioners from four primary care groups. The sampling strategy was stratified and purposive. The contents of interviews were transcribed and analysed according to the principles of “pragmatic variant” grounded theory.

**Setting** North east England.

**Results** Three categories of difficulties contribute to variations in medical practice and to the reasons why general practitioners experience difficulties in diagnosing and managing heart failure. The first is uncertainty about clinical practice, including lack of confidence in establishing an accurate diagnosis and worries about using angiotensin converting enzyme inhibitors,  $\beta$  blockers, and spironolactone in patients who are often elderly and frail, with comorbidity and polypharmacy. The second is a lack of awareness of relevant research evidence in what was perceived to be a complex and rapidly changing therapeutic field. Doubts about the applicability of research findings in primary care, and fear of information overload also emerged. The third category consists of influences of individual preference and local organisational factors. Medical training, negative clinical experiences, and outside agencies influenced the behaviour of general practitioners and professional culture. Local factors included the availability of diagnostic services, resources (such as accessible cardiologists), and interactions between professionals in primary or secondary care, and they seemed to shape the practice and decision making processes in primary care.

**Conclusions** The national service framework for coronary heart disease stresses that the substandard care of patients with heart failure is unacceptable. This study identified barriers to be overcome across primary and secondary care in implementation strategies that are specific to the locality and multifaceted. Single strategies—for example, the provision of guidelines—are unlikely to have an impact on clinical outcomes, and new, conjoint models of care need to be explored.

### Introduction

Heart failure is difficult to define and diagnose.<sup>1</sup> It is common, increasing in prevalence, and has high morbidity and mortality akin to common cancers.<sup>2</sup> It is managed largely in primary care, imposing a heavy burden on the NHS, and accounts for 5% of admissions to medical wards, with high readmission rates.<sup>3,4</sup>

Diagnosis by clinical assessment is difficult and is correct in less than half of cases confirmed by echocardiography.<sup>5,6</sup> Heart failure is poorly managed in general practice for many reasons.<sup>7-11</sup> Uncertainty about diagnosis<sup>8,11</sup>; lack of access to diagnostic services<sup>10</sup>; lack of awareness of research evidence and guidelines<sup>7,9</sup>; worries about adverse effects, cost, and inconvenience of angiotensin converting enzyme inhibitors<sup>7</sup>; and poor communication between professionals in primary and secondary care<sup>11</sup> lead to variable practice, and the reasons for this variability need to be elucidated further.

Much of the current evidence on how to diagnose and manage heart failure comes from a secondary care perspective, where the difficulties of primary care, including differences in patient populations, are not necessarily appreciated. Studies have usually relied on quantitative methods, with little exploration of the complexity of general practice and its relations with patients and secondary care.<sup>7,10</sup>

This study aimed to ascertain the beliefs, current practices, and decision making of general practitioners around the diagnosis and management of suspected heart failure in primary care, with a view to identifying barriers to optimal care.

### Methods

Focus groups with general practitioners were our chosen format for the study, which was set in north east England, an area with a population of 617 532 and with 316 general practitioners in 88 practices. We used a mixed purposive sampling strategy to select participants.<sup>12</sup> Stratification of general practitioners allowed proportionate representation of sex, ethnic group, geographical distribution, employment status (part time or full time), and practice size (group or singlehanded) and avoided selecting general practitioners from the same practice. We contacted 41 general practitioners and organised four focus groups.

Centre for Integrated Health Care Research, Wolfson Research Institute, University of Durham, Stockton-on-Tees TS17 6BH

Ahmet Fuat  
*Northern and Yorkshire Regional Health Authority research training fellow*

A Pali S Hungin  
*professor of primary care and general practice*

Darlington Memorial Hospital, Darlington, County Durham DL3 6HX  
Jeremy James Murphy  
*consultant cardiologist*

Correspondence to:  
A Fuat  
ahmet@fuat.freeserve.co.uk

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Eleven doctors did not attend; their demographic and professional characteristics did not differ from the remaining 30. The four focus groups consisted of six to eight participants, and a co-moderator was used in three of them.

The 30 participants (25 men, overall age range 33-64 years, years since graduation 10-42) represented a wide range of practice size and length of experience, including three singlehanded practices. Twenty seven doctors worked full time and three part time; 20 (66%) had open access echocardiography. The ratio of male to female general practitioners in the locality was 3:1; in the focus groups it was 5:1.

To help the discussion the principal investigator (AF) used a list of points to be considered, compiled from a literature review. The sessions were audiotaped, transcribed, and then corrected and verified by AF.

### Analysis

We analysed the contents of the interviews following the principles of the theory of "pragmatic variant" grounded theory.<sup>13 14</sup> We read transcripts and identified broad themes as the groups progressed. This iterative process allowed ideas and thoughts that were emerging to be brought back to subsequent groups. We analysed deviant cases to question widely accepted practice.<sup>14</sup> No new major themes arose by the end of the fourth focus group, implying that saturation was being reached.<sup>14</sup> The transcripts were read several times, data organised into codes from which categories were identified, and major themes were constructed by AF and APSH. All three investigators contributed to multiple coding and agreed final themes. Analysis was enhanced by constant comparison with the transcripts and available research in this field from the initial literature review.<sup>14</sup>

### Respondent validation

To validate the findings we sent all 30 participants a report summarising the study results and conclusions.<sup>15</sup> Of 28 respondents 27 "strongly agreed" or "agreed" and one "neither agreed, nor disagreed" that the report was an accurate representation of their opinions and the group outcomes.

## Results

We identified three themes that contributed to reasons for the variation in medical practice and why general practitioners experienced difficulties in diagnosing and managing heart failure: firstly, uncertainty about clinical practice, including the availability and use of echocardiographic services; secondly, lack of awareness of relevant research evidence; and thirdly, influences of individual references and local organisational factors.

### Uncertainty about clinical practice

Most participants expressed a lack of confidence in establishing the diagnosis of heart failure. This affected the management of individual patients. Three main categories were identified: the diagnostic process, availability and use of echocardiography services, and treatment issues.

#### *The diagnostic process*

Heart failure was perceived to be a difficult diagnosis to make in general practice because of:

- Problems with subtlety of clinical symptoms and signs: "Some of the clinical signs, if you have a raised JVP or third heart sound, hepatomegaly, are often difficult in the obese to detect, and ankle oedema is common anyway."
- Difficulty in differential diagnosis, especially in elderly patients with comorbidity such as chronic obstructive airways disease and obesity: "I think heart failure would be not too difficult a subject if it occurred in young fit people but the biggest problem is that it's always inevitably older people who get it. It's a co-pathology intermingled with other things, and that makes it often quite difficult to disentangle."
- Time constraints and generally increasing clinical and administrative workload for general practitioners: "20 plus patient surgeries, and having to try and stick to close to 10 minutes, it can be quite difficult to do a really full assessment."
- Lack of availability of diagnostic tests, including electrocardiography, chest radiography, and echocardiography, and lack of confidence in interpreting the results of these: "You get a kind of slightly reduced ejection fraction, and you know an iffy tricuspid valve or two, and you know you're not really that much further forward."
- Inertia or fear of initiating action because of anxieties about committing to an intensive course of action, including investigations, initiation, titration, and monitoring of treatment: "I think it's the milder degrees of heart failure ... that is the difficulty. But once you've diagnosed it you're committed to a course of action, and I suppose it seems quite a drastic course of action, you've obviously got the diuretics, ACE inhibitors, and possibly other medication as well, full investigations, and I suppose that could lead to a bit of inertia, couldn't it?"
- Patients' choices, including reluctance to be investigated or treated further: "Some patients obviously don't want to be hospitalised or don't want a second opinion, and sometimes don't want to go to hospital, so you end up treating them yourself."

### Availability and use of echocardiography services

Perceived handicaps included the variability of open access echocardiography in the same locality; two thirds of the participants had this facility. Some of the inequity resulted from the continuation of access acquired previously by general practice fundholders. Several of the open access services had been funded through pharmaceutical sponsorship but disappeared as "monies dried up." A further perceived problem was variability in echocardiography reporting, some by technicians and some by clinicians, and a lack of guidance for using the procedure or for standardising request forms.

#### *Difficulties for general practitioners concerning echocardiography*

Some general practitioners did not use open access echocardiography even when it was available, chiefly because of not being able to understand it and the inconvenience caused to patients who were often very ill. The reasons given included:

- Uncertainty about the importance of results and interpretation of technical reports: "The problem with echocardiograms is that I really just don't understand

them. I don't think of myself as being really that old, I mean I'm 43 ... and when I went through my post-registration years echocardiograms just weren't around ... I just don't know where I am with them. When does an ejection fraction of such and such per cent stop being reasonable and start being a problem?"

- Not being able to cope with echocardiography, many preferred to refer the patient to a consultant: "I would rather refer than do an echocardiogram, the interpretation of which I am not confident with." "I'm not confident in diagnosis of heart failure. I think I just like to have it rubber stamped."

- Distance to nearest echocardiography clinic may inconvenience patients: "It takes a whole day to go to hospital, and for an elderly person with breathlessness that's a long day, ambulance there and back, sit in a waiting room, and patients do it once and they won't do it again, and they don't all have relatives to take them in."

General practitioners were less likely to use open access echocardiography when reports were technical and lacked a clinical opinion than when a clinician guided report was available. In these circumstances they either treated their patients' symptoms or referred them to hospital; a lack of open access was cited as a reason for increased referrals. Apprehension was expressed about overloading cardiology services, especially with patients who seemed well: "I think there is also a feeling that it's almost an inappropriate cardiac referral ... the cardiologists are so busy and when you first make the diagnosis they [the patients] are often actually not that poorly."

#### *Treatment issues*

Uncertainty about diagnosis cast doubts on the development of strategies for individual treatment of patients. The treatment process was an area that entailed further barriers to evidence based practice.

Doctors had good awareness of non-pharmacological advice and interventions (such as weight reduction, tailored exercise, restriction of salt intake) for patients with heart failure.<sup>16</sup> Most participants agreed the importance of educating patients, but some expressed concerns at informing patients about the diagnosis as this might lead to anxiety. This was countered by those who believed that openness with and involvement of patients improved compliance.

#### *Concerns about using ACE inhibitors in general practice*

Although attitudes were felt to be changing, worries still surrounded the use of angiotensin converting enzyme (ACE) inhibitors, especially about starting treatment in primary care as opposed to in hospital, partly because of previous teaching and a fear of side effects, mainly hypotension, in the community setting:

- Concerns about the use of angiotensin converting enzyme inhibitors in elderly patients and those with renal impairment and worries about side effects including cough, postural hypotension, and renal failure: "I'm not too sure exactly at what degree of renal impairment one should worry too much."

- Polypharmacy and drug interactions was considered a barrier, especially in elderly patients: "The other thing that raises its head is polypharmacy here, where you have got your people who have been chewing their aspirin for years, that a lot of these will be on statins

and antiarthritic drugs. You've got your ACE inhibitors and diuretics. Well that's five or six [drugs], and I think you're going to have rebellion on your hands from people who say they are on far too many tablets ..."

- Ageism was flagged up as a consideration in all four groups: "I think there is an ageist agenda with it as well because you know somebody of 60 who has got heart failure you're going to be much more aggressive with than someone who is 78, not just in terms of making the diagnosis but the investigations and treatment."

- A few general practitioners were happy to keep patients taking diuretics and "spare them the ACE inhibitor unless they are getting worse."

- A minority's perception was that diuretics alone are "OK in mild heart failure."

#### *Barriers to achieving optimal doses of ACE inhibitors in general practice*

Even if treatment with angiotensin converting enzyme inhibitors was initiated in primary care, a further barrier was the inability to attain the recommended doses as in major studies and guidelines<sup>16</sup>:

- Worry that the diagnosis of heart failure was incorrect: "But it worries me that if you are pushing the ACE inhibitors up to the maximum dose, which you are recommended to do, that you've got your diagnosis right in the first place."

- Although some awareness of the benefits of high dose existed, a lack of knowledge of target doses used in major trials became apparent.

- Worries were expressed about "huge doses" leading to side effects and intolerance.

- Reluctance to increase dosage if patient was asymptomatic or stable: "If you've got someone who is stable, you're sometimes a bit reluctant to increase the dosage of any medication if the condition is well controlled."

- It was assumed that it may be more difficult to increase dosage "if already been on a low dose for a while."

Awareness of the use of  $\beta$  blockers in heart failure was widespread, but a unanimous feeling was that it should be a "hospital initiated thing," because of a fear that patients might collapse in the community setting.<sup>17</sup> Most doctors were apprehensive about the use of  $\beta$  blockers, and one, voicing fears, indicated that it was "common sense for general practitioners to be a little bit reticent." Most general practitioners mentioned medical school teaching that emphasised that  $\beta$  blockers were contraindicated in heart failure: "It still seems a contradiction when we were taught  $\beta$  blockers precipitate cardiac failure. I'm sure we've all seen that happen and to turn round and prescribe them; it goes against the grain a bit."

Most general practitioners indicated that they were unaware of the place for other agents including spironolactone and angiotensin II antagonists in treating heart failure<sup>16</sup>; and in spite of its previous use over many centuries digoxin posed a problem: "I'm not (even) up to speed with spironolactone or  $\beta$  blockers yet." A common response was: "Digoxin: I wouldn't use it in sinus rhythm."

#### **Lack of awareness of relevant research evidence**

All focus groups discussed their views on the dissemination of research evidence, guidelines, and applicability of evidence in primary care. Overload with

information was seen as a common cause of stress. Many worried about the “rapidity of change in all fields” and “keeping up to date with changes” but believed that “[we] owe it to our patients” to be in touch.

Existing guidelines about the diagnosis and management of heart failure and treatment with angiotensin converting enzyme inhibitors were not familiar to most participants. To some extent this was due to “guideline fatigue”; one general practitioner felt “bombarded and bamboozled by guidelines.”

Specific to heart failure was the lack of awareness of the importance of confirming left ventricular systolic dysfunction, differences between systolic and diastolic heart failure, and the importance of the NYHA (New York Heart Association) classification—a system of grading the severity of heart failure—in categorising heart failure. A lack of knowledge became obvious as to how this classification could be used to provide a prognosis and guide management.

Some general practitioners were happy to keep patients taking diuretics alone, possibly unaware of potential benefits of angiotensin converting enzyme inhibitors,  $\beta$  blockers, and spironolactone.<sup>16 17</sup> Most had little knowledge of the place for agents other than diuretics and angiotensin converting enzyme inhibitors, and a feeling predominated in some quarters that heart failure should be managed in secondary care: “Can we adequately manage heart failure in general practice, given the modern advances that we are all unsure about?”

#### **Influences of personal preference and local organisational factors**

Medical training, anecdotal experiences, and outside agencies (health authorities, primary care trusts, and the pharmaceutical industry) emerged as influences on individual clinicians’ behaviour and professional culture. In some instances this was deeply entrenched and perversely affected newer influences. An example of this was a participant from a large teaching practice who justified his reluctance to refer all patients for echocardiography; the factors behind this are likely to be complex and to do with coming to terms with a rapidly changing medical environment: “I got through the whole of hospital training, and we didn’t use echocardiograms. In cardiology we managed everyone with heart failure without an echocardiogram.”

Local organisational factors around the provision of diagnostic services, such as open access echocardiography, resources, lack of cardiologists, and professional interactions between primary and secondary care shaped practice and decision making processes among general practitioners. A locality based, contextualised approach was found acceptable:

- “A locally drawn up set of guidelines which are pertinent to the local situation, that is primary and secondary care situations, drawn up by representatives from both primary and secondary care and other interested stakeholders that is owned by everyone who is going to use them.”
- “We are in an imperfect health service, and we are resource starved, and if like every other medical problem we deal with, if we wanted to manage heart failure as we would like to, it’s going to have significant resource implications.”

Waiting lists and the local availability of consultants influenced the general practitioner’s decision in relation to the referral to cardiologists of patients with suspected heart failure: “Being pragmatic you look at waiting lists, we’ve got some very good geriatricians who have excellent clinical skills, and certainly, if the patient has got multiple pathologies, I would have no hesitation in referring to them.”

#### **Discussion**

Heart failure is poorly managed in the United Kingdom, mainly because of inaccurate diagnosis and inappropriate treatment, including the use of treatment for heart failure in a large group of patients who do not actually have heart failure.<sup>8 18</sup> A major reason for failing to make an accurate diagnosis is that the symptoms and signs are not highly specific.<sup>19</sup> This study provides information about the difficulties perceived by general practitioners in achieving accurate diagnosis and instituting modern treatment.<sup>16</sup>

The most accurate method of diagnosis entails the use of echocardiography, but this study confirmed a variation in its availability and discovered that practitioners were not confident about interpreting results.<sup>20</sup> At the same time a reluctance to refer to a consultant for a definitive diagnosis prevailed because of a fear of overloading services and a continuing perception that heart failure remains a problem to be dealt with in primary care.

#### **Perceived advantages and disadvantages of modern management**

Diagnosis and management of heart failure have evolved dramatically, such that they rely on specialised investigations and drug regimens that often require specialist input. Clinicians who trained in the distant past have essentially not come to terms with the more modern approach. In turn, services to capitalise on modern management have been insufficiently developed.

Paradoxically, the general practitioners appreciated the benefits of modern treatment shown in large scale trials, particularly those of angiotensin converting enzyme inhibitors.<sup>16</sup> Although confidence in the use of angiotensin converting enzyme inhibitors has increased in the past 10 years, a substantial minority of general practitioners were reluctant to use them, especially in elderly patients. This was related to fears about side effects, especially hypotension and collapse in the community setting, and the lack of monitoring guidelines in the context of primary care.

Polypharmacy was viewed particularly negatively. If between one and five drugs are prescribed, the likelihood of adverse drug reactions is 3.4%, rising to 24% with six or more.<sup>21</sup> The increased numbers of tablets likely to be required by elderly patients with concurrent conditions, such as diabetes and its associated problems, was considered daunting and detracting from compliance. In such situations decisions about the most appropriate regimens were likely to be weighted by the requirements of the different conditions and perceived returns from intervention. Although chronic heart failure is serious and progressive and appropriate drug intervention proved to be beneficial, many clinicians do not find it easy to judge

the extent of worthwhile returns in older patients with underlying problems such as ischaemic heart disease. Patients whose heart failure has already been diagnosed, who seem stable having conventional treatment but who might benefit from newer interventions,<sup>17</sup> also posed a dilemma; many clinicians were reluctant to initiate newer treatments that may have been around for decades, such as digoxin and spironolactone.<sup>16</sup>

Suboptimal care often results from factors outside the immediate control of the general practitioner.<sup>9</sup> Local circumstances such as resource allocation, priorities, and attitudes of consultants are crucial. This study confirms that general practitioners perceived this to be the case for heart failure. The increasing involvement of primary care in planning local services through primary care trusts may alleviate this problem, providing the trusts can work effectively with secondary care providers.

### Methodological aspects

The qualitative method for this research lent itself well to discovering the barriers to optimal care. Rigour was enhanced by multiple coding and validation of respondent validation.<sup>15</sup> The personal and intellectual bias of the principal investigator was minimised by using a co-moderator in three groups, by allowing discussions to develop naturally, and by reporting the wide range of perspectives. Analysis of deviant cases enhanced the validity of the findings by bringing widely accepted practice into question.<sup>14</sup> Generalisability from qualitative research remains an issue with some doctors. Guba and Lincoln have introduced the concept of transferability as an alternative to generalisability.<sup>22</sup> This implies that the onus is on the reader to evaluate the methods, setting, and results and decide if these are transferable to their own situation. We believe that the findings of this study can be transferred to most settings in the United Kingdom.

### Barriers and overcoming them

A dilemma is inherent in the management of heart failure. Advances in science have outstripped the ability and capacity of NHS delivery systems; rapidly changing therapeutic paradigms have confused clinicians, sometimes because drugs previously regarded as dangerous, such as  $\beta$  blockers, are new cornerstones, and others expelled from the arena, such as spironolactone, are back in vogue. Previous work has explored general reasons why general practitioners do not always implement best evidence.<sup>23</sup> This study identified specific barriers that need to be overcome if aiming for state of the art management. Particular factors needing attention are better and clearer information, improved availability of tests and a useful translation of results from diagnostic methods, and expedient access to specialist advice in case of doubt. Strategies to achieve these objectives might include the development of heart failure clinics and involving general practitioners and nurses with a specialist interest in an integrated care pathway. The national service framework emphasises that substandard care for heart failure is unacceptable, and such new, conjoint strategies are needed urgently.<sup>24</sup>

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## What is already known on this topic

Heart failure is a common condition with a high morbidity and mortality and is largely managed in primary care

Although modern management with accurate diagnosis and treatment improves prognosis considerably, unacceptable variations exist in the clinical application of current guidelines for heart failure

## What this study adds

General practitioners expressed a lack of confidence in establishing an accurate diagnosis of left ventricular systolic dysfunction, even if open access echocardiography was available

Uncertainty about diagnosis led to poor uptake of evidence based treatment strategies for heart failure patients, and, despite awareness, reluctance to initiate modern treatment

Local organisational factors around NHS provision of diagnostic services, resources, and interaction between primary and secondary care influence how general practitioners manage heart failure

Implementation strategies for heart failure management across primary and secondary care are needed that are specific to their locality and multifaceted

practice colleagues for their tolerance in covering his practice workload.

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