Primary care

Doctors’ perceptions of palliative care for heart failure: focus group study
Barbara Hanratty, Derek Hibbert, Frances Mair, Carl May, Christopher Ward, Simon Capewell, Andrea Litva, Ged Corcoran

Abstract

Objectives To identify doctors’ perceptions of the need for palliative care for heart failure and barriers to change.
Design Qualitative study with focus groups.
Setting North west England.
Participants General practitioners and consultants in cardiology, geriatrics, palliative care, and general medicine.
Results Doctors supported the development of palliative care for patients with heart failure with the general practitioner as a central figure. They were reluctant to endorse expansion of specialist palliative care services. Barriers to developing approaches to palliative care in heart failure related to three main areas: the organisation of health care, the unpredictable course of heart failure, and the doctors’ understanding of roles. The health system was thought to work against provision of holistic care, exacerbated by issues of professional rivalry and control. The priorities identified for the future were developing the role of the nurse, better community support for primary care, and enhanced communication between all the health professionals involved in the care of patients with heart failure.
Conclusions Greater consideration should be given to the care of patients dying with heart failure, clarifying the roles of doctors and nurses in different specialties, and reshaping the services provided for them. Many of the organisational and professional issues are not peculiar to patients dying with heart failure, and addressing such concerns as the lack of coordination and continuity in medical care would benefit all patients.

Introduction
Heart failure is a common condition; estimates of prevalence range from 2 to 10 per 1000 population, and the incidence is rising as more people survive acute coronary events. The median survival for heart failure (16 months after first hospital admission, unadjusted) is worse than for many of the common cancers. Despite this poor outlook, those who die of the condition in the United Kingdom seldom access specialist palliative care services, and responsibility for their care lies with primary care, cardiology, geriatrics, or general medicine. Palliative medicine grew out of the hospice movement, and cancer charities still make a substantial contribution to the costs of palliative care. This, coupled with professional doubts over the wisdom of expansion, means that specialist care of the dying is virtually synonymous with cancer care in the United Kingdom. In recent years, however, there have been calls to recognise the needs for palliative care of people with heart failure. The national service framework for coronary heart disease endorsed this view but failed to address the question of how it should be provided or to identify new sources of funding. As the research evidence for unmet needs of care in terminal heart failure grows, it has not been accompanied by investigation into appropriate models of care.

Patients dying with heart failure may have unpredictable illness trajectories; understanding and expectations will also be different to patients with terminal cancer. The needs of health professionals for support and experience with palliative care for heart failure are also likely to vary. Box 1 suggests aspects of palliative care that may not be readily available to patients with heart failure.

In the absence of an evidence base, doctors’ views on terminal care for patients with heart failure are likely to be influential in shaping the development of future care. In our study we used focus groups to explore doctors’ views of palliative care for patients with heart failure, and we aimed to identify barriers to improving the care of this patient group.

Participants and methods
Our study was exploratory owing to the paucity of research, therefore focus groups provided an appropriate approach. Apart from being an efficient means of data collection, focus groups allowed the participants to use their own frames of reference and to identify the topics that were important to them. Clarification of views through discussion and debate was particularly valuable for a topic to which the participants may not have given much prior consideration.

Sampling
We recruited seven specialty groups of doctors; two each of general practitioners and consultant cardiologists and one each of consultants in geriatrics, general psychiatry, cardiology, palliative care, and general medicine.
All hospital and palliative care doctors were NHS consultants.

Recruitment and participants

<table>
<thead>
<tr>
<th>Group</th>
<th>No in group (No male)</th>
<th>Method of recruitment</th>
</tr>
</thead>
<tbody>
<tr>
<td>General practitioners</td>
<td>5 (4)</td>
<td>Written invitation to practices in one area, allied to research consortium</td>
</tr>
<tr>
<td>General practitioners (teaching and academic)</td>
<td>5 (4)</td>
<td>Written invitation to doctors employed by one university</td>
</tr>
<tr>
<td>Cardiologists from district general hospitals</td>
<td>5 (4)</td>
<td>Written invitation and telephone calls to cardiologists in hospitals in one region</td>
</tr>
<tr>
<td>Cardiologists from tertiary referral centre</td>
<td>3 (3)</td>
<td>Introduction by member of study steering group, written invitation and telephone calls</td>
</tr>
<tr>
<td>Geriatricians</td>
<td>5 (5)</td>
<td>Introduction by local secretary of the British Geriatric Society, written invitation plus telephone calls</td>
</tr>
<tr>
<td>General medicine doctors</td>
<td>4 (2)</td>
<td>Written invitation and telephone calls to physicians at hospitals in one area</td>
</tr>
<tr>
<td>Palliative care doctors</td>
<td>6 (1)</td>
<td>Introduction via member of steering group, held after subregional meeting</td>
</tr>
</tbody>
</table>

All hospital and palliative care doctors were NHS consultants.

Box 1: Aspects of palliative care that may not be available to patients with heart failure

Services
- Multidisciplinary support in the community
- Specialist nurse practitioners
- Access to inpatient beds for palliative care
- Professional carers trained in the principles of palliative care
- Social and financial support comparable to that of patients with cancer

Approaches
- A strategy for a timely move from invasive treatment to supportive care
- Optimisation of treatment of the underlying disease
- Improved symptom control and attention to comorbidities
- Emphasis on quality of life
- Discussion of prognosis early in the course of disease, seeking patients’ views
- Acknowledgment of disease specific barriers to effective communication
- Adequate information for patients

Data collection and analysis

The focus group meetings lasted an average of 80 minutes. We developed a topic schedule to address our aims, using published literature and our own experiences. The groups were also encouraged to raise their own issues. The same facilitator and observer attended all the meetings, which were tape recorded and transcribed. These two researchers then coded all the transcripts with Nvivo software. The data were analysed by using the principles of constant comparison. The tapes were scrutinised before examining the transcripts and for checking of final interpretation. Emerging themes and categories were identified independently, and agreement was reached by discussion. The researchers were from different disciplines, and only one had prior knowledge of the area of research. The reliability of the findings was enhanced further by scrutiny from the steering group, which included practising clinicians.

Results

Organisational barriers

The workings of the system were a concern for many of the hospital doctors (box 2). Care for patients dying with heart failure was described as uncoordinated, with patients going from hospital to community and back again. Repeated admissions to different consultant teams were common, and patients’ medical notes were sometimes said to arrive on the wards after the patient had been discharged or died. A picture emerged of poor quality care for the patients and frustration for the doctors. The lack of continuity in current medical practice was highlighted by the geriatricians and palliative care doctors. All the groups thought that poor support in the community contributed to repeated hospital admissions. Adequate basic services, such as district nurses and social services, were a higher priority than more sophisticated forms of palliative care. Although hospital colleagues empathised with the general practitioner struggling to cope without support, the palliative care doctors and cardiologists were also concerned about the impact of the quality of care provided by general practitioners.

Box 2: Organisational barriers

And there are no proper links between our management structures and the community management structures, and this lack of seamlessness in the management of these patients needs to be dealt with. The trouble is because the consultants are managing patients in isolation when they’re on the wards and the general practitioners are trying to manage them at home; they’re falling between two stools, and that seems to me to be a real problem. (Tertiary centre cardiologist 2)

I think it’s something that’s been lost in modern medicine, the continuity of care and not just in heart failure, across the board. I mean I’m ashamed of the way we treat patients in our hospital. You can be discharged on a Monday; you can be readmitted on Wednesday. (Geriatrician 5)

Implicit in the discussions was the need for collaboration between different healthcare professionals and disciplines, as well as the importance of effective communication and support for patients and their families.
colleagues, although the need for their specialty was
care doctors were generally viewed favourably by their
specialties to improve care in the future. The palliative
to place most importance on dialogue between the
whoever had the appropriate skills. They also seemed
work, common goals, and a willingness to involve
In contrast to their colleagues’ image of them, the car-
recognise palliative care needs or practise holistically.
who were charged by all groups with failing to
priateness of the involvement of specific groups. The
heart failure, there was some questioning of the appro-
nomenators, admitting that they may accept the
admitting that patients “losing faith” in their professional carers,
problems more generally. It’s the uncertainty and the unwillingness of cardiologists to manage heart failure compet-
tently and the unwillingness of cardiologists to provide palliative care were used to justify this approach.

Prognostication
Unlike with cancer the diagnosis of heart failure does
not begin with bad news, and when to initiate palliative
care is a difficult question that was discussed by all the
groups. The path of chronic heart failure is unpredict-
able, with half of patients dying suddenly (box 3).
Stories were told of patients being admitted near to
death and being “pulled back from the brink.” Other
patients were perceived as being quite well but able to
switch to being terminal rapidly.
The uncertain prognosis of heart failure meant
that doctors were concerned about the impact on the
patients of giving bad news too soon. This was termed the “therapeutic and anti-therapeutic” use of prognos-
tication by one general practitioner, and it generated
different concerns in the groups. The major fear of the
cardiologists was saying the wrong thing and the
patients “losing faith” in their professional carers,
whereas the general medicine doctors did not want to
see the patients give up the fight for life. The wider
implications for the family and carers were raised by the
general practitioners.
Increasing openness about prognosis brought with it
growing demands on doctors, and patients were
thought to need a lot of psychological support.
Doctors in all groups portrayed themselves as bad
prognosticators, admitting that they may accept the
poor outlook late in the illness. Patients, carers, and
nurses were all suggested as more realistic predictors.
As the beneficial effects of open communication in ter-
mainal care were acknowledged, this may have
represented an unwillingness to engage with difficult
issues.

Doctors’ roles
Although many participants agreed that the general
practitioner is a central figure in palliative care for
heart failure, there was some questioning of the appro-
priateness of the involvement of specific groups. The
most severe criticism was reserved for the cardiologists,
who were charged by all groups with failing to
recognise palliative care needs or practise holistically.
In contrast to their colleagues’ image of them, the car-
diologists articulated an approach supporting team-
work, common goals, and a willingness to involve
whoever had the appropriate skills. They also seemed
to place most importance on dialogue between the
specialties to improve care in the future. The palliative
care doctors were generally viewed favourably by their
colleagues, although the need for their specialty was
questioned by some general practitioners, who felt able
to manage their own dying patients. For these general
practitioners, the palliative care specialists were
inaccessible or liable to “steal” the general practition-
ers’ patients. The general practitioners saw themselves
at the centre of things, both providing and coordinat-
ing care. This was echoed by the geriatricians, who
argued for care provided by community services,
supported by others (box 4). The perceived inability of
palliative care doctors to manage heart failure compet-
tently and the unwillingness of cardiologists to provide palliative care were used to justify this approach.

The future
Our participants invested some hope in the national
service framework as a means of increasing funding in
palliative care for heart failure. A need for discussion
and links between specialties was acknowledged chiefly
by the cardiologists. In contrast, all the groups talked at
some length of an enhanced role for nurses (box 5).
The nurse was seen as a figure who could follow
patients into the community after discharge from hos-
pital, liaise between primary and secondary care,
ensure that treatments were adhered to, and mobilise
appropriate support.

Discussion
Greater consideration is needed towards the care of
patients dying with heart failure, clarifying the roles of

Box 3: The course of heart failure as a barrier
But even when you’re at the very end and it’s the last
few weeks, you still don’t know whether they’re going
to just die suddenly now or whether over the next few
weeks they’re just going to gradually drift away. So that
does make it more difficult in trying to prepare them
and their relatives for what’s actually going to happen.
(Cardiologist 3)
It’s very difficult, you can’t really say who’s going to
recover . . . you know sometimes they respond and
sometimes they don’t. So it’s this sort of roller coaster
type of thing and it’s very difficult to give a prognosis
other than “well it’s his heart, it is serious you know.”
(General practitioner 3)

Box 4: Roles
I mean I haven’t come across a palliative care
physician yet who’s comfortable in treating heart
failure. So I’d have said that it should be the physician
who’s interested, the general practitioner, the district
nurse . . . if they’re heart failure nurses, well great . . .
I really think [specialists in palliative medicine] should,
instead of further fragmenting the service, go back to
supporting the primary care team, the general
practitioner, and the district nurse. (Geriatrician 1)
I think one needs to meet with the two specialties
(cardiology and palliative medicine) to work the
thought and processes through a bit . . there’s too
much of a gap between . . the way I practise and what
I vaguely perceive is available on the other side. And
I’m trying to reach out every so often for specific
patients to be supported, and partly it’s my lack of
knowledge and uncertainties as to what to call for,
that’s holding things back. (Cardiologist 2)

Box 5: The future
Specialist nurses that . . . will keep a focus on the whole
picture. And where that individual then goes or
whether they’re admitted or not, [the nurses] can then
pick it up and coordinate the service so that the total
global picture is kept in focus. So that should be . .
relatively easier to notice a trend and then intervene
with a palliative care approach at a more appropriate
stage. (Geriatrician 4)
I see her [the heart failure nurse] facilitating or
passing on her expertise to the primary care team and
saying . . . this is the programme I want to follow for
the next few days, if it’s not working give me a bell.
(Geriatrician 5)
health professionals in different specialties. Doctors in our study did not dispute the place of palliative care for patients dying with heart failure. However, we identified important potential barriers to the development of a palliative care approach to this patient group. These barriers arose from three main areas: the organisation and delivery of services, the course of heart failure, and doctors' views of their colleagues' roles.

**Strengths and limitations**

From the outset our study was intended as a forerunner to research with nurses, patients, and other groups across the United Kingdom. Doctors were chosen as a starting point because of their role in shaping demand for services. However, we acknowledge that a study involving one professional group cannot expect to generate anything other than cautious conclusions about a multidisciplinary subject such as palliative care.

Our study was novel and made appropriate use of focus group methods to generate issues for further investigation. Our pragmatic approach to recruitment is justified by the pressures on clinicians' time and low response rates to research studies. However, as participants in our study gave their time voluntarily, it is likely that they were more motivated and interested than average. By using single specialty groups we aimed to minimise the impact of power relations between the interviewees and to limit the disparity between their public and private accounts. The data were analysed by a medically qualified doctor and an experienced qualitative researcher. The high level of agreement between the themes generated independently by researchers with different perspectives increases our confidence in the results.

The findings point to the need for health professionals to give greater thought to the care of patients dying with heart failure, clarifying the roles of doctors and nurses in different specialties and possibly reshaping the services provided. Clearly, these are the priorities of doctors, and they may not reflect accurately the patients' experiences. Investigations into the concerns of patients dying with non-cancer diagnoses have tended to focus on the impact of the disease on the individual, rather than organisational issues. However, patients with heart failure have been shown to have worse access than patients with cancer to a range of community services, even when attending a dedicated clinic. These patients also identified a need for their professional carers to improve their dialogue with each other. Prognostication in heart failure is particularly uncertain, but other problems are shared by patients with chronic progressive conditions. Studies of patients with chronic obstructive pulmonary disease have highlighted similar lack of continuity in care and the need for a more holistic approach.

**Implications**

Our participants gave graphic descriptions of the inability of the National Health Service to deliver what they saw as an acceptable level of care to this patient group. Many of the issues they raised were not specific to the care of heart failure, or even to end of life care. Correcting such a failure of the system and challenging attitudes that inhibit collaboration are long term goals. In the short term it is likely that practical solutions for some of the component problems would improve the lot of patients dying with heart failure. Greater use of information technology could ameliorate some of the organisational deficiencies described, for example. Most of the doctors in our study were enthusiastic about developing the role of the nurse in terminal heart failure. They described an often superior ability of the nurse to liaise with other specialties and to communicate with the patients. Underlying this is a dilemma often seen in general practice, that of balancing a desire to maintain ownership of an area of care, with existing heavy workloads. The solution proposed goes some way towards avoiding the competing claims to holism among medical specialties. A nurse with expertise in cardiac palliative care is ideally placed to act as a coordinator of services, as well as influencing medical practice. However, delegation, rather than empowerment, does not remove the question of which specialty should take the lead. In recent years several nurses have been appointed to work with patients with heart failure, usually attached to a hospital cardiology centre. Research suggests that specialist nurses may reduce the number of hospital readmissions and improve disease management for patients with heart failure discharged back to the community. A role in palliative and terminal care has yet to be defined, although specialist palliative care nurses such as those from the Macmillan service provide a successful model that could be adapted.

As the palliative care needs of patients with heart failure are acknowledged, the demands on health and social care services in the community are likely to

---

**What is already known on this topic**

- Patients with heart failure have unmet needs for health care at the end of life
- Specialist palliative care services see few patients with heart failure
- The national service framework for coronary heart disease endorses the provision of palliative care for heart failure
- Little evidence exists on how this care should be provided, and doctors' views are not known

**What this study adds**

- Barriers to adopting a palliative care approach in heart failure care relate to the current organisation of health services, the difficulties of prognostication, and doctors' understanding of roles and responsibilities
- Doctors believe that the general practitioner should be the central figure in palliative care for heart failure, supported by specialists
- Doctors' future priorities are developing the role of nurses, increasing essential community services, such as district nursing, and improving communication with colleagues

---

BMJ VOLUME 325 14 SEPTEMBER 2002 bmj.com
increase. Furthermore, there is growing recognition that palliative care services need to be integrated into primary care. Recent changes in the NHS, such as the introduction of joint commissioning by health and social services and the development of primary care trusts, may, in the long term, herald a more favourable attitude to developing community support for patients with heart failure. While primary care trusts are in their infancy it may prove difficult for them to innovate and develop services. Although primary care trusts are to control about three quarters of the NHS budget, they are immature organisations, with unproven processes and inexperienced staff. It also seems unlikely that palliative care for heart failure will be a high priority compared with many other targets that are explicitly highlighted in national service frameworks. However, with the prevalence of heart failure increasing, planning for the needs of people dying with heart failure in the NHS must become a priority issue. We thank the participants.

Contributors: BH had the idea for the study, collected and analysed data, and wrote the paper; she will act as guarantor for the paper. DH contributed to the study design, collected and analysed data, and helped to write the paper. CM assisted with the conception and design of the study, supported the interpretation of data, and contributed to drafting of the paper. FM supported the organisation and management of the project and contributed to the study design, data interpretation, and writing of the paper. SC supported the organisation of the project, study design, and data interpretation and commented on drafts. GW helped with the study design, supported data collection, and commented on drafts. AL assisted with the development of the study and data interpretation and approved the final draft. GC assisted with the conception and study design and recruitment of participants and commented on drafts.

Funding: Mersey Primary Care Research and Development Consortium, the Cardiology Research Fund, Department of Cardiology, South Manchester University Hospitals NHS Trust, and the Scientific Foundation Board of the Royal College of General Practitioners.

Competing interests: None declared.

A memorable message

It was the monthly meeting between clinicians and management. It had been going on for three quarters of an hour. The discussion was disjointed and downbeat. Colleagues were sad and disappointed by the effects of the latest round of NHS reorganisation on clinical services. Since 1974 the psychiatric services for Neath, Port Talbot, and Swansea had been integrated. This was successful. It was now to be broken up to recreate the pattern seen before 1974. In future, Neath and Port Talbot would be reintegrated with Bridgend.

Our meeting was starting to go round in circles, mirroring planning in the NHS. At this point I looked to my left. My young colleague, who had been listening intently, was now doodling, and this was taking up most of her concentration. A picture of a lighthouse or a beacon was emerging. Clearly this was a message from the unconscious that our discussions lacked focus. The meeting needed direction and a firm steer. I brought this to the attention of my colleagues, who could see how apt it was. The intervention was successful, and we began to think more positively about the way ahead.

As medicine becomes more "scientific," the art of being a good doctor is marginalised. This example reinforces the need to maintain the more subtle intuitive skills in our work. It is still worth reading Freud's Psychopathology of Everyday Life, an interesting account of common mental mechanisms.

D R Williams consultant psychiatrist, Cefn Coed Hospital, Swansea

We welcome articles up to 600 words on topics such as A memorable pattern, A paper that changed my practice, My most unfortunate mistake, or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk. Permission is needed from the patient or a relative if an identifiable patient is referred to.