

Doctors' perceptions of palliative care for heart failure: focus group study

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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.¹ The median survival for heart failure (16 months after first hospital admission, unadjusted) is worse than for many of the common cancers.² 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.³

In recent years, however, there have been calls to recognise the needs for palliative care of people with heart failure.⁴⁻⁶ 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.⁷ 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.⁶⁻⁸ 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

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

Services

- Multidisciplinary support in the community^{5,7}
- Specialist nurse practitioners^{9,10}
- Access to inpatient beds for palliative care
- Professional carers trained in the principles of palliative care⁵
- Social and financial support comparable to that of patients with cancer

Approaches

- A strategy for a timely move from invasive treatment to supportive care⁵
- Optimisation of treatment of the underlying disease⁴
- Improved symptom control⁴ and attention to comorbidities
- Emphasis on quality of life⁴
- Discussion of prognosis⁸ early in the course of disease, seeking patients' views⁷
- Acknowledgment of disease specific barriers to effective communication⁸
- Adequate information for patients¹¹

medicine, and palliative medicine. These were chosen to reflect the specialties that are most concerned with patients with heart failure. We included doctors from tertiary referral centres (one cardiologist group), teaching hospitals, and district general hospitals to ensure access to a wide range of views. One general practitioner group was made up of doctors with either a teaching or research post at a university. We took a pragmatic approach to recruitment, and participants were found from several different sources, depending on circumstances (table).

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.¹² The data were analysed by using the

principles of constant comparison.¹³ 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 that care for people dying with heart failure had not been planned. This was most clearly expressed by the cardiologists, who acknowledged the need to develop those formal and informal connections between specialties that are essential to coherent care. All the groups suggested that different models of care in the community might be needed. The concept of a key worker was raised as a possible solution by both general practitioners and cardiologists. This is a model seen in psychiatry, whereby a member of the team coordinates and oversees the care received.

Recruitment and participants

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

All hospital and palliative care doctors were NHS consultants.

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)

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 unpredictable, 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 prognostication 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 terminal 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 appropriateness 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 cardiologists articulated an approach supporting teamwork, 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 speciality 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 practitioners' patients. The general practitioners saw themselves at the centre of things, both providing and coordinating 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 competently and the unwillingness of cardiologists to provide palliative care were used to justify this approach.

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)

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 hospital, 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 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.^{8 14 15} 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.¹⁶ 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.^{17 18} Communication with doctors is a common source of dissatisfaction for patients of all diagnoses needing palliative care.^{8 19 20}

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.^{9 10} 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

increase. Furthermore, there is growing recognition that palliative care services need to be integrated into primary care.²¹ 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.²² 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.

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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 D R Williams *consultant psychiatrist, Cefn Coed Hospital, Swansea*

We welcome articles up to 600 words on topics such as *A memorable patient*, *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.