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# Communication and choice in dying from heart disease

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## SUMMARY

**In heart disease palliative care has received less attention than in cancer. In the Regional Study of Care for the Dying, carers of a random sample of deaths in 20 English health districts were interviewed about 10 months after the death. There were 675 respondents for patients dying with heart disease, and we report data on 600 deaths that were not sudden.**

**54% of patients died in hospital, 30% in their own home, 11% in a nursing or residential home, and 4% in other places. Half the patients were said to have known, or probably known, that they were likely to die; of these, 82% were said to have worked this out for themselves rather than been told by a doctor or nurse. More than one-third of patients (39%) died without an informal carer present. Respondents said that a quarter of the patients had wanted to die earlier: this desire was associated with older age and the number and severity of symptoms.**

**The study suggests the need for health services to give greater attention to palliative care for patients dying with heart disease.**

## INTRODUCTION

There is growing recognition of the importance of health services in care for the dying[1,2]. With the development of effective therapies during the twentieth century, the aim of medicine has shifted from care to cure. Palliative care has developed as a full specialty[3] with the aims of securing the best quality of life for patients with terminal illness and promoting open communication about dying.

National Health Service funding for health districts has supported palliative care provision for patients with cancer, especially hospices established by voluntary organizations and community nursing services provided by cancer charities. Increased choice to die at home and improved communication about dying are among the key features of palliative care for cancer patients[3]. However, while heart disease is as frequent a cause of death as cancer, there has been little discussion of the health-services arrangements for dying with heart disease[4].

The Regional Study of Care of the Dying was a population-based investigation of the needs, services and outcomes of care for dying people, using the reports of their main informal carers after the death[5]. We have described elsewhere the high level of symptoms and distress reported for patients with heart disease, who formed about one in six of the total sample, during their last 6 months of life[6]. Pain, dyspnoea and mental disturbance were the commonest symptoms, and between a quarter and a third of patients obtained little or no relief of symptoms. We report here the health-services arrangements for dying, the communication about dying and the place of death for these patients.

## METHODS

The Regional Study of Care for the Dying followed the methods used in previous national surveys by Cartwright in 1969[7] and Seale and Cartwright in 1987[8]. All health districts in England were invited to participate through the directors of public health in the fourteen regional health authorities. 20 districts did so, and they ranged from inner and outer urban districts to county and rural districts. Although self-selected, the districts together were nationally representative on indicators of deprivation and death rates and in health service provision. Full details of the study methods have been published elsewhere[5].

A sample of death certificates in the last quarter of 1990 was drawn in each district. Because of districts' concerns, the study used a sampling fraction ensuring that about half of all the interviews were for cancer patients. A letter was sent to the deceased's usual address, introducing the study, informing the recipients that they would shortly be contacted by an interviewer and enabling people who did not want to participate to contact the study interviewer managers. If no reply was received, trained interviewers contacted the address, seeking the best informant about the deceased's final 12 months. Of 5375 death certificates drawn for the sample there were 3696 completed interviews, a response rate of 68.8%. There were 675 patients for whom heart disease (International Classification of Diseases codes 391–429) was the underlying cause of

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death. The analysis excluded 75 patients with sudden death, where respondents gave no history of previous illness.

Since not all questions were answered by respondents, sample numbers and percentages are given together in this report. The $\chi^2$ test was used to assess statistical significance. A logistic regression model was constructed to identify predictors of the patients' desire to die sooner: independent variables were dichotomized around the median and a forward stepwise procedure was used for selection.

## RESULTS

For the 600 heart disease patients, 210 (35%) respondents were close relatives of the deceased, 199 (33%) a spouse, 72 (12%) another relative, 47 (8%) a friend or neighbour and 72 (12%) formal carers. There were 62 (10%) aged 65 or under, 159 (27%) aged 65 to 74, 238 (40%) aged 75 to 84, and 139 (23%) aged 85+. The main cause of death on the death certificate was described as acute myocardial infarction in 304 (51%), chronic ischaemic heart disease in 194 (32%), and other forms of heart disease in 102 (17%).

### Information about illness

Just under half (234, 47%) of the respondents who were family or friends of the deceased felt they had not been able to get all the information regarding the deceased's illness that they had wanted, when they had wanted it. Of the family and friends who had received information from both general practitioners (GPs) and hospital doctors about the deceased's illness, 43% (43) said hospital doctors had been the most informative and 36% (36) said GPs had been (the remaining respondents named other professionals). However, these respondents had found GPs more supportive than hospital doctors (28, 29% versus 14, 14%).

### Knowledge of prognosis

Respondents who were family or friends were asked about their knowledge of the deceased's illness, and both their and the deceased's knowledge of the prognosis. Of these respondents, 170 (37%) said they had known the deceased was likely to die, and 99 (26%) said they had 'half known'; this latter group varied with the age of the deceased, rising from 26% (12) of respondents for those who were aged under 65 at death, to 51% (51) for those aged 85 and over ($P<0.05$). Of the deceased, for all respondents, 122 (26%) were reported to have known that they were likely to die and 124 (25%) were said to have probably known; there were no statistically significant differences in this between age groups.

### Learning about dying

Most (193, 82%) of the deceased who were said to have known, or probably known, they were likely to die were reported to have worked this out for themselves: only 11 (4%) were said to have been told by a hospital doctor and nine (4%) by a GP; 18 (10%) respondents replied 'not known'. 131 (65%) of these decedents were thought to have known for at least a week and 64 (31%) for at least three months.

Of the respondents, 170 (37%) of family or friends of the deceased said they had known the deceased was likely to die, and 99 (22%) had 'half known'. 77 (45%) said they had worked this out for themselves, 49 (29%) had been told by a hospital doctor, and 26 (15%) had been told by a GP. 71 patients (58%) were said to have known for at least a week and 69 (41%) for at least three months. 97 respondents (58%) said they had known the prognosis for at least a week and 69 (41%) for at least 3 months.

### Support in dying

Sudden deaths excluded, more than one-third (189, 36%) of patients were reported to have died alone: this proportion increased from 32% (71) of those under 55 to 40% (154) of those aged over 75 ($P<0.05$). Overall, 30% (157) of respondents were present at the death—47% (93) of the spouses and 25% (52) of close relatives, 11% (8) of other relatives and 9% (4) of friends and neighbours. Two-thirds (223, 63%) of those not present at the death said they would have liked to be present.

### Where to die

Half of the patients (316, 54%) died in hospitals, 30% (175) in their own or another person's home, 11% (67) in a nursing or residential home, and 4% (24) in other places. Patients aged under 75 were less likely to die in a hospital or another institution, and more likely to die at home, than patients 75+ (Table 1). Women aged 75 and over more frequently died in residential or nursing homes than their male counterparts. A little under half (43%, 206) of respondents who were family or friends felt that the family or carers had not had enough choice in where the deceased had died. Similarly, 192 (40%) respondents (for those who had not died suddenly) thought the deceased had not had enough choice in where they died, but for only 37 (8%) did the respondents say that the deceased was too ill to be capable of making a choice.

### The time to die

A quarter (128, 23%) of the deceased were reported to have expressed a wish to die sooner; more women than men were said to have expressed such a wish (81, 30% versus 47, 17%, $P<0.01$). Logistic regression was used to explore predictors of expressing a wish to die sooner. Decedents who were aged 75 or over were 2.6 times more

*Table 1* **Place of death by age by sex**

| ***Place of death*** | ***Male**** | | ***Female†*** | | ***All‡*** | |
|---|---|---|---|---|---|---|
| | <75 | 75+ | <75 | 75+ | <75 | 75+ |
| Own home | 59 | 41 | 24 | 38 | 83 | 79 |
| | 41% | 27% | 37% | 17% | 40% | 21% |
| Other person's home | 3 | 1 | 1 | 8 | 4 | 9 |
| | 2% | 1% | 2% | 4% | 2% | 2% |
| Hospital | 71 | 87 | 32 | 125 | 103 | 212 |
| | 49% | 58% | 49% | 57% | 49% | 57% |
| Other institution | 3 | 16 | 3 | 45 | 6 | 61 |
| | 2% | 11% | 5% | 20% | 3% | 16% |
| Ambulance/street | 8 | 6 | 5 | 5 | 13 | 11 |
| | 6% | 4% | 8% | 2% | 6% | 3% |

Some percentages do not total 100% owing to rounding.
**P*=0.005; †*P*=0.0002; ‡*P*<0.00001.

likely to have expressed a wish to die sooner (confidence interval 1.55–4.57); those with four or more symptoms perceived as 'very distressing' were 2.3 times more likely (CI 1.27–4.16); those who had six or more symptoms were 2.1 times more likely (CI 1.19–3.72); and those who had a poor quality of life were 1.9 times more likely to have been reported to have been known to have expressed a wish to die sooner (CI 1.13–3.18). The patient's sex did not quite reach statistical significance within the model, being strongly associated with age.

## DISCUSSION

As judged by the views of informal carers, this aspect of heart disease deserves more attention. The 5-year survival rate of chronic heart disease is about 50%, comparable with that in many of the common types of cancer[9]. Some have suggested that heart failure should likewise be considered a 'malignant disease'[5] although, at an individual level, death from heart disease may be less predictable than for cancer. There has been little research on the accuracy of clinicians' prognosis for patients with cancer[10], and none reported for heart disease.

### Communication

Our results suggest that clinical staff very rarely discussed with heart disease patients their likelihood of dying. Yet, despite this lack of formal acknowledgement, half the patients were said by their friends and carers to have recognized that they were likely to die. While clinicians may wish to be optimistic about therapy, open discussion about the possibility of death can also be good clinical practice. A quarter of the patients in this study were reported to have wished to die sooner. Apart from old age, there was a significant association with poor symptom control.

In cancer care the need for open communication to assist in relieving symptoms is well recognized. Buckman has said that communication 'usually requires greater thought and planning than a drug prescription, and unfortunately it is commonly administered in sub-therapeutic doses'[11]. Our results suggest that clinicians caring for patients with heart disease—and perhaps also other chronic diseases, such as cirrhosis or emphysema—may need to establish an understanding of communication about dying similar to that of cancer physicians.

### Place of death

While some patients with heart disease die suddenly, most have been ill beforehand. In this population-based study about a third of the heart disease patients with previous illness died in their own or others' homes. A substantial minority of informal carers reported that they, and the patient, had had insufficient choice in place of death. This finding does not necessarily mean that more patients would like to die at home, but it does suggest lack of discussion between clinical staff and informal carers about the preferred place for death. Hospital clinicians and GPs need to have a shared understanding of the range of hospital and community support available.

While only one in three informal carer respondents were present at the death, two-thirds of respondents who were not at the death said that, in retrospect, they would have liked to have been. This is one reason perhaps for supporting dying at home where possible. Clinicians should consider discussing preferences for place of care more actively than at present, both with patients and with family or carers.

## Validity of the study

Patients in this study were identified through a death certificate diagnosis of heart disease. Although post-mortem studies have shown discrepancies between clinical and pathological diagnoses, and the specific cause of death may be difficult to determine in elderly patients with multisystem disease, death certificates remain an important and relatively reliable basis for analysis. This study was based on reports from carers rather than patients themselves: there is some evidence that informal carers may overestimate palliative care problems—and patients under-report them—compared with clinicians[12]. However, the carer's memories of the death are themselves an important outcome.

## Implications

Better palliative care, with concern for symptom control and psychological care, should be available to patients with heart disease as they approach death. Open communication about death and dying is needed to allow agreement on the preferred place for death and to achieve the best outcome for the bereaved. Texts in cardiology should include advice on palliative care, and prospective clinical research should be undertaken. Improved care does not require a new specialist service but rather an increased understanding, by primary care and hospital doctors of the need for palliative care.

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