

Dying from heart disease

Objectives. To describe the symptoms experienced in the last year of life by people with heart disease, their relation to quality of life, and informal carers' satisfaction with hospital services.

Methods. Interview survey of informal carers of 600 patients aged 15 and over, approximately ten months after their death from heart disease in 1990 in 20 English health districts. The districts, while self-selected, were nationally representative in social characteristics and indicators of health service provision and use.

Results. Pain, dyspnoea and low mood were reported to have been experienced by more than half the patients in their last year of life. Anxiety, constipation, nausea/vomiting, urinary incontinence and faecal incontinence, although not suffered by the majority of patients, also caused much distress. Hospital symptom control was reported to be limited: little or no symptom relief was reported for 35% patients with pain, 31% with constipation, 24% with dyspnoea and 24% with nausea/vomiting. Nevertheless, high levels of satisfaction with hospital staff were reported.

Conclusions. Patients dying from heart disease experience a wide range of symptoms, which are frequently distressing, and often last for more than six months. There is room for an improvement in palliative care for patients with heart disease in hospital.

Interest and research in the care of the dying has been increasing over the past 25 years in the United Kingdom and has resulted in better symptom control and psychological support for people dying from cancer and for their families [1]. Although heart disease is the leading cause of death in the UK, research into, and specialist services for, care of patients with heart disease has been negligible [2]. More than 1000 reports on dying with cancer have been published between 1983 and 1993, but there have been no reports on dying with heart disease; nor are dying and death described in standard cardiological texts [3,4]. Recently, however, there have been calls for more attention to be paid to dying from causes other than cancer, and specifically from cardiac causes [5-7].

The *Regional Study of Care for the Dying* [8] was a

population-based survey of the family members or others who knew about the last year of life of a random sample of people aged 15 and over dying in the last quarter of 1990 in 20 English health districts. The districts, although self-selected, were nationally representative in terms of social characteristics and on most indicators of health services provision [9]. The primary purpose of the study was to describe the informal carers' views of palliative care at local level. We have used data from the study to investigate the symptoms and hospital care of people dying with heart disease.

Methods

Deceased patients were identified locally through death certificates, and random samples were drawn. Interviewers sought to contact the person who could tell them most about the last 12 months of the deceased person's life. Information was obtained on 3696 (68.8%) of the initial sample of 5375 deaths. Because of their special interest for palliative care services, patients dying of cancer were over-sampled, making up 54% of the total. The methods and sample characteristics are described in more detail elsewhere [8].

A total of 675 people for whom heart disease (ICD codes 391-429) was the main cause of death were selected. Seventy-five people (11%) who had died suddenly without illness, warning or time for care were excluded from the present analysis. For those patients who died from heart disease, 35% of respondents were close relatives of the deceased, 33% a spouse or common-law partner, 12% other relative, 12% officials, and 8% a friend or neighbour. They were interviewed about ten months after bereavement, which was timed to allow recovery from normal grief reaction, but before the anniversary of the death, which is sometimes associated with further mourning.

Both percentages and sample numbers are given, as not all questions were answered for all the deceased. The chi-squared statistical test was used. A model was constructed to identify predictors of a poor quality of life using logistic regression. Illness-related independent variables were dichotomised around the median and a forward stepwise procedure was used for selection criteria. Factor analysis was also used to group symptoms predicting quality of life.

Results

Characteristics of sample

Of the 600 heart disease patients included in this analysis, 62 (10%) were aged under 65 at death, 159

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(27%) were 65 to 74, 238 (40%) were between 75 and 84, and 139 (23%) were aged 85 and over (age was unknown for two patients). There were large differences between the sexes in age at death: 50% (154/309) of men were under 75 compared with 23% (67/289) of women. The main causes of death, as described on the death certificates, were 304 (51%) from acute myocardial infarction, 194 (32%) from chronic ischaemic heart disease, and 102 (17%) from other forms of heart disease. Over half the patients, 54% (316/582), died in hospital and 30% (175/582) at home, while 11% (67/582) died in a residential or nursing home and 4% (24/582) elsewhere.

Symptoms

Pain was the most common symptom, and was reported for 78% (447/576) patients in the last year of life and 63% (326/520) in the last week of life. Pain was reported as having been 'very distressing' in 50% (219/437) of cases, but this decreased with age from 67% (8/12) of those aged under 55 to 33% (31/95) of those aged 85 or over ($p < 0.01$).

Dyspnoea was the second most frequent symptom, and was reported for 61% (363/592) of patients in the last year of life and 51% (284/558) in the last week of life. Dyspnoea was more frequent in men, (66%, 201/306) than in women (57%, 162/287; $p < 0.05$), as was a persistent cough (29%, 89/309 compared with 18%, 51/284; $p < 0.01$). Dyspnoea was reported to have been very distressing in 43% (151/355) of patients with the symptom, and it was also a long-term problem—72% (257/357) were reported to have suffered from it for six months or more.

Mental disturbances were the third most frequent symptoms. Low mood was reported in 59% (349/589) of patients, 45% (259/580) had sleeplessness and 30% (177/588) suffered anxiety or 'nerves'. Anxiety was more frequent in younger patients; 43% (20/47) in patients aged 55–64 versus 26% (35/134) in patients aged 85 or over ($p < 0.01$). All three symptoms lasted longer than six months for at least 80% of patients affected by them (282/343; 212/249; 158/176). Low mood and anxiety were reported to have been very distressing (50%, 168/334 and 55%, 91/166, respectively)—ranking as high as pain and urinary incontinence for distress.

Mental confusion occurred in 27% (4/15) of patients aged under 55 and in 42% (58/137) of patients aged 85 or over ($p < 0.05$). It caused great distress to 43% (22/51) of patients under 75 and to 33% (37/113) patients over 75 ($p < 0.05$).

Loss of appetite (43%, 251/585), constipation (37%, 191/521) and nausea/vomiting (32%, 187/580) were common symptoms; of those who experienced the last two symptoms, 43% (78/180) and 42% (74/177) respectively found them very distressing. Faecal incontinence occurred in 16% (92/567) patients, and persisted for more than six months in

46% (41/90). It was the symptom most frequently reported as being very distressing (64%, 52/81) and was more common in older patients. Urinary incontinence occurred in 29% (167/575) patients, and persisted for more than six months in 55% (88/160) of them. Women reported urinary incontinence more frequently than men (36%, 100/277 compared with 23%, 67/298; $p < 0.001$).

Quality of life

Respondents were asked to rate the patient's quality of life during the last year of life; 45% said it had been 'good', 29% 'fair', 24% rated it as 'poor', and 2% made some other comment. In the logistic regression model, two variables had the best predictive power: having four or more very distressing symptoms increased the likelihood of having a poor quality of life nearly fivefold (o.r.=4.9; c.i.=3.1–7.9); and having needed assistance with three or more self-care tasks during the final year increased the likelihood of a poor quality of life more than threefold (o.r.=3.7, c.i.=2.3–5.8). Socio-demographic variables, including age, sex and social class, did not predict quality of life, nor did use of hospital services.

Factor analysis was used to group symptoms, and the relationship of these clusters to the quality of life was explored using logistic regression. The presence of 'very distressing' mental confusion, loss of bladder or bowel control more than doubled the likelihood of a poor quality of life (o.r.=2.5, c.i.=1.6–4.0), as did the presence of one or more 'psychiatric' symptoms (low mood, anxiety, or insomnia) perceived to have been 'very distressing' (o.r.=2.4, c.i.=1.5–3.9). Those who were reported to have had 'very distressing' difficulties with swallowing, loss of appetite, pain, or constipation were almost twice as likely to have had a poor quality of life (o.r.=1.9, c.i.=1.1–3.1). However, dyspnoea, cough, dry mouth, or a bad smell did not predict poor quality of life in the final model.

Hospital admissions and care

Altogether, 70% (422/600) of patients who did not die suddenly spent some time in hospital in their last year. The duration of hospital admissions tended to be relatively brief; 25% (105/417) spent less than 3 nights, and a further 49% (203/417) 3 nights to one month.

Respondents described the patient's symptoms in relation to hospital care (the hospital to which the patient had been admitted longest if there were more than one admission). Pain was experienced by 74% (234/318) patients in hospital, and 94% (181/193) received treatment for it. Complete relief was reported for 23% (36/155), complete relief some of the time for 42% (65/155), and only partial or no relief for 34% (54/155). Dyspnoea was reported for 56% (184/327) of patients in hospital, and 89% (149/167)

received treatment for it. Considerable relief was gained by 36% (51/140), some relief by 39% (55/140), and little or no relief by 24% (34/140). Nausea or vomiting, and constipation were also reported to have been poorly controlled in some patients, with 24% (10/41) getting little or no relief from nausea or vomiting and 31% (10/132) little or no relief from constipation.

Satisfaction with hospital care

Respondents were asked to give an overall rating of the care given to the deceased by the hospital doctors and nurses. The hospital doctors' care was rated as excellent or good for 81% (278/344) patients compared with 84% (300/359) for hospital nurses' care. Only 6% of respondents rated doctors' or nurses' care as poor. Some 13% (51/398) felt that the hospital doctors had been unwilling or unable to give the deceased the time they had needed; and 29% (103/350) felt that the deceased had not had as much choice in their treatment as they had wanted.

Discussion

We believe this to be the first reported study of the symptoms and hospital care of a population-based sample of people dying from heart disease. It is estimated that 5% of patients admitted to hospital have heart failure and 5% a heart attack [5]. In this study of 600 patients, the most frequently reported symptoms during the last year of life were pain, dyspnoea, low mood and sleeplessness. These symptoms were said to have caused considerable distress for many and to have troubled them for more than six months. Loss of bladder and bowel control, although not suffered by the majority, also caused much distress.

It is of some concern that hospital management of pain, dyspnoea, nausea or vomiting, and constipation was reported to have brought little or no relief to between a quarter and a third of patients suffering these symptoms. Efforts to remove the cause of distressing symptoms, or to control such symptoms, are likely to be worthwhile in improving quality of life. Patients with heart disease might benefit from the knowledge and expertise developed within palliative medicine [10], although further research is needed to investigate whether treatments devised primarily to meet the needs of cancer patients are appropriate to symptoms resulting from heart disease.

A limitation of this study is that the data were collected retrospectively from friends and family and others who knew the patient, rather than directly from the patients themselves. In prospective studies, patients dying with cancer appear to be less concerned about their symptoms than their carers [11]. The views of patients and informal carers about satisfaction with services appear to be similar, but carers' views are more polarised after the death than before [12].

Respondents' knowledge of symptoms vary according to their relationship with the deceased [13]. Since it is the memory of the death that lives on, the informal carers' views after the death have their own validity.

Some of the symptoms and service use reported here may not be specifically related to heart disease: the survey did not obtain the date of onset of heart disease or what additional illnesses existed other than those recorded on the death certificates. Co-morbidity with heart disease is common, especially in older patients [14]. In addition, the broad scope of the survey meant that little information is available on, for instance, what treatment was offered to patients whose respondents reported inadequate relief of symptoms. A prospective study of patients dying from heart disease would be desirable to describe more accurately symptoms of dying and needs for palliative care. However, studies in cancer patients indicate the difficulty of predicting the time of death [15], and prospective population-based studies of care for the dying that achieve representative samples are difficult to design [16], for example because of loss of patients in the sample [17].

Patients with heart disease are in some ways similar to patients with cancer: both face an uncertain future and cure of the underlying pathology is often not possible [5]. It is time for the concerns of palliative care to be extended from cancer patients to the broad range of patients dying in hospital, at home and in nursing and residential homes.

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ADOLESCENT MEDICINE

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