THE EXPERIENCE OF DYING WITH DEMENTIA:
A RETROSPECTIVE STUDY

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ABSTRACT

Objective. To describe the last year of life of people with dementia, their symptoms, care needs, use of and satisfaction with health services and the bereavement state of the respondent.

Methods. The study is drawn from the Regional Study of Care for the Dying, a retrospective sample survey of the carers, family members or others who knew about the last year of life of a random sample of people age 15 and over dying in the last quarter of 1990. The samples were drawn in 20 English health districts which, although self-selected, were nationally representative. There was a total of 3696 patients (response rate of 69%) dying from all causes. Within this sample, 170 dementia patients were identified and compared with 1513 cancer patients.

Results. The symptoms most commonly reported in the last year were mental confusion (83%), urinary incontinence (72%), pain (64%), low mood (61%), constipation (59%) and loss of appetite (57%). Dementia patients saw their GP less often than cancer patients and their respondents rated GP assistance less highly. Dementia patients needed more help at home compared with cancer patients, and received more social services; 78% of respondents for dementia patients and 64% for cancer said they had come to terms with the patient’s death.

Conclusion. Patients dying from dementia have symptoms and health care needs comparable with cancer patients. Greater attention should be given to these needs. (© 1997 by John Wiley & Sons, Ltd.)

KEY WORDS—dementia; palliative care; health services; informal carers

Dementia is a major concern for nations in Europe (Hofman et al., 1991). The population prevalence of dementia increases with age, rising to one in four people age 85+. There is little clear evidence on the aetiology of dementia, of which Alzheimer’s and cerebrovascular disease are the most common types. Supportive management and help for informal carers are the main objectives of health services. Patients die with the disease, if not directly of it. However, dementia varies in intensity, and not all people suffering with it come to the attention of services.

Concern for palliative care has developed over the past two decades. Hospices and palliative care services were initially started to provide for younger patients with cancer; but the United Kingdom Standing Medical and Nursing Advisory Committee (Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committee, 1992) has recommended that palliative care services—in primary care, specialist community teams and inpatient services—’should be developed for patients dying from other diseases’.

Within a national survey of care for people in the last year of life we have been able to identify a group of patients who had a primary death certificate diagnosis of dementia. We report here the experience of these patients and their informal carers over the last year of their life, as reported by the informal carer, and the bereavement period of the carer. The patients dying with dementia are compared with patients with cancer, who are the usual focus of palliative care, allowing a view of the implications for health services.

METHODS AND SAMPLE

The Regional Study of Care of the Dying was a collaboration between 20 health districts in England which sought to record the needs of dying people as a basis for health services planning (Addington-Hall and McCarthy, 1995a). The districts joined the study voluntarily; however, inner-city, suburban and rural districts participated, and together the districts closely matched...
national averages for most social characteristics and for many indicators of health service provision and use (Addington-Hall and McCarthy, 1995b).

Death certificates for the last quarter of 1990 were provided by each district. A sample of 270 deaths per district was prepared using random numbers. Cancer deaths were sampled disproportionately (because of special interest) and made up 54% of all deaths. There were 5378 deaths in the sample; a response rate of 69% yielded 3696 completed interviews.

The methods, following the approach used by Seale and Cartwright (1994), have been reported in detail elsewhere (Addington-Hall and McCarthy, 1995a). An initial letter explained the purpose of the study and asked people who did not wish to participate to telephone the local contact person. Trained survey staff sought to interview the person who knew most about the deceased’s last year of life. For people in residential or long-term care this was either a relative who visited frequently or a professional carer. The interviews were, on average, 10 months after the death. The interview schedule was semi-structured and took on average 2 hours to complete.

Based on the death certificate diagnosis, and following the diagnostic coding rules used by the Office of Population Censuses and Surveys, there were 2074 cancer and 1622 non-cancer deaths. For the present study deaths under 65 were excluded (this included two deceased with dementia); there were 170 deceased with a diagnosis of dementia or senility. We chose cancer patients as a comparison group because they are normally associated with concern for palliative care services: there were 1513 deceased age 65 and not dying suddenly. The experience of patients dying with cancer is described more fully elsewhere (Addington-Hall and McCarthy, 1995c).

Not all questions were answered about all deceased; percentages are based on replies. The chi-squared test was used to compare frequencies. All differences reported were statistically significant at the level $p < 0.05$, and remained so after controlling for respondents (spouses; relatives, friends, neighbours; officials) using logistic regression.

RESULTS

Sample characteristics

There were 108 women and 62 men with dementia, compared with 756 women and 757 men with cancer. The dementia patients were older—54% age 85+ compared with 18% of cancer patients. Forty-three per cent of dementia patients had lived (and died, 41%) in a nursing or residential home for the whole of their last year of life, compared with 6% (and died, 9%) of cancer patients. No dementia patients died in a hospice compared with 13% of cancer patients. Fifteen per cent of respondents for dementia patients were spouses and 30% staff compared with 34% spouses and 8% staff for cancer patients.

Symptoms

The most frequent symptoms reported for dementia patients in the last year of life were mental confusion (83%), urinary incontinence (72%), pain (64%), low mood (61%), constipation (59%) and loss of appetite (57%). Similar frequencies were reported for cancer patients, but dementia patients experienced them for longer (Fig. 1).

Assistance

Levels of need for assistance at home were high for patients with dementia (Table 1), and greater than for cancer patients. Similarly, the proportion of dementia patients needing help with five or more of the reported activities was higher than for cancer patients (77% compared with 51%) and the dementia patients had been restricted for longer than the cancer patients, 50% having needed help for over a year with five or more of the reported activities compared with 9% for cancer patients.

Health services

Seventy-two per cent of dementia patients saw their GP at least five times in the last year of life compared with 80% of cancer patients. Similar proportions of respondents for dementia patients (75%) and cancer patients (72%) thought the GP’s care was excellent or good, but only 50% for dementia patients compared with 60% for cancer patients felt the GP was very understanding. Forty-eight per cent of the dementia patients had had care from a district nurse compared with 60% of cancer patients. Forty-six per cent of the dementia patients receiving assistance from a home nurse had had it for at least 6 months; most nurses came at least once a week; and most home nursing care was rated favourably.

Although dementia patients were much more likely (67%) to have lived in residential care during
Fig. 1. Symptoms reported to have been experienced for at least 6 months by cancer and dementia patients in the last year of life

Table 1. Need for, and sources of help with self-care and domestic activities of patient†

<table>
<thead>
<tr>
<th>Needed help at home in last year of life with:</th>
<th>Cancer</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting in and out of bath/shower</td>
<td>1050 (73)</td>
<td>99 (93)</td>
</tr>
<tr>
<td>Dressing and undressing</td>
<td>825 (57)</td>
<td>85 (78)</td>
</tr>
<tr>
<td>Using the toilet</td>
<td>702 (48)</td>
<td>74 (68)</td>
</tr>
<tr>
<td>Washing or shaving</td>
<td>731 (50)</td>
<td>78 (71)</td>
</tr>
<tr>
<td>Cutting toenails</td>
<td>952 (70)</td>
<td>99 (91)</td>
</tr>
<tr>
<td>Making hot drinks</td>
<td>786 (54)</td>
<td>84 (76)</td>
</tr>
<tr>
<td>Help at night</td>
<td>777 (54)</td>
<td>85 (78)</td>
</tr>
</tbody>
</table>

Number of self-care activities needed help with:

| None                                          | 292 (20)  | 7 (6)    |
| One to four                                   | 423 (29)  | 19 (17)  |
| Five or six                                   | 282 (19)  | 26 (24)  |
| All seven                                     | 461 (32)  | 58 (53)  |

Number of self-care activities needed help with for more than 1 year:

| None                                          | 860 (60)  | 18 (16.5) |
| One to four                                   | 451 (31)  | 37 (34)   |
| Five or six                                   | 72 (5)    | 18 (16.5) |
| All seven                                     | 60 (4)    | 36 (33)   |

Had meals on wheels                            | 168 (12)  | 20 (24)   |
Had social services home help                   | 334 (24)  | 34 (41)   |
Had attendance allowance                        | 340 (25)  | 41 (51)   |
Needed more help with self-care activities      | 465 (40)  | 39 (39)   |
Needed more help with shopping, cooking or cleaning | 353 (26)  | 31 (38)   |

* * p < 0.05; ** p < 0.01.
† Patients in nursing or residential home or hospital for whole of last year are excluded.
their last year than cancer patients (16%), there was no significant difference reported between the two groups in satisfaction with the care received at these institutions. There was low use of day hospitals reported—12% for dementia patients and 8% for cancer patients. Dementia patients (33%) were much less likely to go for outpatient care than cancer patients (70%).

Sixty-seven per cent of dementia patients were in a hospital during their last year compared with 90% of cancer patients, but 26% of dementia patients were in hospital for more than 3 months in their last year of life compared with 9% of cancer patients. The ratings of satisfaction with hospital care by the respondents for dementia and cancer patients were similar. However, respondents for dementia patients more often (34%) than for cancer patients (22%) described the room the patient had spent most time in (or died in) as ‘not at all peaceful and quiet’.

**Information**

Thirty-nine per cent of respondents for dementia patients said they had been unable to get all the information they had wanted relating to the patient’s medical condition when they had wanted it; the proportion for cancer patients (51%) was higher. In particular, 21% of dementia respondents wanted to know more about what was wrong with the patient, while 13% wanted to know more about how to care for the patient and 10% wanted to know more about the likely outcome, about medication and about reasons for decisions about treatment or care. There was no significant difference between the dementia and cancer patient respondents in the proportion who reported that they had known what was wrong with the deceased. Although proportionately fewer respondents for dementia patients (57%) than for cancer patients (75%) said they knew the patient was likely to die, the level was still high enough to suggest that a terminal phase was recognized by the carer.

**Self-care**

Dementia patients were more likely than cancer patients to have had help from a home help, to have received meals on wheels and to have received attendance allowance (Table 1). Nevertheless, similar proportions of respondents said the patients needed more help with self-care activities while at home in the last year of life, and more dementia patients than cancer patients were reported to need more help with shopping, cooking or cleaning.

**Informal carers’ experiences**

Respondents who were not officials and who helped with caring for the patient were asked whether they had found caring rewarding, a burden, or equally balanced between the two. Informal carers of dementia patients gave substantially fewer positive responses, proportionately, than cancer informal carers, with 35% reporting that they had found caring rewarding compared with 60% of cancer carers. A high proportion of dementia carers was in contact with a support group (25% compared with 10% for cancer carers), but the level was low. Both groups of informal carers reported similar levels of restriction on their activities.

**Bereavement**

The effects of bereavement on informal carers at the time of the interview included sleep problems, depression and loss of appetite. Twenty-four per cent of respondents for both dementia and cancer patients had talked about the death to a GP, but fewer respondents of dementia patients (46%) than cancer patients (62%) to a friend or neighbour. Dementia carers (59%) were less likely than cancer carers (75%) to have reported missing the patient ‘a great deal’, and more (70% compared with 51%) reported being able to look forward to things.

**DISCUSSION**

Our study used the objective criterion of the death certificate to define the diagnosis. This is likely to be an underestimate of the true numbers of people with dementia in the total study sample, but may reflect clinical recognition. The relationship between clinical diagnosis and death certificate diagnosis is not always close, but dementia is unlikely to be certified as a result of a postmortem examination. The study subsample probably represents the more severe end of the spectrum of all dementia patients.

The study describes the experience of patients dying with dementia, as perceived by their principal carer about 10 months after the death. Previous population-based studies of care in the last year of
life (Cartwright et al., 1973; Seale, 1991) have not had sufficient size to focus specifically on patients with dementia. The Oxford Textbook of Palliative Medicine (Doyle et al., 1993) mentions dementia only as a symptom accompanying organic disease. As most palliative care services, and research, have been concerned with cancer, we have compared patients with dementia with cancer patients in this study.

The study was retrospective, gaining the views of informal carers several months after the death—a time period when the 'normal' grief reaction is expected to be over (Parkes, 1986). The validity of retrospective studies can be questioned. One small study comparing the views of informal carers before and after death (Higginson et al., 1994) showed an association with the views of informal carers about satisfaction with services, but carers' views were more polarized after the death than before. This may reflect a psychological 'making sense' of the death process. Nevertheless, since it is the memory of the death that lives on, the carers' views after the death have their own validity.

Although the number of symptoms that dementia and cancer patients were reported to have experienced was similar, there were differences between the two groups in the frequencies of the symptoms and the dementia patients were reported to have experienced symptoms for longer than cancer patients. Pain was reported for dementia as well as cancer patients; this aspect requires further investigation. Dementia patients may have had other coexistent diseases, or the meaning of pain may have been interpreted differently compared with cancer patients.

Informal carers of people with dementia have needs which could be met by generalist health and social services, but community and nursing home staff appear to require further education in what support informal carers are seeking. While respondents for dementia patients considered their caring substantially less rewarding than respondents for cancer patients, they reported fewer mental health problems at the time of the interview. Informal carers are frequently relieved when the person with dementia is admitted to a nursing home (Levin et al., 1992).

Probably one of the hardest tasks of clinical practice for chronic disease is to understand when to change from actively seeking remission of disease to accepting positively the approach of death. Both carers and professional staff have concerns about the extent of active treatment for patients with dementia (Luchins and Hanrahan, 1993), so it is important to anticipate important decisions about the treatment. Use of predictive ratings (Volicer et al., 1993) may assist in these decisions. Recognition of approaching death will help clinical staff in supporting informal carers of people with dementia.

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REFERENCES


