The experiences of older adults in the community dying from cancer and non-cancer causes: a national survey of bereaved relatives

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Abstract

Background: there is limited understanding of symptoms and care in the last few months of life for adults dying from causes other than cancer.

Objective: the aim of the study is to compare the experiences in the community in the last 3 months of life of older adults dying from cancer and non-cancer causes.

Design: the study employed a retrospective cross-sectional survey of bereaved relatives.

Setting: the survey took place across eight cancer networks in England.

Subjects: a random sample of 1,266 adults who registered a death occurring in someone aged 65 and over between August 2002 and February 2004 was drawn.
Experiences of older adults at the end of life

Introduction

Understanding the symptom, treatment and care experiences of people who die from causes other than cancer and how these differ from those of cancer patients is crucial for the provision of humane and effective health care at the end of life [1]. In the last year of life, trajectories of physical function and health care use vary according to illness type [2, 3]. Older people are more likely to die from non-cancer causes, and access to appropriate health care and support may be insufficient [4, 5]. Improvements in our understanding of symptoms and care needs for non-cancer compared to cancer patients are required [6].

The most detailed research in the UK to date is the Regional Study of Care for the Dying (RSCD), a retrospective national population-based interview survey of 3,696 bereaved relatives investigating reported experiences in the last months of life [7]. This suggested that, at all ages, adults dying of cancer and non-cancer causes had different patterns of dependency and symptoms. Cause of death, rather than age, was the crucial distinguishing factor [8].

Since then, the focus on end-of-life services for non-cancer patients has intensified. The NHS End of Life Care Strategy aims to facilitate access to high quality care for all, regardless of diagnosis or care setting [9]. This builds on a number of government initiatives aimed at general practitioners (GPs), community/district nurses (DNs) and hospital medical and nursing staff. These include the Macmillan Gold Standards Framework (guidelines and tools to help standardise and improve community palliative care), the Liverpool Pathway for the Care of the Dying (a document-based approach to care in the last days of life) [10, 11] and a 3-year education and support programme for DNs in the principles and practise of palliative care [12]. Marie Curie’s Delivering Choice Programme aims to support local services to enable more people to die at home regardless of diagnosis [13]. The English government is expecting to see major improvements in the quality and accessibility of end-of-life care in the community [14].

The study reported in this paper uses reports from bereaved carers to compare the experiences of older adults (aged 65 and over at death) in the community during the last 3 months of life, in relation to cause of death (cancer versus non-cancer causes).

Methods

We conducted this study as part of the national evaluation of the England Department of Health palliative care education programme for district and community nurses [15]. We undertook a two-phase postal survey to investigate the experiences of older adults in the last 3 months of life, as reported by bereaved relatives, before and after the launch of the programme. There were no statistically significant differences between phase 1 and phase 2 [15]. We thus combined data and present our analysis here.

Participants

The survey took place across eight cancer networks, with one network randomly selected from each of the former English Health Authority Regions. Respondent sampling was conducted by the Office for National Statistics (ONS), a UK government department providing national statistical and registration services. For each phase, ONS drew a random sample of 190 people who registered a death occurring in someone aged 65 and over in each network, giving a sample size of 1,520 for each phase and a total sample of 3,040. The sample size was calculated to give sufficient power to address the primary aim, to detect change over time as a result of the education programme.

Deaths were sampled from those registered between 3 and 9 months before the planned mailing date, to ensure a suitable distance of time from the death. In phase 1, deaths...
were sampled from August 2002 to February 2003 and in phase 2, from August 2003 to February 2004. Deaths registered by a coroner were excluded.

The analysis presented here is confined to patients who resided at home or in a residential home at some point during the last 3 months of life (939/1,156, 81.2%). We excluded patients who remained in a nursing home or in a hospital throughout this period (217/1,156, 18.8%).

### Procedures

A VOICES (Views of Informal Carers—Evaluation of Services) questionnaire was sent by ONS to the person who registered each death (the informant). Each informant was assigned a unique identifier number to ensure confidentiality; no identifying information was released to the research team. Two reminders, with a further copy of the questionnaire, were sent at three-weekly intervals to those who did not respond. In Phase 1, the first mailing took place in May 2003 and in Phase 2, in May 2004.

### The VOICES questionnaire

The VOICES questionnaire was developed following the RSCD [7]. The interview schedule used for the RSCD was based on that used by Cartwright et al. in 1969 [16] and by Cartwright and Seale in 1987 [17]. VOICES is a survey questionnaire rather than an outcome measure, and its exact content varies depending on the precise aims and objectives of the survey: principles of questionnaire design and testing have been applied at each stage of development [18,19]. The eight sections of the questionnaire used in this survey covered the following: help at home, district nursing (DN) care, GP care, symptoms and treatment, other health care received, care received in the last week and circumstances surrounding the patient’s death. Items are predominantly fixed-response, with the opportunity for free-text comments. There are two versions, one for female deaths and one for male deaths.

Variables of interest derived from the questionnaire included age (65–69, 70–79 and 80 and over); symptom prevalence, distress, and treatment; receipt and perceived quality of DN and GP care; receipt of hospital care; receipt of palliative care; help with self-care activities; place of death; and the respondent’s experiences of caring for the decedent. The time frame was the last 3 months of life. Cause of death was determined by ONS from death certificate.

### Analysis

The statistical significance of differences between the reported experiences of cancer and non-cancer decedents in their symptoms and health and social care support were assessed using Pearson’s chi square test. We stratified the analysis of variables of interest by age (65–69 years, 70–79 years and 80+ years).
There was a statistically significant difference in place of death by age, independent of cause of death, with 31.5% of 65–69 year olds dying at home, compared to 26.4% of 70 to 79 s and 15.1% of those aged 80 and over ($P>0.001$).

### Symptoms and symptom control

According to the informants, more than two-thirds of decedents suffered pain (83.8%), breathlessness (71.0%) or constipation (68.4%) during the last 3 months of life. Nausea or vomiting (47.3%) and bedsores (32.4%) were also reported.

There were a number of significant differences in reported symptoms and treatment for those symptoms between cancer and non-cancer patients (Table 2). These differences remained after stratifying by age. Whilst cancer decedents were significantly more likely to have pain, nausea and vomiting and constipation, non-cancer decedents were significantly more likely to experience breathlessness. Across all causes of death, only a minority of decedents received effective treatment which completely relieved symptoms of pain (34.6%), nausea or vomiting (44.4%), breathlessness (39.7%), constipation (41.5%) and bedsores (31.5%) some or all of the time. The proportion of non-cancer patients receiving treatment for nausea and vomiting was particularly low in comparison to cancer patients. A greater proportion of adults dying of cancer received effective treatment for their pain, with those dying in a hospice receiving the most effective care (34.4% of those in a hospice had their pain in the last week of life relieved completely, compared to 18.5% at home and 15.7% in hospital). For other symptoms, treatment was equally likely to be effective in both groups.

### Table 3. Reported experiences of care and support in the last 3 months of life

<table>
<thead>
<tr>
<th></th>
<th>Non-cancer % (n)</th>
<th>Cancer % (n)</th>
<th>$\chi^2$</th>
<th>$P$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health and social care</strong> support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DN care</td>
<td>49.8 (319)</td>
<td>69.8 (201)</td>
<td>32.3</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>DN visited every day at peak</td>
<td>14.2 (37)</td>
<td>35.1 (65)</td>
<td>44.4</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Always treated with respect by DNs</td>
<td>72.4 (205)</td>
<td>83.2 (158)</td>
<td>7.3</td>
<td>0.007</td>
</tr>
<tr>
<td>DN care very understanding</td>
<td>58.8 (150)</td>
<td>72.1 (132)</td>
<td>8.2</td>
<td>0.004</td>
</tr>
<tr>
<td>DN care excellent</td>
<td>27.5 (72)</td>
<td>51.1 (95)</td>
<td>25.90</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>GP care</td>
<td>47.0 (234)</td>
<td>56.8 (138)</td>
<td>6.3</td>
<td>0.043</td>
</tr>
<tr>
<td>GP care excellent</td>
<td>27.1 (139)</td>
<td>35.5 (87)</td>
<td>5.61</td>
<td>0.018</td>
</tr>
<tr>
<td>Other care and support</td>
<td>62.9 (358)</td>
<td>66.3 (165)</td>
<td>0.8</td>
<td>NS</td>
</tr>
<tr>
<td>Received attendance allowance</td>
<td>1.4 (9)</td>
<td>38.9 (110)</td>
<td>242.62</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Received Macmillan/palliative care nursing</td>
<td>15.9 (73)</td>
<td>22.8 (50)</td>
<td>4.73</td>
<td>0.030</td>
</tr>
<tr>
<td>Overall health and social care support excellent</td>
<td>58.9 (83)</td>
<td>73.1 (79)</td>
<td>5.49</td>
<td>0.019</td>
</tr>
<tr>
<td>Healthcare received at home after hospital discharge</td>
<td>65.7 (110)</td>
<td>83.2 (158)</td>
<td>6.3</td>
<td>0.043</td>
</tr>
</tbody>
</table>

### Ethical approval

Ethics approval for the study was granted by the London Multi-Centre Research Ethics Committee (MREC/02/2/82).

### Results

#### Response rate

Across both phases, we received a total of 1,266 questionnaires (response rate, 41.6%). Response rate was associated with informant’s gender (males less likely to respond than females, $P>0.001$) and relationship to the deceased (highest response rate from sons and daughters compared to spouses/partners, siblings and other relatives or friends, $P=0.007$). Variations in response rates were also seen by age of the deceased ($P>0.001$); these may reflect different informant/decedent relationship patterns across decedent age bands.

#### Sample characteristics

There was an association between age and cause of death, with a greater proportion of non-cancer deaths in older age groups; 70.0% ($n=447$) of non-cancer decedents were 80 and over, compared to 42.2% ($n=119$) of cancer decedents ($\chi^2 (1, n=921)=65.71, P>0.001$). Decedents dying of non-cancer causes were more likely to be female and to have died in hospital (Table 1). There were no differences in the proportions of cancer and non-cancer decedents needing help with self-care activities, but cancer decedents were more likely to have required hospital care.

There was a statistically significant difference in place of death by age, independent of cause of death, with 31.5% of...
incidence, treatment received and quality of care suggest that, whilst cancer patients may have a higher symptom burden, non-cancer patients may be less likely to receive effective symptom control. Non-cancer patients were less likely to receive care from specialist palliative care nurses, reflecting the historic focus of specialist palliative care on advanced cancer [20]. They were also less likely to receive care from DNs; whilst this may be accounted for by differences in symptom experience, disparities in satisfaction with the quality of district nursing care cannot be. Informants caring for non-cancer patients were less likely to feel fully supported and informed and less likely to have found looking after their loved one rewarding. Overall, a picture emerges of cancer patients receiving more health and social services in the last 3 months of life and of these services being more satisfactory from the perspective of carers.

Although there is debate about the robustness of the underlying research [21], three illness trajectories have been presented to inform appropriate end-of-life care for all [22, 23]. The first describes the typical cancer trajectory, with a rapid decline over weeks or months before death; the second chronic organ failure with slow decline interrupted by acute exacerbations that may end in death; and the third typical to dementia or frailty with slow decline and poor long-term function [22]. Non-cancer patients in our sample following the latter trajectories may not have been identified as being in the last months of life. Recognition that the end of life is approaching can be challenging, and use of the ‘surprise question’ (‘Would I be surprised if this patient died within the next 12 months?’) is recommended to provide an indication of need for care [24, 25]. However, even with more accurate prognostication, service developments to better meet the needs of all patients may struggle to resource and maintain palliative care approaches throughout long end-of-life periods. Furthermore, although most people die in older age, older people have been relatively neglected in end-of-life care with, for example, evidence of age bias in access to specialist palliative care services [26].

Retrospective surveys have a number of strengths for researching care at the end of life. Prospective studies often exclude people not recognised to be dying or too ill or cognitively impaired to participate in research. This is a particular issue for non-cancer causes of death due to the difficulties in identifying terminal phases [22]. By retrospectively identifying deaths and using bereaved relative reports, we were able to include the full range of experiences at the end of life. Whilst relatives’ views are unlikely to agree completely with those of the patient before death or with their own views before bereavement, reasonable agreement has been demonstrated for service use and satisfaction [27].

Our response rate of 41.6% was lower than we had anticipated. It is not possible to assess the accuracy of ONS data on sampled informants; in particular, spouses of the deceased may have moved, become ill or died since the death was reported. However, the response rate compares favourably with 37% in another recent VOICES survey [28]. It is possible that motivation to respond was higher in those who had strong feelings about the care received (whether negative or positive), and thus our sample is not fully representative. Comparison of place of death data with published data for cancer deaths in England and Wales for the same period suggests that hospice deaths are under-represented in our sample (14 versus 20%), and home deaths are over-represented (27 versus 23%), with few other differences (hospital, 48 versus 47%; care homes, 9 versus 8%) [29].

This was an exploratory analysis of data collected for the primary purpose of an evaluation and has the usual limitations of such approaches. Sample size calculations were conducted for the primary endpoint of the study. We were reliant on variables collected as part of the original evaluation. Finally, we conducted a stratified rather than a multivariable analysis as in this exploratory study we were interested in presenting a descriptive account to provide ideas and impetus for future research. Differences in experiences between cancer- and non-cancer groups as a result of systematic variations in important variables such as the relationship of the informant and place of death have not, therefore, been controlled for.

Regardless of diagnosis, this study reveals that a large proportion of older adults in the community in the last months of life experienced high symptom burden, distress from symptoms and difficulties accessing high quality care. The finding that older non-cancer patients were doing less well than older cancer patients may indicate particular disadvantage. Improving care at the end of life for older people, particularly for the majority who die from causes other than cancer, presents major challenges: these need to be addressed if ‘the care of all dying patients is to improve to the level of the best’ [30].

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**Key points**

- Cancer decedents were reported to have experienced more pain, nausea or vomiting and constipation than non-cancer decedents, a greater proportion of whom experienced breathlessness.
- Across all causes of death, only a minority of decedents were reported to receive treatment which completely relieved symptoms of pain, nausea or vomiting, breathlessness, constipation and bedsores some or all of the time.
- There were significant variations in the reported receipt and quality of DN, GP and overall health and social care between cancer and non-cancer decedents.

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Conflicts of interest

The authors declare no conflict of interest.

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