Learning from the public

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Learning from the public: citizens describe the need to improve end-of-life care access, provision and recognition across Europe

Barbara A. Daveson1, Juan P. Alonso2, Natalia Calanzani3, Christina Ramsenthaler1, Marjolein Gysels3, Barbara Antunes1, Katrien Moens1, Esther I. Groeneveld1, Gwenda Albers4, Silvia Finetti5, Francesca Pettenati5, Claudia Bausewein6, Irene J. Higginson1, Richard Harding1, Luc Deliens7, Franco Toscani5, Pedro L. Ferreira8, Lucas Ceulemans9, Barbara Gomes1; on behalf of PRISMA

Introduction

Despite the foreseeable strain that ageing populations and increased cancer deaths will place on our health systems,1 European citizens’ access to end-of-life services varies. There are a number of good examples of national end-of-life care policies within Europe, such as in the UK,2 but most European countries lack national policies regarding this. Services are not always state funded; existing services often rely on multiple funding sources, including charitable funds.3 Care in the last year of life accounts for up to 20% of all health care expenditure.4 Expenditure is highest for those with cancer.5 These high costs persist, despite evidence showing that palliative care can help control for costs associated with hospital admissions during the last year of life.6 Controlling health care costs is essential to the fiscal management of national budgets, and this is important within the current economic crisis.

At the same time, developing health care systems responsive to people’s preferences and views remains paramount;7 the integration of public preferences into policy is key to democratic theory,8 and health care systems should aim to deliver care that is responsive to citizens’ legitimate expectations.9 Surveys are often used to examine patient and public views and preferences for health care, and they are beginning to be viewed as a vital complement to performance indicator data used to monitor health policy effectiveness.10 However, most surveys rely primarily on closed-ended questions, which elicit responses regarding pre-defined areas linked to a dominant agenda based on existing knowledge.11 In contrast, open-ended questions can identify what is important to respondents, invite exploration of issues outside of the dominant agenda, provide respondents with a voice10 and help identify new information.11 Plus, ethical requirements are fulfilled when open-ended data are analysed because all survey data are analysed.11

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1 King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, UK
2 CONICET and University of Buenos Aires, Buenos Aires, Argentina
3 Barcelona Centre for International Health Research (CRISIS – Hospital Clinic), Universitat de Barcelona, Barcelona, Spain
4 Department of Public and Occupational Health, EMGO Institute for Health and Care Research, VU University Medical Center, Amsterdam, The Netherlands
5 Istituto di Ricerca in Medicina Palliativa, Fondazione Lino Maestroni Fondazione ONLUS, Cremona, Italy
6 Interdisciplinary Centre for Palliative Medicine, Munich University Hospital, Munich, Germany
7 End-of-Life Care Research Group, Ghent University and Vrije Universiteit Brussel, Brussels, Belgium
8 Faculty of Economics, Centre for Health Studies and Research (CEISUC), University of Coimbra
9 University Antwerp, Antwerp, Belgium

Background: Despite ageing populations and increasing cancer deaths, many European countries lack national policies regarding palliative and end-of-life care. The aim of our research was to determine public views regarding end-of-life care in the face of serious illness. Methods: Implementation of a pan-European population-based survey with adults in England, Belgium (Flanders), Germany, Italy, the Netherlands, Portugal and Spain. Three stages of analysis were completed on open-ended question data: (i) inductive analysis to determine a category-code framework; (ii) country-level manifest deductive content analysis; and (iii) thematic analysis to identify cross-country prominent themes. Results: Of the 9344 respondents, 1543 (17%) answered the open-ended question. Two prominent themes were revealed: (i) a need for improved quality of end-of-life and palliative care, and access to this care for patients and families and (ii) the recognition of the importance of death and dying, the cessation of treatments to extend life unnecessarily and the need for holistic care to include comfort and support. Conclusions: Within Europe, the public recognizes the importance of death and dying; they are concerned about the prioritization of quantity of life over quality of life; and they call for improved quality of end-of-life and palliative care for patients, especially for elderly patients, and families. To fulfill the urgent need for a policy response and to advance research and care, we suggest four solutions for European palliative and end-of-life care: institute government-led national strategies; protect regional research funding; consider within- and between-country variance; establish standards for training, education and service delivery.
Determining public views about end-of-life care in the face of serious illness is timely, as higher levels of educational attainment, access to information and rising consumerism are reframing individuals’ expectations of health care. Accordingly, the aim of our research was to determine public views regarding end-of-life care in the face of serious illness. To ensure that the urgent need for an European policy response is informed by contemporaneous views, we analysed data from an open-ended survey question to answer the research question ‘What do the public want to say about care in the context of serious illness at the end of life?’

Methods

We conducted a population-based telephone survey (May–December 2010) using random-digit dialling in England, Germany, Italy, the Netherlands, Spain, Portugal and Belgium (Flanders). Further details about our (linguistic validation procedures, data and methodology are available. Our 28-item survey, that was conducted in a uniform manner in all countries, comprised six sections: (i) socio-demographics; end-of-life care preferences and priorities regarding (ii) information; (iii) care options; (iv) symptoms and problems; (v) decision-making; and (vi) preferred place of death. A hypothetical scenario formed the basis of the survey: ’imagine . . . a situation of serious illness, for example cancer, with less than one year to live’. The open-ended question we analysed was positioned at the end of the survey: ‘Is there anything else you would like to say?’ Interviewers were instructed to type verbatim the participant’s comments. Eligibility criteria were as follows: ≥16 years, able to provide informed consent and no hearing or language barrier that precluded participation.

A post-positivist paradigm informed analysis, meaning we aimed to produce verifiable, accurate and consistent findings through the use of a selection of systematically applied research methods, including low-level statistics; we sought to establish findings through attending to recurring patterns within the data. Data quality was checked (for clarity, completeness and accuracy); and data of insufficient quality were not analysed. Qualitative analysis involved three stages. First, open coding to generate an inductively derived category-code framework was completed. Informed by maximum variation principles, we analysed a subset of countries (England, Portugal and Spain) with contrasting health care systems, income per capita and palliative care provision to build a comprehensive framework. The framework was structured around categories that had been successfully used previously in palliative care research and tested with all countries for outliers. Second, country-level manifest deductive content analysis was conducted by a multi-lingual research team to identify the top country message and to construct a textual-representation of this top country message. The top message was the most frequently shared message relevant to care-giving can be improved (815 codes) (table 3). During deductive analysis, the 31 codes for the message category were assigned 2298 times (table 3).

The final framework consisted of three categories and 45 codes: (i) content; (ii) agent; and (iii) message (five sub-categories) (Supplementary tables S2 and S3). During deductive analysis, the 31 codes for the message category were assigned 2298 times (table 3). After removing categories that were not related to policy recommendations, e.g. personal stories and suggestions on how to improve our survey, the top message for each country and across all countries was a call for better quality care, information and access for patients and carers (815 codes) (table 3).

England

Respondents were grateful for the mostly good care they received ‘. . . care was excellent’ (ID8004236563) and also expected improved support for carers ‘There is not enough support for carers’ (ID8004035553) and better access for all, including in people’s homes ‘. . . put palliative care into people’s homes’ (ID800426795). Many emphasized the importance of dying and not extending life unnecessarily ‘I really don’t think the medical institutions should try to extend life. They should let people go when they need to go, if there is no future for them’ (ID800423605). Respondents were divided about their support or lack of support for euthanasia, but most said that choice about this was important.

Belgium (Flanders)

Respondents called for improved quality of care ‘The present way of care-giving can be improved’ (ID800506056) especially for the elderly
Table 1 Respondent characteristics of those who provided comments

<table>
<thead>
<tr>
<th>Table 2 Length of interviews, quality assessment of data, number of respondent comments analysed, number of words analysed and average number of words per respondent (depth of data)</th>
<th>England (n = 227)</th>
<th>Belgium (Flanders) (n = 42)</th>
<th>Germany (n = 390)</th>
<th>Italy (n = 380)</th>
<th>Netherlands (n = 62)</th>
<th>Portugal (n = 334)</th>
<th>Spain (n = 108)</th>
<th>All countries (n = 1543)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean length of interviews in minutes (SD)</strong></td>
<td>15.4 (4.9)</td>
<td>13.1 (4.6)</td>
<td>16.6 (5.5)</td>
<td>16.8 (5.8)</td>
<td>13.6 (4.8)</td>
<td>18.1 (7.6)</td>
<td>14.9 (5.5)</td>
<td>15.5 (5.8)</td>
</tr>
<tr>
<td><strong>Number of respondents who responded to the open-ended question</strong></td>
<td>227</td>
<td>42</td>
<td>390</td>
<td>380</td>
<td>62</td>
<td>334</td>
<td>108</td>
<td>1543</td>
</tr>
<tr>
<td><strong>Number of respondents’ comments excluded</strong></td>
<td>0</td>
<td>8</td>
<td>5</td>
<td>12</td>
<td>10</td>
<td>20</td>
<td>12</td>
<td>91</td>
</tr>
<tr>
<td><strong>Number of respondents’ comments analysed</strong></td>
<td>222</td>
<td>32</td>
<td>372</td>
<td>372</td>
<td>62</td>
<td>314</td>
<td>102</td>
<td>1052</td>
</tr>
<tr>
<td><strong>Depth of data: total number of words analysed</strong></td>
<td>7052</td>
<td>713</td>
<td>6956</td>
<td>8590</td>
<td>894</td>
<td>7346</td>
<td>2183</td>
<td>33734</td>
</tr>
<tr>
<td><strong>Depth of data: average number of words per respondent</strong></td>
<td>32</td>
<td>17</td>
<td>18</td>
<td>26</td>
<td>17</td>
<td>22</td>
<td>22</td>
<td>23</td>
</tr>
</tbody>
</table>

SD, standard deviation; NS, not significant.

a: Sums may not always amount to the total sample number because of missing values on variables. Percentages may not always add up to 100 because of rounding.

b: Missing data:
- Financial hardship, 0.2% for urbanisation level, 0.7% for marital status, 0.8% for religion/denomination, 2.2% for education, 1.1% for financial hardship, 0.6% for health, 0.4% for being personally diagnosed with a serious illness, 0.4% for having a close friend diagnosed with a serious illness, 0.3% for experiencing the death of a relative or friend, and 0.3% for caring for someone ill. There was no missing data for gender. *P<0.001, **P=0.003, ***P=0.009.
Table 3 The number of times each code appeared in each country for the message category

<table>
<thead>
<tr>
<th></th>
<th>England (Flanders)</th>
<th>Germany</th>
<th>Italy</th>
<th>Netherlands</th>
<th>Portugal</th>
<th>Spain</th>
<th>All countries (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comments about research in general or the survey in particular (but not related to funding)*</td>
<td>101</td>
<td>6</td>
<td>102</td>
<td>107</td>
<td>30</td>
<td>173</td>
<td>33</td>
</tr>
<tr>
<td>Call for better quality care, information and access to care for patients and carers†</td>
<td>69</td>
<td>16</td>
<td>227</td>
<td>106</td>
<td>27</td>
<td>329</td>
<td>41</td>
</tr>
<tr>
<td>Funding for informal carers, care for older adults, palliative and end-of-life care, and curative research</td>
<td>8</td>
<td>0</td>
<td>12</td>
<td>8</td>
<td>1</td>
<td>52</td>
<td>5</td>
</tr>
<tr>
<td>Reflections on experiences of life, caring, health, diagnosis, prognosis, illness, death and dying, and hope for the future*</td>
<td>97</td>
<td>27</td>
<td>220</td>
<td>121</td>
<td>14</td>
<td>164</td>
<td>50</td>
</tr>
<tr>
<td>Legislation and government</td>
<td>25</td>
<td>3</td>
<td>38</td>
<td>35</td>
<td>1</td>
<td>31</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td>300</td>
<td>52</td>
<td>599</td>
<td>377</td>
<td>73</td>
<td>749</td>
<td>148</td>
</tr>
</tbody>
</table>

a: Discarded as not specifically related to policy.

b: Ranked first.

'They should improve the care and the accompaniment of the elderly' (ID8004988500).

Germany
Better quality care and access was required for patients, especially the elderly, and families. Plus, the need for free and affordable health care, increased numbers of hospices and palliative care institutions, better rural health care and more information on death, dying and palliative care was identified. Most with illness experiences (past or present) were grateful for the good care they received, but respondents worried about the affordability of health care in the face of public and private health insurance, which was perceived to create huge social difference and inequalities, especially among those with little money and the elderly. Respondents called for re-introducing the human element into health care ‘Hospital needs to care better for patients and their relatives – not treat them like a number’ (ID10647008), including an emphasis on psychological care and quality of life. ‘...clinicians don’t do enough to improve the quality of life of patients’ (ID10644877). Achieving individual preferences, respecting wishes at the end of life and not being kept alive when there was no hope was important ‘To keep people alive artificially is against people’s dignity because it does not consider the needs of that person’ (ID10644463).

Italy
One-third of Italian respondents were dissatisfied with the care they had received, and they complained about the Public Health Service ‘The Public Health Service must...change. The waiting time is too...long’ (ID800498420). Respondents commented on the inefficiency of some hospitals, especially in the south ‘The bad practice in the south (of Italy) is incredible’ (ID800433745) and particularly regarding home care ‘In Italy home care is lacking, especially in the south’ (ID800476711). Respondents wanted palliative care in the home ‘Home care assistance should be available everywhere’ (ID800436444). Not extending life unnecessarily and the need to be able to refuse unnecessary treatments were important. ‘We have to do something against the practice of the aggressive treatments. It’s wrong to extend life when it is unnecessary’ (ID800431819).

The Netherlands
Personal accounts stressed the need for improved quality of end-of-life and bereavement care for families ‘...there is much room to improve care for people who are bereaved. The “buddy system” (a volunteer who makes regular visits) works well’ (ID800490615). The importance of more information and openness of medical staff was highlighted ‘More openness from medical doctors would be appreciated’ (ID800482446). A small number of people described illness experiences (past or present), which were sometimes combined with a preferred place of care and a wish to be in control.

Portugal
Respondents called for more hospital palliative care units ‘I wish more hospitals had more palliative care units...which should have good conditions as well as enough doctors and nurses. Many times patients are placed in care homes where they do not have access to proper care and treatment which would help them in their last months of life...’ (ID800473749) and increased palliative care access ‘I wish palliative care would broaden and reach as many people who need it...’ (ID800496130). A call for better quality care that included a human touch and adequate symptom control was evident ‘At the end of their lives, they should get all the comfort and affection from their families and from palliative care so that the person is not abandoned’ (ID800447189). Respondents wanted the right to die with dignity. Dying with dignity meant to die with autonomy and adequate pain control ‘People should die with some dignity, especially when facing a disease like cancer, they should die free of pain’ (ID800488331), recognized personal preferences and the choice of having loved ones close at all times. Some reported that family had to quit their jobs to be the main carer. The need for improved family support was evident ‘More help for people who are looking after relatives, someone who can go from time to time to help with logistics, allowing families to breathe and leave that context a bit, which is extremely heavy, physically and psychologically’ (ID800473015).

Spain
Calls for better quality care and access mainly focused on the human element within health care, access and better choice, information and quality ‘Sick people should be supported and have a better quality of life. Palliative care should be improved’ (ID800501476). Calls for person-centred care and the recognition of families’ needs were evident. Requests for better access and health care for specific conditions were found ‘There is a lack of help for people with Alzheimer’s disease from public institutions’ (ID800502331). Respondents said they worried about burdening others ‘If I had a serious condition I’d prefer to die rather than suffer. For me, it’s more important the quality of life. I wouldn’t like to be a burden to others’ (ID800499078).

Prominent message
Thematic analysis revealed six themes; two were evident in most countries: (i) an overall need for improved quality of end-of-life and palliative care, and access to this care for patients and families and (ii) the recognition of the importance of death and dying, the
cessation of treatments to extend life unnecessarily and the need for holistic care to include comfort and support (table 4).

Discussion

A call for improved quality and access

Our study showed that European citizens want improved access and quality palliative and end-of-life care for patients and families. Our finding is supported by the current situation within Europe where palliative care services have developed locally in culturally responsive ways in relation to local needs and populations. However, coverage remains patchy, with the number of services per million ranging from 0 to >20.25 Disparities between the quality of death and end-of-life care exist within Europe.2 Only a small number of national government-led palliative care strategies are available in Europe (including the UK, Poland, Switzerland, Turkey and Portugal). Existing strategies focus primarily on process measures, although a recent emphasis on outcome measures is evident, e.g. in Portugal. A growing body of evidence is mounting with regards to the increasing aggressiveness of cancer care towards the end of life30 and the implications of this, including (i) financial consequences; (ii) compromised quality of life; and (iii) lost opportunities for the introduction of non-invasive, life-prolonging interventions, such as palliative care.34 Research shows that physician–patient discussions about preferences are associated with lower rates of intensive interventions35 and care better aligned with preferences.36 We suggest a cohesive pan-European approach to training and education regarding preferences at the end-of-life, as this may help address the perceived imbalance between quantity and quality of life. Establishing European standards of training, education and service delivery may also be useful.

Study strengths and limitations

The limitations of our study should be considered including the following: (i) the overall low survey response rate and the possibility of systematic bias in our respondent group; (ii) the smaller group of respondents that supplied an answer to the open-ended question of systematic bias in our respondent group; (iii) the variable data quality between countries; (iv) the absence of data from central and eastern Europe; and (v) the over- and under-representation of characteristics of those that commented; (iii) the variable data quality between countries; (iv) the absence of data from central and eastern Europe; and (v) the position of the open-ended question in the survey. To help overcome these limitations, we took steps to reduce selection bias, and we clearly reported the characteristics of those that did and did not make comments to allow for comparisons. We also discarded poor quality data and took steps to achieve theoretical and procedural rigor.

Our study shows that the European public recognize the importance of death and dying, and there is concern regarding the prioritization of quantity over quality of life, patient autonomy, comfort, support and dignity. Also, in the eyes of the public, poor palliative and end-of-life care quality and access persists. Our study provides a platform from which to integrate European citizens’ views into policy arenas. Achieving this integration is important, as it is central to democratic theory, and health care systems should aim to deliver care responsive to legitimate expectations of their citizens. We have provided four solutions to the European palliative and end-of-life care policy imperative. However, as some of our solutions are not new, it is necessary to ask a fundamental question on behalf of patients and families, a question that was evident in our data: is anybody really listening? ‘I wonder how much of what the public want will be acted on, there are all sorts of various funds and politics. I don’t mind giving my views I just, just hope that they’re recognised’ (ID800403265).

Table 4 The six themes that emerged in relation to the top message for each country

<table>
<thead>
<tr>
<th>Themes</th>
<th>Countries</th>
</tr>
</thead>
<tbody>
<tr>
<td>A need for improved family support</td>
<td>England, Germany, Portugal, the Netherlands, Spain</td>
</tr>
<tr>
<td>A need for better end-of-life and palliative care and access to this care for patients and families</td>
<td>England, Flanders, Germany, the Netherlands, Portugal, Spain</td>
</tr>
<tr>
<td>The importance of death and dying, the cessation of treatments to unnecessarily extend life and the need for holistic care to include comfort and support</td>
<td>England, Flanders, Germany, Italy, Portugal, Spain</td>
</tr>
<tr>
<td>The need to prioritize care for the elderly</td>
<td>England, Flanders, Germany</td>
</tr>
<tr>
<td>A need for improved home care</td>
<td>England, Italy, Germany</td>
</tr>
<tr>
<td>A need for better communication and information</td>
<td>England, Germany, the Netherlands, Spain</td>
</tr>
</tbody>
</table>
Supplementary Data
Supplementary data are available at EURPUB online.

Acknowledgements

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Conflicts of interest: None declared.

Key points
• In this study, we analysed open-ended survey question from seven European countries to identify European citizens’ views regarding end-of-life care in the face of serious illness.
• Results showed that the European public recognize the importance of death and dying, and they are concerned about the prioritization of quantity over quality of life.

Also, they shared that palliative and end-of-life care access and quality needs to be improved in Europe.
• Four policy solutions are outlined for palliative and end-of-life care in Europe: institute government-led national strategies; protect regional research funding; consider within and between country variance; establish standards for training, education and service delivery.
• We have provided a model of how to use qualitative methods to achieve the integration of public concerns into both national and cross-national (regional) policy arenas.

Reference

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