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


Published in:
European Journal of Public Health

DOI:
10.1093/eurpub/ckt029

Link to publication

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: https://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

UvA-DARE is a service provided by the library of the University of Amsterdam (http://dare.uva.nl)

Download date: 29 Apr 2020
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 Calanzani1, Christina Ramsenthaler1, Marjolein Gysels3, Barbara Antunes1, Katrien Moens1, Esther I. Groeneveld1, Gwenda Albers4, Silvia Finetti5, Francesca Pettenati5, Claudia Bausewein6,1, Irene J. Higginson1, Richard Harding1, Luc Deliens2, Franco Toscani5, Pedro L. Ferreira8, Lucas Ceulemans9, Barbara Gomes1; on behalf of PRISMA

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

Correspondence: Barbara A. Daveson, Department of Palliative Care, Policy & Rehabilitation, King’s College London, Cicely Saunders Institute, 6 Bessemer Road, London SE5 9PJ, UK, tel: +44 (0) 20 78 485565, fax: +44 (0) 20 78 485517, e-mail: barbara.daveson@kcl.ac.uk

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.

Introduction

Despite the foreseeable strain that ageing populations and increased cancer deaths will place on our health systems, 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, 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. Care in the last year of life accounts for up to 20% of all health care expenditure. Expenditure is highest for those with cancer. 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. 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; the integration of public preferences into policy is key to democratic theory, and health care systems should aim to deliver care that is responsive to citizens’ legitimate expectations. 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. 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. 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 voice and help identify new information. Plus, ethical requirements are fulfilled when open-ended data are analysed because all survey data are analysed.

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 policy recommendations, e.g. personal stories and suggestions on how to improve our survey. Third, thematic analysis of country-level findings to identify prominent themes was completed. A prominent theme was a message shared across five or more countries.

Standard coding templates were used, analysis was conducted by one or more native speaker per country, and analysis was checked by a second researcher. Findings were translated into English after the top message was identified. To determine the transferability of beliefs and experiences within the data, we compared socio-demographic characteristics of those that did and did not provide comments to identify significant differences. Chi-square tests were used for gender; living arrangements; marital status; religion/denomination; experiences of illness, death, and dying. Mann–Whitney tests were used for urbanization level, educational attainment, financial hardship and health. A t-test was conducted for age (mean age). Ethics approval was secured from the lead academic centre (ref: BDM/08/09-48). Local ethics approvals and/or data protection agency notifications were also secured where necessary.

Results
Respondents
Of 45242 approached, 9344 (21%) participated. Refusal reasons included the following: disinterest (59%), time (17%), reluctance to complete a telephone survey (3%), the topic (3%). Across countries, the mean age was 51 years. Respondents were mostly female (66%); married/partnered (65%); primary-secondary school level educated (61%); religious (64%); born in the country that the survey was conducted in (93%). In the past 5 years, 10% had been seriously ill, 53% had cared for someone in their last months of life, 65% had a close relative or friend who had either been seriously ill or had died (70%) (Supplementary table S1).

Of the 9344 respondents that completed the survey, 1543 (17%) provided an answer to the open-ended question. For those who commented, we had an over-representation of older individuals (P < 0.001), females (P < 0.001), the religious (P < 0.001), those who lived in big/small town/city (P < 0.001), those who had experiences of serious illness (P < 0.001), experiences of death (P = 0.009) and of providing care during the end-of-life (P < 0.001). Fewer divorced and single people made comments; yet, more widowed individuals commented (P = 0.003). There was an under-representation of those who were living comfortably on their income (P < 0.001) (table 1).

Interviews and quality
On average, all interviews took 15.5 min (standard deviation 5.8) to complete. Results from quality checks meant that data from 1452 respondents was analysed. Responses to open-ended questions averaged 23 words (table 2).

Category-code framework and top country-level messages
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’ (ID800403563), but they also wanted improved support for carers ‘There is not enough support for carers’ (ID800403553) 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 ‘They should improve the care and the accompaniment of the elderly’ (ID8004898500).
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 ‘Hospitals need to care better for patients and their relatives – not treat them like a number’ (ID 10647008), 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’ (ID80047819). 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. Disparities between the quality of death and end-of-life care exist within Europe. 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 the UK. Our findings show that European citizens have concerns about this variable quality and access.

We suggest three strategies to help address this. First, government-led national palliative care strategies that emphasise both process and outcome measures need to be established. European consensus regarding a core set of free brief measures, with adequate psychometric properties, that allow for cross-national comparisons will help advance outcome measurement in Europe. Second, protected research funding for palliative and end-of-life care designed to advance regional developments is needed. Our data suggest that regional research frameworks, such as the European Commission frameworks, need to allocate funds for palliative and end-of-life research for non-malignant groups and the elderly.

Three, recognizing within and between country-level variations will aid regional development. Our data revealed perceptions of inequality between southern and northern Italy and fears about growing gaps between rich and poor citizens in relation to health care in Germany. Research has shown that regional differences matter, and internal regional policies are important in Italy. Additional national Italian palliative care issues, such as the general reluctance of physicians to prescribe opioid medications, need attention. In Germany, despite recent legislation to help ensure health care for all (the Statutory Health Insurance Competition Act), the number of uninsured individuals has been increasing.

Supplementary Data

Supplementary data are available at EURPUB online.
Acknowledgements

The authors are most grateful to all the survey participants. They thank the European Commission for the financial support needed to undertake this study; BMG Research and ZEM University of Bonn for assistance in survey administration and data collection. They also thank our colleagues from PRISMA including the scientific committee who contributed to discussions and scientific review of the survey, including Stein Kaasa, Natalie Evans, Hamid Benalia, Ana Barros Pinto, Noël Derycke, Martine de Vlieger, Let Dillen, Michael Echteld, Nancy Gikaara, Johan Menten, Bregje Onwuteaka-Philipsen, Robert Pool, Richard A. Powell, Miel Ribbe, Katrin Sigurdardottir, Bart Van den Eynden, Paul Vanden Berghe and Trudie van Iersel. They thank Susana Bento, Carolina Comabella, Filomena Ferreira, Grethe Iversen, Carmen López-Dóriga, Constanze Rémi, Christian Schulz and Wessex Translations for their work translating and back- translating the questionnaires. The invaluable work of Ron Irwin, Sian Best and Mike Gover at King’s College London is also highly appreciated. PRISMA aimed to provide evidence and guidance on best practice across settings where end of life care is delivered. Principal Investigator: Richard Harding. Scientific Director: Irene J Higginson. PRISMA members: Gwenda Albers, Barbara Antunes, Ana Barros Pinto, Claudia Bausewein, Dorothee Bechinger-English, Hamid Benalia, Emma Bennett, Lucy Bradley, Lucas Ceulemans, Barbara A Daveson, Luc Deliens, Noël Derycke, Martine de Vlieger, Let Dillen, Julia Downing, Michael Echteld, Natalie Evans, Dagny Faksvåg Haugen, Silvia Finetti, Nancy Gikaara, Barbara Gomes, Marjolein Gysels, Sue Hall, Richard Harding, Irene J Higginson, Stein Kaasa, Jonathan Koffman, Pedro Lopes Ferreira, Arantza Menaca, Johan Menten, Natalia Monteiro Calanzani, Fliss Murtagh, Bregje Onwuteaka-Philipsen, Roelie Pasman, Francesca Pattentati, Robert Pool, Richard A. Powell, Miel Ribbe, Katrin Sigurdardottir, Steffen Simon, Franco Toscani, Bart Van den Eynden, Paul Vanden Berghe and Trudie van Iersel.

Funding

PRISMA was funded by the European Commission’s Seventh Framework Programme (Health-F2-2008-201655) with the overall aim to co-ordinate high-quality international research into end-of-life cancer care. The writing and analysis of this paper was also supported by project BuildCARE and the Cicely Saunders International. This document reflects the authors’ views and the European Commission is not liable for any use that may be made of the information contained here.

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


