



THE UNIVERSITY *of* EDINBURGH

Edinburgh Research Explorer

Learning from the public

Citation for published version:

Daveson, BA, Alonso, JP, Calanzani, N, Ramsenthaler, C, Gysels, M, Antunes, B, Moens, K, Groeneveld, El, Albers, G, Finetti, S, Pettenati, F, Bausewein, C, Higginson, IJ, Harding, R, Deliens, L, Toscani, F, Ferreira, PL, Ceulemans, L, Gomes, B & on behalf of PRISMA 2014, 'Learning from the public: citizens describe the need to improve end-of-life care access, provision and recognition across Europe' *European Journal of Public Health*, vol. 24, no. 3, pp. 521-527. DOI: 10.1093/eurpub/ckt029

Digital Object Identifier (DOI):

[10.1093/eurpub/ckt029](https://doi.org/10.1093/eurpub/ckt029)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Publisher's PDF, also known as Version of record

Published In:

European Journal of Public Health

Publisher Rights Statement:

© The Author 2013. Published by Oxford University Press on behalf of the European Public Health Association.

This is an Open Access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/3.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited. For commercial re-use, please contact journals.permissions@oup.com

General rights

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.



.....
European Journal of Public Health, Vol. 24, No. 3, 521–527

© The Author 2013. Published by Oxford University Press on behalf of the European Public Health Association.

This is an Open Access article distributed under the terms of the Creative Commons Attribution Non-Commercial License

(<http://creativecommons.org/licenses/by-nc/3.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited. For commercial re-use, please contact journals.permissions@oup.com

doi:10.1093/eurpub/ckt029 Advance Access published on 13 March 2013

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 Bausewein^{6,1}, Irene J. Higginson¹, Richard Harding¹, Luc Deliens⁷, 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 Clínic), 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 fulfil 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,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

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.¹² 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^{13,14} linguistic validation procedures,¹⁵ data and methodology are available.^{14,16} 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;¹⁷ we sought to establish findings through attending to recurring patterns within the data.¹⁸ 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^{19–21} 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^{1,3,22} build a comprehensive framework. The framework was structured around categories that had been successfully used previously in palliative care research²³ and tested with all countries for outliers. Second, country-level manifest deductive content analysis^{23,24} 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 and commissioning excluding, for example, 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,¹¹ we compared socio-demographic characteristics of those that did and did not provide comments to identify significant differences ($P < 0.05$). 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

Table 1 Respondent characteristics of those who provided comments

Variables ^{a,b}	England <i>n</i> = 227 <i>n</i> (%)	Belgium (Flanders) <i>n</i> = 42 <i>n</i> (%)	Germany <i>n</i> = 390 <i>n</i> (%)	Italy <i>n</i> = 380 <i>n</i> (%)	Netherlands <i>n</i> = 62 <i>n</i> (%)	Portugal <i>n</i> = 334 <i>n</i> (%)	Spain <i>n</i> = 108 <i>n</i> (%)	All countries <i>n</i> = 1543 <i>n</i> (%)
Age								*
Mean in years (SD)	58.7 (14.2)	54.5 (11.6)	50.0 (14.7)	50.4 (14.5)	56.6 (12.3)	52.1 (14.6)	51.2 (12.8)	52.4 (14.6)
16–29	7 (3)	1 (3)	36 (9)	27 (9)	1 (2)	26 (8)	6 (6)	104 (7)
30–39	15 (7)	3 (8)	48 (13)	43 (15)	3 (5)	38 (12)	13 (12)	163 (12)
40–49	40 (18)	6 (17)	108 (28)	60 (21)	11 (19)	63 (20)	26 (25)	314 (22)
50–59	49 (22)	14 (39)	93 (24)	82 (29)	20 (35)	89 (28)	34 (32)	381 (27)
60–69	60 (27)	8 (22)	61 (16)	47 (16)	13 (23)	60 (19)	16 (15)	265 (19)
70+	55 (24)	4 (11)	37 (10)	28 (10)	9 (16)	38 (12)	10 (10)	181 (13)
Gender								*
Female	159 (70)	27 (64)	234 (60)	296 (78)	47 (76)	255 (76)	84 (78)	1102 (71)
Urbanisation level								*
Big city or suburbs/outskirts	86 (38)	11 (26)	171 (44)	66 (17)	16 (26)	167 (50)	24 (22)	541 (35)
Town or small city	86 (38)	8 (19)	127 (33)	142 (38)	11 (18)	94 (28)	49 (45)	517 (34)
Country village	38 (17)	21 (50)	64 (17)	161 (43)	29 (47)	59 (18)	29 (27)	401 (26)
Farm or home in countryside	16 (7)	2 (5)	27 (7)	10 (3)	6 (10)	14 (4)	6 (6)	81 (5)
Marital status								*
Married or with a partner	130 (58)	31 (74)	224 (58)	267 (70)	39 (65)	223 (67)	78 (72)	992 (65)
Divorced or separated	37 (16)	5 (12)	54 (14)	22 (6)	9 (15)	30 (9)	8 (7)	165 (11)
Widowed	30 (13)	1 (2)	31 (8)	27 (7)	7 (12)	34 (10)	3 (3)	133 (9)
Single	29 (13)	5 (12)	75 (20)	64 (17)	5 (8)	46 (14)	19 (18)	243 (16)
Religion/denomination								*
With a religion or denomination	145 (65)	29 (73)	212 (55)	306 (81)	21 (34)	270 (81)	78 (74)	1061 (69)
Education								NS
Less than primary	14 (7)	0 (0)	0 (0)	0 (0)	0 (0)	4 (1)	6 (6)	24 (2)
Primary to secondary	75 (36)	19 (48)	211 (55)	282 (76)	32 (52)	259 (78)	66 (61)	944 (63)
Post secondary to tertiary	118 (57)	21 (53)	174 (45)	90 (24)	28 (47)	70 (21)	36 (33)	539 (36)
Financial hardship								*
Living comfortably on present income	94 (42)	27 (66)	186 (48)	104 (28)	32 (53)	57 (17)	35 (33)	535 (35)
Coping on present income	92 (41)	19 (29)	167 (43)	198 (52)	21 (35)	175 (53)	46 (43)	710 (47)
Difficult on present income	26 (12)	2 (5)	24 (6)	65 (17)	5 (8)	64 (19)	19 (18)	205 (13)
Very difficult on present income	11 (5)	0 (0)	10 (2.6)	11 (3)	2 (3)	36 (11)	6 (6)	76 (5)
Health								*
Very good	97 (43)	16 (38)	97 (25)	57 (15)	10 (16)	40 (12)	20 (19)	337 (22)
Good	87 (39)	18 (43)	189 (59)	191 (50)	30 (48)	124 (37)	45 (42)	684 (45)
Fair	35 (16)	7 (17)	76 (20)	126 (33)	16 (26)	150 (45)	32 (30)	442 (29)
Bad	4 (2)	1 (2)	23 (6)	4 (1)	6 (10)	14 (4)	9 (8)	61 (4)
Very bad	1 (0)	0 (0)	3 (1)	1 (0)	0 (0)	4 (1)	1 (1)	10 (1)
Experience of illness, death and dying								NS
Diagnosed with a serious illness in the past 5 years	31 (14)	5 (12)	40 (10)	42 (11)	11 (18)	25 (8)	20 (19)	174 (11)
Close relative/friend seriously ill in last 5 years	164 (73)	27 (64)	281 (72)	283 (75)	57 (92)	224 (67)	87 (81)	1123 (73)*
Death of close relative/friend in last 5 years	171 (75)	33 (79)	285 (74)	275 (73)	53 (86)	222 (67)	85 (79)	1124 (73)***
Cared for close relative/friend in last months of life	149 (66)	32 (76)	235 (61)	257 (68)	45 (73)	215 (64)	77 (71)	1010 (66)*

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: 8.8% for age, 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 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)

	England (<i>n</i> = 1351)	Belgium (Flanders) (<i>n</i> = 1269)	Germany (<i>n</i> = 1363)	Italy (<i>n</i> = 1352)	Netherlands (<i>n</i> = 1356)	Portugal (<i>n</i> = 1286)	Spain (<i>n</i> = 1367)	All countries (<i>n</i> = 9344)
Mean length of interviews in minutes (SD)	15.4 (4.9)	13.1 (4.6)	16.6 (5.5)	16.8 (5.8)	13.6 (4.8)	18.1 (7.6)	14.9 (5.5)	15.5 (5.8)
Number of respondents who responded to the open-ended question	227	42	390	380	62	334	108	1543
Number of respondents' comments excluded	5	0	8	53	9	8	8	91
Number of respondents' comments analysed	222	42	382	327	53	326	100	1452
Depth of data: total number of words analysed	7052	713	6956	8590	894	7346	2183	33734
Depth of data: average number of words per respondent	32	17	18	26	17	22	22	23

SD, standard deviation.

Table 3 The number of times each code appeared in each country for the message category

	England	Belgium (Flanders)	Germany	Italy	Netherlands	Portugal	Spain	All countries (%)
Comments about research in general or the survey in particular (but not related to funding) ^a	101	6	102	107	30	173	33	552 (24%)
Call for better quality care, information and access to care for patients and carers ^b	69	16	227	106	27	329	41	815 (35%)
Funding for informal carers, care for older adults, palliative and end-of-life care, and curative research	8	0	12	8	1	52	5	86 (4%)
Reflections on experiences of life, caring, health, diagnosis, prognosis, illness, death and dying, and hope for the future ^a	97	27	220	121	14	164	50	693 (30%)
Legislation and government	25	3	38	35	1	31	19	152 (7%)
Total	300	52	599	377	73	749	148	2298 (100%)

a: Discarded as not specifically related to policy.

b: Ranked first.

'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'* (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

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

Themes	Countries
A need for improved family support	England, Germany, Portugal, the Netherlands, Spain
A need for better end-of-life and palliative care and access to this care for patients and families	England, Flanders, Germany, the Netherlands, Portugal, Spain
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	England, Flanders, Germany, Italy, Portugal, Spain
The need to prioritize care for the elderly	England, Flanders, Germany
A need for improved home care	England, Italy, Germany
A need for better communication and information	England, Germany, the Netherlands, Spain

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 the UK.² 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.^{26–28} 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 inequity 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.²⁹ Additional national Italian palliative care issues, such as the general reluctance of physicians to prescribe opioid medications,³⁰ need attention. In Germany, despite recent legislation to help ensure health care for all (the Statutory Health Insurance Competition Act),³¹ the number of uninsured individuals has been increasing,³² and palliative services remain patchy. Concern regarding this was evident in the data, especially for the elderly and poor. The public concerns identified in our study present a challenge for commissioners and policy makers. They also provide good examples of why it is important to consider intra- and inter-country variation when developing regional policies within Europe.

Recognition of the importance of death and dying, unnecessary treatments and holistic care

Our data show that the public wants death and dying to remain important, care to involve a human touch and unnecessary

aggressive treatments that prolong life unnecessarily to stop. For the English respondents, this meant recognizing the importance of not extending life unnecessarily and having the right to refuse treatments. For the Italians, it meant taking action to stop unnecessary treatments. Concerns regarding the use of artificial devices to prolong life were apparent in Germany. The importance of a dignified death and being able to have family and friends nearby surfaced in Portugal. A growing body of evidence is mounting with regards to the increasing aggressiveness of cancer care towards the end of life³³ 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 and 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).

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 Echteid, 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 to ensure that research can measure and improve outcomes for patients and families. PRISMA activities aimed to reflect the preferences and cultural diversities of citizens, the clinical priorities of clinicians and appropriately measure multidimensional outcomes 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 Echteid, 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, Roeline Pasman, Francesca Pattenati, 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

- 1 World Health Organisation. *The Global Burden of Disease: 2004 Update*. Switzerland: The World Health Organisation, 2008.
- 2 Department of Health. *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life*. London: Department of Health, 2008.
- 3 Economist Intelligence Unit. *The Quality of Death. Ranking End-of-Life Care Across the World*. London: The Economist Intelligence Unit, 2010.
- 4 Roos NP, Montgomery P, Roos LL. Health-care utilization in the years prior to death. *Milbank Q* 1987;65:231–54.
- 5 Polder JJ, Barendregt JJ, van Oers H. Health care costs in the last year of life - the Dutch experience. *Soc Sci Med* 2006;63:1720–31.
- 6 Hatziandreu E, Archontakis F, Daly A. in conjunction with the National Audit Office. *The Potential Cost Savings of Greater Use of Home- and Hospice-Based End of Life Care in England*. Cambridge, UK: The Rand Corporation, 2008.
- 7 Legido-Quigley H, McKee M, Nolte E, Glinos IA. *Assuring the quality of healthcare in the European Union. WHO 2008, on behalf of the European Observatory on Health Systems and Policies*, 2008.
- 8 Soroka SN, Lim ET. Issue definition and the opinion-policy link: public preferences and healthcare spending in the US and the UK. *Br J Pol Int Relat* 2003;5:576–93.
- 9 WHO. *The World Health Report 2000: Health Systems: Improving Performance*. Geneva: WHO, 2000.
- 10 Coulter A, Jenkinson C. European patients' views on the responsiveness of health systems and healthcare providers. *Eur J Public Health* 2005;15:355–60.
- 11 O' Cathain A, Thomas KJ. "Any other comments?" Open questions on questionnaires - a bane or a bonus to research? *BMC Med Res Methodol* 2004;4:25.
- 12 WHO. *People-Centred Healthcare: A Policy Framework*. Geneva, Switzerland: The World Health Organization, 2007.
- 13 Daveson BA, Bechinger-English D, Bausewein C, et al. Constructing understandings of end-of-life care in Europe: a qualitative study involving cognitive interviewing with implications for cross-national surveys. *J Palliat Med* 2011;14:343–9.
- 14 Gomes B, Higginson IJ, Calanzani N, et al. Where would you prefer to die if you had a serious illness? A cross-sectional telephone survey of citizens in seven European countries. *Ann Oncol* 2012;23:2006–15.
- 15 Cull A, Sprangers M, Bjordal K, et al. *EORTC Quality of Life Group Translation Procedure*. Brussels: EORTC quality of life group publication, 2002.
- 16 Daveson BA, Bausewein C, Murtagh F, et al. To be involved or not to be involved: a survey of public preferences for self-involvement in decision making involving mental capacity (competency) within Europe. *Pall Med*. 2013; DOI: 10.1177/0269216312471883 [Epub ahead of print].
- 17 Denzin NK, Lincoln YS. Introduction: the discipline and practice of qualitative research. In: Denzin NK, Lincoln YS, editors. *The Landscape of Qualitative Research: Theories and Issues*, 2nd edn. London: Sage, 2003; 1–46.
- 18 Rice PL, Ezzy D. *Qualitative Research Methods: a Health Focus*. Oxford: Oxford University Press, 1999.
- 19 Corbin J, Strauss A. *Basics of Qualitative Research*, 3rd edn. London: Sage Publications, 2008.
- 20 Strauss A, Corbin J. *Basics of Qualitative Research*. London: Sage publications incorporated, 1990.
- 21 Strauss A, Corbin J. *Basics of Qualitative Research: Techniques for Procedures for Developing Grounded Theory*, 2nd edn. London: Sage publications incorporated, 1998.

- 22 World Health Organisation. *The Solid Facts: Palliative Care*. Copenhagen, Denmark: World Health Organisation, 2004.
- 23 Hack TF, McClement SE, Chochinov HM, et al. Learning from dying patients during their final days: life reflections gleaned from dignity therapy. *Palliat Med* 2010;24:715–23.
- 24 Potter WJ, Levine-Donnerstein D. Rethinking validity and reliability in content analysis. *J Appl Commun Res* 1999;27:258–84.
- 25 Higginson IJ, Costantini M. Dying with cancer, living well with advanced cancer. *Eur J Cancer* 2008;44:1414–24.
- 26 Bausewein C, Steffen S, Benalia H, et al. Applying patient reported outcome measures (PROMs) in palliative care – user’s cry for help. *Health Qual Life Outcomes* 2011;9:27.
- 27 Daveson BA, Simon ST, Benalia H, et al. Are we heading in the same direction? European and African doctors’ and nurses’ views and experiences regarding outcome measurement in palliative care. *Palliat Med* 2012;26:242–9.
- 28 Harding R, Simon ST, Benalia H, et al. The PRISMA Symposium 1: outcome tool use. Disharmony in European outcomes research for palliative and advanced disease care: too many tools in practice. *J Pain Symptom Manage* 2011;42:493–500.
- 29 Franzini L, Giannoni M. Determinants of health disparities between Italian regions. *BMC Public Health* 2010;10:296.
- 30 Floriani FC. FPC: why Italy is a special case when it comes to palliative care. *Eur J Palliat Care* 2009;16:204–6.
- 31 Green DG, Irvine B. *Health Care in France and Germany: Lessons for the UK*, 1st edn. London, UK: Institute for the Study of Civil Society, 2001; 52–76.
- 32 Bertelsmann Stiftung G. Health care reform in Germany: not the big bang. 2006. Report No. (8)2006.
- 33 Ho TH, Barbera L, Saskin R, et al. Trends in the aggressiveness of end-of-life cancer care in the universal health care system of Ontario, Canada. *J Clin Oncol* 2011;29:1587–91.
- 34 Sullivan R, Peppercorn J, Sikora K, et al. Delivering affordable cancer care in high-income countries. *Lancet Oncol* 2011;12:933–80.
- 35 Zhang B, Wright AA, Huskamp HA, et al. Health care costs in the last week of life: associations with end-of-life conversations. *Arch Intern Med* 2009;169:480–8.
- 36 Mack JW, Weeks JC, Wright AA, et al. End-of-life decisions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol* 2010;28:1203–8.