

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

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Abstract

Background: The Council of Europe has recommended that member states of European Union encourage their citizens to make decisions about their healthcare before they lose capacity to do so. However, it is unclear whether the public wants to make such decisions beforehand.

Aim: To examine public preferences for self-involvement in end-of-life care decision-making and identify associated factors.

Design: A population-based survey with 9344 adults in England, Belgium, Germany, Italy, the Netherlands, Portugal and Spain.

Results: Across countries, 74% preferred self-involvement when capable; 44% preferred self-involvement when incapable through, for example, a living will. Four factors were associated with a preference for self-involvement across capacity and incapacity scenarios, respectively: higher educational attainment ((odds ratio = 1.93–2.77), (odds ratio = 1.33–1.80)); female gender ((odds ratio = 1.27, 95% confidence interval = 1.14–1.41), (odds ratio = 1.30, 95% confidence interval = 1.20–1.42)); younger-middle age ((30–59 years: odds ratio = 1.24–1.40), (50–59 years: odds ratio = 1.23, 95% confidence interval = 1.04–1.46)) and valuing quality over quantity of life or valuing both equally ((odds ratio = 1.49–1.58), (odds ratio = 1.35–1.53)). Those with increased financial hardship (odds ratio = 0.64–0.83) and a preference to die in hospital (not a palliative care unit) (odds ratio = 0.73, 95% confidence interval = 0.60–0.88), a nursing home or residential care (odds ratio = 0.73, 95% confidence interval = 0.54–0.99) were less likely to prefer self-involvement when capable. For the incapacity scenario, single people were more likely to prefer self-involvement (odds ratio = 1.34, 95% confidence interval = 1.18–1.53).

Conclusions: Self-involvement in decision-making is important to the European public. However, a large proportion of the public prefer to not make decisions about their care in advance of incapacity. Financial hardship, educational attainment, age, and preferences regarding quality and quantity of life require further examination; these factors should be considered in relation to policy.

Keywords

Decision-making, Europe, cancer, palliative care, family, caregivers, physicians, mental competency

Introduction

Advance directive legislation varies across Europe. Some countries have existing legislation, including Germany, the United Kingdom, Spain, Belgium and the Netherlands. However, other countries, such as Portugal, do not recognise advance directives. Difficulties with enforcing advance directives in some countries are also evident, for example, in Italy.^{1–4} In order to address this variation and promote unity, the Council of Europe recently recommended that all member states of the European Union (EU) should promote self-determination for capable adults in the event of their future incapacity, including through the use of advance directives. This recommendation was issued in order to protect the growing number of elderly citizens and to facilitate individual autonomy and self-determination.²

Living wills, advance decisions and advance directives all have the potential to help enable and retain autonomy and self-determination, and protect citizens' rights to make decisions about their own future care. Living wills and advance directives are used to explain preferences for care in future scenarios where mental capacity is lost. An advance decision to refuse treatment is a legally binding document that enables an individual to refuse medical treatment in the future when they may lack capacity.⁵

The Council's emphasis on autonomy aligns well with policy and data that confirm the importance of patient involvement in decision-making. A collaborative model of decision-making has been broadly adopted within medicine, especially towards the end of life,⁶ and autonomy is mostly viewed as fundamental to patient involvement in decision-making within healthcare.⁷ However, whether this emphasis on autonomy aligns with public preferences is less clear. Presently, only a small minority of European citizens have advance directives.⁸ Surveys have shown that not all members of the public prefer to make decisions about their care,

their preferences for self-involvement in decision-making may decline with age,⁹ and they may prefer to delegate to family members when too ill to participate in decisions.¹⁰ Plus, qualitative research has shown that some members of the public are less concerned about the role of advance care statements in relation to their own autonomy at the end of life. Rather, they are concerned about how their advance statements may help their families.¹¹ Higher levels of educational attainment, access to information and rising consumerism are reframing individuals' expectations of healthcare and the ways that they engage with healthcare.¹² A contemporary understanding of public preferences is required.

Identifying public preferences regarding self-involvement in decision-making about care is useful for the development of public health education campaigns. Data can also help situate the current discourse about advance planning within a context that is meaningful to the public. To help establish preferences for involvement in decision-making within the context of serious illness, our European study aimed to examine variations in preferences for wanting to be involved in decision-making about care at the end of life in capacity and incapacity scenarios. We also aimed to identify associated factors in order to clarify people's preferences for self-involvement in decision-making.

Methods

Study design

A population-based, computer-assisted telephone survey, with the assistance of 149 trained interviewers, was conducted throughout May to December 2010 in England, Belgium (Flanders), Germany, Italy, the Netherlands, Portugal and Spain. Further details about the methods¹³

“This set of questions concerns the care for people with a serious illness and towards the end of life. I will ask you what your preferences and priorities would be for care at end of life. The questions will ask you to imagine a situation of serious illness, for example cancer, with less than one year to live. Please keep this in mind for the rest of the interview, continue to imagine this situation as you answer the questions.”

Figure 1. Hypothetical scenario that formed the basis of the survey questions.

Capacity scenario question	Incapacity scenario question
“Keeping in mind a situation of serious illness with less than one year to live, please consider that you were able to make decisions. Who would you like to make decisions about your care? Please choose as many as apply, you can choose more than one.”	“What if you had lost your ability to make decisions, who would you like to make decisions about your care? Please choose as many as apply, you can choose more than one.”
Capacity scenario answer options	Incapacity scenario answer options
“Yourself, your spouse or partner, other relatives, friends, the doctor, others, don't know, refusal / prefer not to say.”	Yourself, by specifying your wishes before losing ability - for example, in a living will, your spouse or partner, other relatives, friends, the doctor, others, don't know, refusal / prefer not to say.

Figure 2. Capacity and incapacity questions and answer options.

and the wider project are provided elsewhere.¹⁴ Random digit dialling¹⁵ was used to randomly select households, and then one individual from the household was invited to complete the interview. Once a respondent was identified, no substitution was allowed. To reduce selection bias and increase response rates, arrangements were made to survey on weekdays and weekends during and outside of working hours (i.e. after 18:00). At least one call attempt occurred after 18:00. Eligible respondents were those ≥ 16 years, able to provide informed consent and those with no hearing or language barrier that would preclude their participation. Sample sizes were determined by the overall aim of the larger study regarding preferences related to place of death.¹³ To ensure quality, data checks were completed at the point of entry; 10% of interviews were checked for accuracy. Ethical approval was obtained from the lead academic centre (King’s College London BDM/08/09-48). Local research ethics approvals and national data protection agency notifications were also obtained when required.

The survey tool

Four stages of work were completed to develop the survey, namely, a literature scoping exercise, cognitive interviewing, pilot testing¹⁶ and linguistic questionnaire validation using the European Organisation for Research and Treatment of Cancer (EORTC) guidelines.¹⁷ A hypothetical scenario formed the basis of the 28-item survey that resulted (Figure 1). The survey was broadly divided into six sections: (1) socio-demographics, and end-of-life care preferences and priorities regarding (2) information, (3) care

options, (4) symptoms and problems, (5) decision-making involvement and (6) place of death. Two questions about decision-making were included and multiple answers were permissible (Figure 2).

Analysis

Crude percentages were calculated for respondents and decision-making answer options for both scenarios (see Figure 2) at the country and cross-country level. Two primary, dependent variables were converted into a binary score – that is wanting to be involved in decision-making (self-involvement) versus not wanting to be involved in decision-making (no self-involvement). The self-involvement option allowed for the involvement of others and self. This meant, for example, that when a respondent said they wanted to be involved in decision-making and they also wanted their doctor and family to be involved – this was scored as a preference for self-involvement. The dependent variables were examined in relation to preferences for capacity and incapacity scenarios. Bivariate analysis was used to examine variations of 18 independent variables identified within the first three stages of survey development as relevant to end-of-life care priorities and preferences (Figure 3). We used χ^2 tests or Fisher’s exact test, when required, for categorical data, Mann–Whitney U tests for ordinal data and t-tests for continuous data. Missing data were excluded using the standard SPSS procedure of listwise deletion (entire cases were excluded when there was any missing value).

Two steps of multivariable analysis (generalised estimating equations (GEE)) were completed to identify factors

Category of independent variables	List of independent variables for each category‡
Socio-demographic variables	Age, <i>age bands</i> , gender, marital status, country of birth, length of time in the country, urbanisation, living arrangements (i.e., living alone or with others), education, financial hardship, health
Value and or preference-based variables	Preferences for the <i>type of problem or symptom</i> rated as most concerning to the respondent with the choice being between either a) social-focussed problems / concerns, such as a fear of being alone or being a burden to someone else, and b) physical—psychological focussed problems / concerns, such as pain, energy, nausea, appearance, appetite; <i>preferred place of death</i> ; a preference for <i>quality of life or quantity of life</i> specifically a preference for the extension of life, a preference for an importance on both the extension of life and quality of life, or a preference for quality of life only
Experiential variables	<i>Self being diagnosed with a serious illness in the last five years; diagnosis of a close relative / friend in the last five years; death of a close relative or friend in the last five years; caring for a relative or friend in their last few months of life</i>

Figure 3. Three categories involving a total of 18 independent variables that were examined: (1) socio-demographic, (2) value and/or preference based and (3) experiential variables.

GEE: generalised estimating equations.

‡The italicized variables were identified for inclusion in the first step of GEE analysis.

associated with a preference for self-involvement for both the capacity and the incapacity scenarios. GEE was used as it is a marginal or population-averaged method of analysis, meaning it allowed for the investigation of each country as a cluster. GEE enabled the examination of the average odds ratios of multiple countries as opposed to each individual's odds ratios.¹⁸ This was useful in terms of exploring variations between countries. GEE analysis also allowed for the relative influence of multiple independent variables on the dependent variable, adjusting for any confounding effect.

First, potential explanatory variables were identified and entered into the GEE model. Any variables associated with the outcome at a significance level of $p \leq 0.05$ for all countries, combined with shared directionality or significance in a majority of countries, were carried forward into multivariate analysis. Highly significant variables ($p \leq 0.01$) were then entered into the second GEE step. SPSS 19.0 was used for all calculations.

Results

Of 45,242 approached, 9344 (21%) participated in our survey. Reasons for not responding included lack of interest (59%), lack of time (17%) and refusal to take part generally in telephone surveys (3%). The nature of the topic (3%) was another reason for refusal: 497 because they had a physical disability or illness, 385 due to the sensitive nature of the topic, 223 because a relative or friend had a physical disability or illness and 146 due to a recent household bereavement or death. The interview took an

average of 15 minutes to complete. Across countries, the mean age was 51 years (standard deviation (SD) = 16, 16–98 years). Most respondents were female (66%) and most were married or had a partner (65%). Ten percent reported having been seriously ill in the past 5 years and half had cared for a close relative or friend in their last months of life (Table 1).

For the capacity scenario, across countries, 74% preferred self-involvement (Portugal (60%)–Germany (91%)). The three most frequently selected answer options were yourself (74%), followed by spouse or partner (53%) and other relatives (40%). For the incapacity scenario, across countries, fewer respondents (44%) preferred self-involvement beforehand in the event of their future incapacity, for example, through the use of a living will (Portugal (18%)–Germany (83%)). The three most frequently selected answer options across countries were spouse or partner (62%) followed by other relatives (48%) and yourself, by specifying your wishes before losing the ability to do so (44%) (Table 2). The rank order of countries in relation to their self-involvement preferences was mostly the same across scenarios. Portugal always preferred less self-involvement followed by Belgium. Germany always preferred more self-involvement followed by England and Italy.

Of the potential 18 independent variables, 13 potential explanatory variables for inclusion in the first step of GEE analysis were identified for the capacity (Appendix 1) and incapacity scenario (Appendix 1). Table 3 shows the results of the second step of GEE analysis for the capacity scenario. Younger-middle age (30–59 years), female gender, higher educational attainment, increased financial

Table 1. Respondent characteristics by country (n(%)).

	England (N = 1351)	Flanders (N = 1269)	Germany (N = 1363)	Italy (N = 1352)	The Netherlands (N = 1356)	Portugal (N = 1286)	Spain (N = 1367)	All countries (N = 9344)
Age								
Mean in years (SD)	54 (16)	52 (15)	47 (16)	49 (16)	55 (15)	50 (17)	48 (17)	51 (16)
Range (minimum to maximum)	16–92	16–89	16–91	16–90	16–98	16–87	16–95	16–98
Gender								
Female	863 (64%)	832 (66%)	790 (58%)	974 (72%)	891 (66%)	893 (69%)	935 (68%)	6178 (66%)
Living arrangements								
Living alone	325 (24%)	197 (16%)	281 (21%)	142 (11%)	294 (22%)	136 (11%)	156 (12%)	1531 (17%)
Urbanisation level								
Big city or suburbs/outskirts	500 (37%)	289 (23%)	556 (41%)	269 (20%)	363 (27%)	643 (50%)	324 (24%)	2944 (32%)
Town or small city	495 (37%)	224 (18%)	419 (31%)	526 (39%)	311 (23%)	368 (29%)	589 (43%)	2932 (31%)
Country village	287 (21%)	591 (47%)	301 (22%)	521 (39%)	578 (43%)	221 (17%)	401 (29%)	2900 (31%)
Farm or home in countryside	66 (5%)	165 (13%)	85 (6%)	34 (3%)	103 (8%)	54 (4%)	52 (4%)	559 (6%)
Marital status								
Married or with a partner	822 (61%)	951 (76%)	784 (58%)	860 (64%)	932 (69%)	814 (64%)	847 (62%)	6010 (65%)
Divorced or separated	175 (13%)	100 (8%)	152 (11%)	86 (6%)	110 (8%)	91 (7%)	100 (7%)	814 (9%)
Widowed	131 (10%)	96 (8%)	83 (6%)	92 (7%)	142 (11%)	109 (9%)	113 (8%)	766 (8%)
Single	212 (16%)	110 (9%)	330 (25%)	310 (23%)	162 (12%)	265 (21%)	301 (22%)	1690 (18%)
Religion/denomination								
With a religion or denomination	778 (58%)	664 (53%)	771 (57%)	1094 (82%)	616 (46%)	1017 (80%)	959 (71%)	5899 (64%)
Where born								
Born in country where survey is taking place	1201 (89%)	1205 (95%)	1233 (91%)	1298 (96%)	1275 (94%)	1168 (91%)	1275 (93%)	8655 (93%)
Educational level								
Post secondary to tertiary education	551 (43%)	575 (48%)	516 (38%)	310 (23%)	498 (37%)	303 (24%)	466 (34%)	3219 (35%)
Financial hardship								
Living comfortably on present income	585 (44%)	689 (55%)	608 (46%)	430 (32%)	813 (61%)	222 (18%)	440 (33%)	3787 (41%)
Coping on present income	576 (43%)	497 (40%)	618 (46%)	677 (51%)	441 (33%)	681 (54%)	633 (47%)	4123 (45%)
Difficult on present income	136 (10%)	60 (5%)	85 (6%)	203 (15%)	62 (5%)	239 (19%)	203 (15%)	988 (11%)
Very difficult on present income	38 (3%)	3 (0%)	26 (2%)	25 (2%)	20 (2%)	129 (10%)	73 (5%)	314 (3%)
Health								
Very good	565 (42%)	490 (39%)	310 (23%)	305 (23%)	302 (22%)	170 (13%)	293 (22%)	2435 (26%)
Good	535 (40%)	583 (46%)	699 (52%)	642 (48%)	748 (55%)	488 (38%)	560 (41%)	4255 (46%)
Fair	191 (14%)	176 (14%)	289 (21%)	377 (28%)	254 (19%)	558 (44%)	437 (32%)	2282 (25%)
Bad	47 (4%)	16 (1%)	53 (4%)	21 (2%)	43 (3%)	46 (4%)	67 (5%)	293 (3%)
Very bad	7 (1%)	3 (0%)	5 (0%)	3 (0%)	5 (0%)	19 (2%)	7 (1%)	49 (1%)
Experience of illness, death and dying								
Diagnosed with seriously illness in last 5 years	172 (13%)	190 (15%)	107 (8%)	113 (8%)	137 (10%)	99 (8%)	119 (9%)	937 (10%)
Close relative/friend seriously ill in last 5 years	849 (63%)	760 (61%)	862 (64%)	900 (67%)	969 (72%)	728 (58%)	923 (68%)	5991 (65%)
Death of close relative/friend in last 5 years	949 (71%)	876 (70%)	933 (69%)	928 (69%)	1036 (77%)	771 (61%)	1006 (74%)	6499 (70%)
Cared for close relative/friend in last months of life	679 (51%)	625 (50%)	647 (48%)	815 (61%)	702 (52%)	673 (53%)	771 (57%)	4912 (53%)

SD: standard deviation.

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.

Table 2. Self-involvement preferences for capacity and incapacity scenarios across countries and at country level.

	Belgium (N = 1269)	England (N = 1351)	Germany (N = 1363)	Italy (N = 1352)	The Netherlands (N = 1356)	Portugal (N = 1286)	Spain (N = 1367)	All countries (N = 9344)
Capacity scenarios^a								
Self-involvement preferences^b								
Self-involvement	63	82	91	78	72	60	68	74
No self-involvement	37	18	9	22	28	40	32	26
Multiple answer options allowed								
Yourself	63	82	91	78	72	60	68	74
Your spouse or partner	57	59	72	47	62	38	38	53
Other relatives	32	47	60	34	40	36	30	40
Friends	3	10	16	3	6	2	2	6
Doctor	20	40	36	32	28	29	23	30
Others	0	5	1	10	0	1	1	3
Incapacity scenarios^c								
Self-involvement preferences^b								
Self-involvement	24	61	83	47	32	18	38	44
No self-involvement	76	39	17	53	68	82	62	56
Multiple answer options allowed								
Yourself, by specifying your wishes before losing ability (e.g. in a living will)	24	61	83	47	32	18	38	44
Your spouse or partner	67	63	75	58	67	51	53	62
Other relatives	35	54	60	45	44	51	43	48
Friends	2	8	13	3	4	2	2	5
Doctor	22	33	29	27	19	23	16	24
Others	1	6	1	13	0	3	2	4

Note: All values are given in percentage.

^a0.5% (n = 44) missing data for all capacity scenario answer options.

^bBinary values.

^c0.9% (n = 80) missing data for all answer options for the incapacity scenario except for answer option 'others' where the following was missing: 0.9% (n = 81).

Table 3. Self-involvement in decision-making within capacity scenarios GEE model 2.

GEE model for capacity scenario	
Socio-demographic variables	OR (95% CI)
Age bands (years)	
16–29	1.00
30–39	1.24 (1.02–1.52)
40–49	1.40 (1.17–1.69)
50–59	1.27(1.06–1.52)
60–69	1.11 (0.92–1.33)
70+	0.72 (0.59–0.88)
Gender	
Male	1.00
Female	1.27 (1.14–1.41)
Highest level of education	
Less than primary education	1.00
Primary to secondary education	1.93 (1.52–2.45)
Post secondary to tertiary education	2.77 (2.15–3.57)
Financial hardship	
Living comfortably on present income	1.00
Coping on present income	0.94 (0.84–1.05)
Difficult on present income	0.83 (0.70–0.98)
Very difficult on present income	0.64 (0.49–0.84)
Value/preference-based variables	
Quantity–quality of life	
Extend life	1.00
Both are equally important	1.49 (1.17–1.91)
To improve the quality of time left	1.58 (1.25–2.00)
Preferred place of death	
Own home	1.00
Home of a relative or friend	0.63 (0.39–1.01)
Hospice or palliative care unit	1.06 (0.93–1.21)
Hospital – but not a palliative care unit	0.73 (0.60–0.88)
Nursing home or residential home	0.73 (0.54–0.99)
Somewhere else	1.13 (0.79–1.59)

GEE: generalised estimating equations; OR: odds ratio; CI: confidence interval.

Note: Only significant and highly significant variables are shown. CI = 95% Wald confidence intervals. Excluded cases: 1334 (14%).

hardship, a valuing of quality over quantity of life or both equally and a preference to die in hospital (but not a palliative care unit), nursing home or residential home were included in the model for self-involvement for the capacity scenario (Table 3). Table 4 shows the results of the second step of the GEE analysis for the incapacity scenario. Younger-middle age (50–59 years), female gender, higher educational attainment and a valuing of quality over quantity of life or both equally were associated with self-involvement for the incapacity scenario. For the incapacity scenario, marital or partner status, in particular being single, was associated with self-involvement (Table 4). No association was found for preferred place of death for the incapacity scenario.

Table 4. Self-involvement in decision-making within incapacity scenarios GEE model 2.

GEE model for incapacity scenario	
Socio-demographic variables	OR (95% CI)
Age bands (years)	
16–29	1.00
30–39	1.03 (0.87–1.23)
40–49	1.17 (0.99–1.38)
50–59	1.23 (1.04–1.46)
60–69	0.98 (0.82–1.18)
70+	0.86 (0.70–1.05)
Gender	
Male	1.00
Female	1.30 (1.20–1.42)
Marital status	
Married or with partner	1.00
Single	1.34 (1.18–1.53)
Widowed	1.01 (0.86–1.19)
Divorced or separated	1.11 (0.96–1.28)
Highest level of education	
Less than primary education	1.00
Primary to secondary education	1.33 (1.05–1.68)
Post secondary to tertiary education	1.80 (1.42–2.28)
Value/preference-based variables	
Quantity–quality of life	
Extend life	1.00
Both are equally important	1.35 (1.07–1.70)
To improve the quality of time left	1.53 (1.23–1.91)

GEE: generalised estimating equations; OR: odds ratio; CI: confidence interval.

Note: Only significant variables are shown. CI = 95% Wald confidence intervals. Excluded cases: 1126 (12%).

Discussion

This study determined and compared self-involvement preferences in decision-making about care involving serious illness at the end of life across seven European countries. Our data showed that in the context of serious illness, the majority (74%) of the public preferred self-involvement when capable. Our study also showed that the majority preferred no self-involvement beforehand in the event of their future incapacity (56%). A preference for no self-involvement in the event of future incapacity was evident in five out of seven countries. The exceptions to this were England, where a large minority preferred no self-involvement (39%), and Germany (17%), which recently passed advance directive legislation in 2009.⁴ Portugal, the only country in the study where advance directives are not legally recognised, preferred less self-involvement in comparison with the other six countries; 82% preferred no self-involvement for the incapacity scenario in Portugal.

Across scenarios, involvement of self, spouse or partner and other relatives was preferred most frequently, except in

Portugal where the involvement of doctors (23%) was more frequently preferred over self-involvement (18%) for the incapacity scenario. Currently, the most common relationship researched in relation to shared decision-making in palliative care is the patient–physician relationship. The role of relatives is under-examined.⁶ Our findings highlight the important role of surrogate decision-making, notably the involvement of family, in future events of incapacity, especially in Portugal where four out of every five respondents preferred no self-involvement beforehand. An examination of the role of friends within England (8%) and Germany (13%) is also warranted as the preference for their inclusion was high compared to the other countries. If self-involvement preferences in Europe remain constant over time, it follows that clinicians should be adequately equipped and resourced to facilitate family discussions regarding care options. Such discussions may need to include several family members such as a spouse or partner and other relatives. The inclusion of several family members, as compared to one primary carer, may have resource implications for services. Other data have shown that bereaved family members of those with written advance directives reported fewer concerns related to physician communication and reported being more informed regarding their family member's dying process.¹⁹ The links between advance directives and the implications for family members in the event of incapacity warrant examination.

Our study identified four factors for self-involvement across both scenarios: younger-middle age, female gender, higher education attainment and a valuing of quality over quantity of life or both equally. In addition, those with increased financial hardship and a preference to die in hospital (but not a palliative care unit), a nursing home or residential home were less likely to prefer self-involvement when capable. While for the incapacity scenario, single people (as compared to those who were married or partnered) were more likely to prefer self-involvement. These factors now need to be examined in more detail. It is presently unclear whether our finding regarding age is a cohort effect or a life-cycle effect. For example, are older people less likely to prefer self-involvement in decision-making about their own care due to some shared temporal experience or common life experience? Other research conducted with the Canadian public showed that preferences for self-involvement in decision-making may decline with age.⁹ Longitudinal research, for example, panel survey studies, will help progress knowledge about self-involvement preferences of the elderly in Europe. This is important in light of ageing populations. Also, we do not know whether lower educational attainment and increased financial hardship are inequities that we need to safeguard against or whether individuals with lower educational attainment and increased financial hardship simply prefer to not be involved in decision-making. It is important to further examine these findings in order to ensure equity. The consideration of these

factors in national policies may help safeguard against potential inequities.

Limitations and considerations

Our study has two main limitations. Our response rate was low²⁰ and an unavoidable selection bias is inherent in our study with the exclusion of those without a landline. We recommend the inclusion of mobile–phone (cell–phone) users in future cross-national telephone surveys.²¹ The overrepresentation of older people in our study is understandable since a telephone survey reliant on landlines was conducted, and even though we surveyed during and outside of working hours, perhaps older people were more likely to be at home during the survey. Second, the use of a hypothetical scenario meant that respondents mostly used an imagined situation to inform their response rather than using current illness experience as their reference point. Even though this is appropriate for research with the general public, other research has shown that end-of-life care decisions and preferences may change over time,²² once diagnosis of illness occurs¹⁶ and after more knowledge about one's own condition has been acquired.²³ The applicability of our findings for patients therefore needs to be considered when appraising our study. In addition, our study mainly focused on one, albeit important, member of the health-care team: the physician. A broader focus on various multidisciplinary professions, for example, nurses, social workers and therapists, may be useful in addressing the current emphasis on the patient–physician dyad. Despite these considerations, our study ensured cross-national comparative data and the examination of an under-researched area. We are unaware of any other pan-European survey addressing this topic, and the comparison between capacity and incapacity preferences is novel. Also, our population-based, cross-national approach has helped overcome methodological limitations of previous decision-making research.

Conclusion

A collaborative model of decision-making has been broadly adopted within medicine, especially towards the end of life,⁶ and autonomy is mostly viewed as fundamental to patient involvement in decision-making within healthcare.⁷ Our study shows that although self-involvement in decision-making is preferred by the European public in scenarios of capacity related to serious illness, a sizeable proportion of the public prefers no self-involvement in advanced decision-making regarding scenarios of incapacity. Financial hardship, educational attainment, age, and preferences for quality and quantity of life require further examination; these factors should be considered in relation to policy.

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Conflict of interest

We declare that we have no conflict of interest. The funder had no role in preparation of this article or the study design.

Disclosure

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Authors' contributions

All authors contributed to study design, survey development and data analysis, and took part in the interpretation of findings and article preparation. Gomes and Calanzani coordinated the development and implementation of the computer-assisted telephone interview by BMG Research and ZEM University of Bonn. Daveson, Higginson and Harding aided this process and the commissioning of the study. Daveson, Simon, Bausewein, Gomes, Harding and Bechinger-English conducted the pilot study. Daveson conducted the analysis of decision-making data with the assistance of Bausewein, supervised by B Gomes. Calanzani aided data management. Higginson and Harding helped to conceive the idea for the main study, collaborated in its design and interpretation. Daveson took primary responsibility for writing the article and the concept of this article. Murtagh aided the initial development of the idea behind this article. All other named authors helped notably with survey development, and cultural adaptation of the survey and the interpretation of its findings, and the preparation of the article. Guarantors of the study are Gomes, Harding, Daveson and Higginson.

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