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Research priorities relating to the debate on assisted dying: what do we still need to know? Results of a modified Delphi technique

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ABSTRACT

Objective: To identify the main areas of uncertainty and subsequent research priorities to inform the ongoing debate around assisted dying.

Design: Two-round electronic modified Delphi consultation with experts and interested bodies.

Setting and participants: 110 groups and individuals interested in the subject of end-of-life care and/or assisted dying were approached to participate. Respondents included health and social care professionals, researchers, campaigners, patients and carers predominantly based in the UK. In the first round, the respondents were asked to propose high-priority research questions related to the topic of assisted dying. The collected research questions were then deduplicated and presented to all respondents in a second round in which they could rate each question in terms of importance.

Results: 24% and 26% of participants responded to the first and second rounds, respectively. Respondents suggested 85 unique research questions in the first round. These were grouped by theme and rated in terms of importance in the second round. Emergent themes were as follows: palliative care/symptom control; patient characteristics, experiences and decisions; families and carers; society and the general public; arguments for and against assisted dying; international experiences/analysis of existing national data; suicide; mental health, psychological and psychosocial considerations; comorbidities; the role of clinicians; environment and external influences; broader topics incorporating assisted dying; and moral, ethical and legal issues. 10 of the 85 proposed questions were rated as being important (≥7/10) by at least 50% of respondents.

Conclusions: Research questions with the highest levels of consensus were predominantly concerned with understanding how and why people make end-of-life decisions, and which factors influence those decisions. Dissemination of these findings alongside a focused examination of the existing literature may be the most effective way to add evidence to the ongoing debate around assisted dying.

Strengths and limitations of this study

- To the best of our knowledge, this is currently the only attempt to identify the main areas of uncertainty and subsequent research priorities to inform the ongoing debate around assisted dying.
- All research questions were generated and refined by a group of interested parties from both sides of the debate, most of whom considered themselves to be very knowledgeable about the topic.
- The research priorities were collectively identified by health and social care professionals, researchers, campaigners, patients and carers, rather than by researchers alone.
- The response rate and overall level of consensus as defined in this study were relatively low.
- Very few of the religious groups that we approached responded to the survey.

INTRODUCTION

Public debate around end-of-life issues has increased in recent years, partly because of demographic changes caused by a rapidly ageing population without a corresponding increase in healthy life expectancy.[1] The debate on assisted dying has become particularly prominent, to the extent that individual 'right to die' appeals frequently receive national media coverage[2–4] and the topic has been explored in novels,[5] movies[6] and even popular soap opera storylines.[7]

'Assisted dying' is not a legal term but is typically understood to mean a circumstance in which a chronically or terminally ill person is allowed to end their own life, either by assisted suicide (the patient is given lethal drugs to take themselves) or by euthanasia (somebody else administers lethal drugs to the patient).

The majority of jurisdictions that have legalised assisted dying permit assisted suicide (in which the patient must themselves take action to end their own life), though some permit voluntary euthanasia or both. Some form of assisted dying is legal in Columbia, Switzerland, the Netherlands, Belgium,

Luxembourg, Canada, and the US states of Oregon, Washington, Montana and Vermont.

Assisted dying remains illegal in the UK, with proposed bills for legalisation recently having been strongly rejected by Members of the Scottish Parliament (MSPs) and Members of Parliament (MPs) in May 2015 and September 2015, respectively.[8 9] Contrastingly, legislators in the state of California have agreed to allow doctor-assisted dying from June 2016,[10] while the Canadian government proposed similar legislation in April 2016.[11]

The debate around any proposed legal changes is strongly polarised, and a number of opposing arguments have been put forward. Many arguments focus on moral, ethical, religious or legal issues and are often strongly informed by pre-existing beliefs. Far fewer arguments are based on objective empirical evidence or else evidence is used only selectively. As such, debates often end in impasse.

Some key areas of debate include individual autonomy, patient choice, the roles of doctors and relatives in assisting death, the nature of 'unbearable' illness, the impact of availability and efficacy of palliative care, the effectiveness of safeguards to protect vulnerable people and the extent of 'unseen' assisted dying/suicide within the current system. Each of these raises questions about 'what we know' about the current state of affairs, whether there is a need for further objective evidence to illuminate the debate on assisted dying and, if so, what focus and form this evidence might take.

We therefore conducted a modified Delphi exercise with experts and interested parties to identify the main areas of uncertainty and subsequent research priorities to inform the ongoing debate around assisted dying.

METHOD

Design

The Delphi technique is a structured and iterative method for collecting anonymous individual opinions from a panel of topic experts where a consensus is required. The basic principle is for the panel to receive successive questionnaires, each one containing the anonymous responses to the previous round, and for them to modify their responses until a consensus is reached.[12–14] The method has been used to identify research priorities in a number of different topic areas.[15–17]

For the debate around assisted dying, this approach allowed respondents to generate a number of relevant research questions and then identify those of the highest priority. The aim was to identify any commonly agreed areas of perceived uncertainty, regardless of prior stance or beliefs.

In the first of two rounds, participants were invited to suggest areas of uncertainty that could be addressed by research:

> A number of arguments have been made both for and against changing the law around assisted dying. Some of these are moral or ethical arguments, others are legal arguments and others are medical or pragmatic arguments. These different arguments require differing degrees of supporting evidence. The aim of this study is to identify the most important areas where the facts are unknown or uncertain, either because there is no evidence or because the evidence we have is limited.
>
> In this first stage, we would simply like you to suggest—as concisely as possible—where you think there is a need for either new evidence or a better summary of the existing evidence in this area.

Participants were presented with illustrative examples of research questions and then provided space to suggest their own (see online supplementary appendix 1 for a complete list of questions proposed by the respondents). No restrictions were placed on the number of suggestions a participant could make. After the first round was closed, thematic analysis was used to deduplicate, code and group items.[18]

In the second round, participants were asked to rate the importance of each research question on a scale from 1 (not at all important) to 10 (extremely important). Participants were encouraged to give a low score to questions that have already been fully answered or are of little interest, but to highly score questions where there is still uncertainty and where research is urgently needed. Questions receiving a score of ≥7 points on the 10-point scale were interpreted as having high importance. A 'No opinion' option was also provided. Since the respondent population in this second round was unlikely to be identical to that in the first round, participants in both stages were briefly asked to rate their current level of knowledge and give their stance on hypothetical changes in the law.

Results of both rounds were shared with respondents.

Questionnaires were administered electronically using online survey software Survey Monkey (http://www.surveymonkey.com).

Participants

Experts and parties interested in the subject of end-of-life care and/or assisted dying (clinicians, charities, religious groups, specialist research groups, think tanks, pressure groups, patient and carer representatives) were approached to participate.

An initial list of individuals, organisations and groups was identified through searches of academic, government and mass media publications, including the 2012 report published by the Commission on Assisted Dying in which a broad range of interested parties submitted evidence.[19] In addition, proassisted and antiassisted dying groups (eg, Dignity in Dying, Living and Dying Well and Care Not Killing) were contacted directly. These sources identified a range of groups and individuals who have previously shown an interest in the legal status of assisted dying in the UK.

Email addresses were collected from personal contact lists and publicly available sources (eg, organisational websites). All emails were personalised to individuals. Groups

were encouraged to disseminate the invitation to their members via their own websites, electronic mailing lists and newsletters. Anyone responding to a link cascaded by an original contact was added to the contact list and sent a questionnaire. All contacts were assured confidentiality, with the aim of encouraging participation and openness.

All contacts were invited to both rounds of the survey, including first-round non-responders (unless they had chosen the option to withdraw from further contact).

In order to assess representation from different stakeholder groups and identify any differences in the responses between them, participants were also asked to categorise and/or briefly describe their background, rate their self-perceived level of knowledge on the topic of assisted dying and give their general prior opinion on the issues of assisted dying and voluntary euthanasia.

Backgrounds were categorised as follows: clinician, patient, carer/ex-carer, patient representative, researcher, campaigner, legislator or other. Respondents could choose one or more categories and were encouraged to provide further details where necessary.

Respondents' prior opinions were elicited with three questions on hypothetical changes to the existing law. These asked: 'Do you think that under certain defined circumstances, the law should allow…'

1. …assisted suicide (providing someone with the means to end his or her own life)?
2. …voluntary euthanasia (ending another person's life at their own request) by a doctor?
3. …voluntary euthanasia (ending another person's life at their own request) by a close family member?

These three scenarios reflect proposed or existing legal arrangements in jurisdictions outside the UK and reflect the chief options contested in the debate around assisted dying. Respondents could reply 'Yes', 'No', 'Don't know' or 'Rather not say'.

Questionnaires

Questionnaires were piloted before distribution, resulting in minor wording changes to improve clarity. Round one was initially 'open' for responses for 2 weeks, though this was extended by a week after several contacts requested extra time to formulate their questions. Round two was open for 3 weeks. Reminder emails were sent to all contacts ~1 week before the close of each round. A mixture of prespecified and free text responses were used to facilitate ease of response and analysis of data. In order to ensure that sufficient data were collected and to prevent inadvertent missing data, 'pick list' questions were made mandatory. It was not mandatory to complete the free text boxes.

Analysis

All responses were collected in 'Survey Monkey' for initial tabulation and analysis. Subsequent analyses and outputs were produced in Excel. Descriptive statistics were calculated and used to investigate the distribution of scores. An initial consensus level was set at a score of ≥7 points on the 10-point importance scale from ≥50% of respondents. Where a respondent did not provide a score, this value was recorded as missing; there was no imputation of missing values.

The relationship between respondents' prior position and scoring of higher consensus questions was explored. Variances were unequal across groups, with small numbers of observations for some questions, precluding the calculation of meaningful hypothesis tests. Therefore, these data were displayed graphically.

Results

A total of 110 individuals and organisations were initially invited to participate. An additional 16 contacts were suggested by first-round respondents, and a further 31 were suggested by second round respondents, all of whom were also invited to participate.

First round

Respondent characteristics

Thirty (24%) invitees (28 of whom completed all questions) responded to the initial questionnaire that required the formulation of research questions. Seven invitees declined the invitation, one email was undeliverable and the remainder provided no response.

Seventy-five per cent of respondents rated themselves as being 'very knowledgeable' or 'expert' on the topic of assisted dying (table 1). Only one respondent considered themselves to have 'limited knowledge'.

Respondent backgrounds included health and social care professionals (palliative care, oncology, nursing, general practice, public health and social work), researchers, campaigners and patients or their carers/representatives (table 2).

A large majority of respondents (93%) were UK based, though responses were also received from elsewhere in Europe, including Belgium and Switzerland.

Opinions on assisted dying and voluntary euthanasia were mixed. In response to the question 'Do you think that under certain defined circumstances, the law should allow assisted suicide (providing someone with the means to end his or her own life)?', 50% of respondents answered 'Yes', 36% answered 'No' and 14% responded that they did not know or would rather not

Table 1 Respondents' self-rated knowledge

	Round 1		Round 2	
	Count	Per cent	Count	Per cent
How would you rate your own knowledge on the topic of assisted dying?				
Know nothing	0	0	1	2.9
Limited knowledge	1	3.6	2	5.7
Reasonably knowledgeable	6	21.4	14	40.0
Very knowledgeable	15	53.6	12	34.3
Expert	6	21.4	6	17.1
Total	28	100	35	100

Table 2 Respondents' background

	Round 1	Round 2
How would you describe your background?		
Clinician	11	9
Patient	2	2
Carer or excarer	1	9
Patient representative	5	4
Researcher	8	9
Campaigner	5	9
Legislator	0	0
Other	5	5
Additional background details (where reported)		
Palliative care	4	5
Hospital consultant	4	1
Oncology	1	1
Public health	1	0
Gerontology	0	1
Nursing	1	0
General practice	1	2
Psychiatry	0	1
Right to die group/organisation	3	2
Policy advice	2	0
Social work	1	1
Charity sector	2	1
Law	0	1
Chaplaincy	0	1
Veterinary medicine	0	1
Relative	0	1

say. A similar pattern of responses was seen for voluntary euthanasia by a doctor (Yes 46%, No 40%, Don't know/Rather not say 14%), though a majority of respondents were opposed to voluntary euthanasia by a close family member (60% vs 21% in favour and 18% uncertain or unwilling to respond).

Respondent-generated research questions and themes

Respondents made 102 separate suggestions for research questions. Thematic analysis identified 13 interrelated themes (table 3).

Where two or more responses expressed an identical research question in different ways, the most concise formulation was kept. Where two or more responses expressed similar but not necessarily identical questions, both versions were retained for the second round. Some responses were categorised as 'Non-research questions' where they posed largely moral/ethical questions or statements of opinion that could not be rephrased without the risk of changing the meaning intended by the respondent (eg, 'Moral arguments around autonomy and dignity').

After deduplication, a total of 85 questions in the 13 categories were sent to participants to be rated in the second round (see online supplementary appendix 1).

Second round

Respondent characteristics

A greater number of participants (n=39; 26%) responded in the second round than the first. Respondent

Table 3 Research question themes

Theme	Number of suggested questions
Palliative care/symptom control	7
Patient characteristics, experiences and decisions	13
Families and carers	3
Society and the general public	7
Arguments for and against assisted dying	4
International experiences/analysis of existing national data	18
Suicide	2
Mental health, psychological and psychosocial considerations	9
Comorbidities	3
The role of clinicians	7
Environment and external influences	4
Broader topics incorporating assisted dying	2
Moral, ethical and legal issues	6

backgrounds, where reported, were similar between rounds, though a greater number of respondents in the second round categorised their backgrounds as 'carer/ex-carer', 'campaigner' or both (table 2).

Participants were again asked to rate their current level of knowledge and give their stance on hypothetical changes in the law. Compared with the first round, a smaller proportion of respondents (51.4%) rated themselves as being 'very knowledgeable' or 'expert' on the topic of assisted dying than did in the first round (table 1).

A greater proportion of respondents were sympathetic to assisted dying and voluntary euthanasia by a doctor than in the first round (74% vs 50% and 66% vs 46%, respectively); the majority remained opposed to voluntary euthanasia by a close family member (54%; figure 1).

Respondent ratings of research questions

A median of 32 ratings (range 23–36) were available for each of the 85 questions.

The distribution of scores was negatively skewed (ie, in favour of high ratings of importance) for all questions but varied widely between individual respondents (76 questions received ratings ranging from 1 to 10 points). Online supplementary appendix 1 shows box-and-whisker plots summarising the mean, median, range and IQR values for each question.

The level of consensus among respondents on whether a question was important (ie, score≥7) ranged from 4% to 56% (see online supplementary appendix 2 for details).

Summary of highest priority questions

Ten of the 85 rated questions met the consensus level of receiving a score of ≥7 points from ≥50% of respondents. These are shown in table 4.

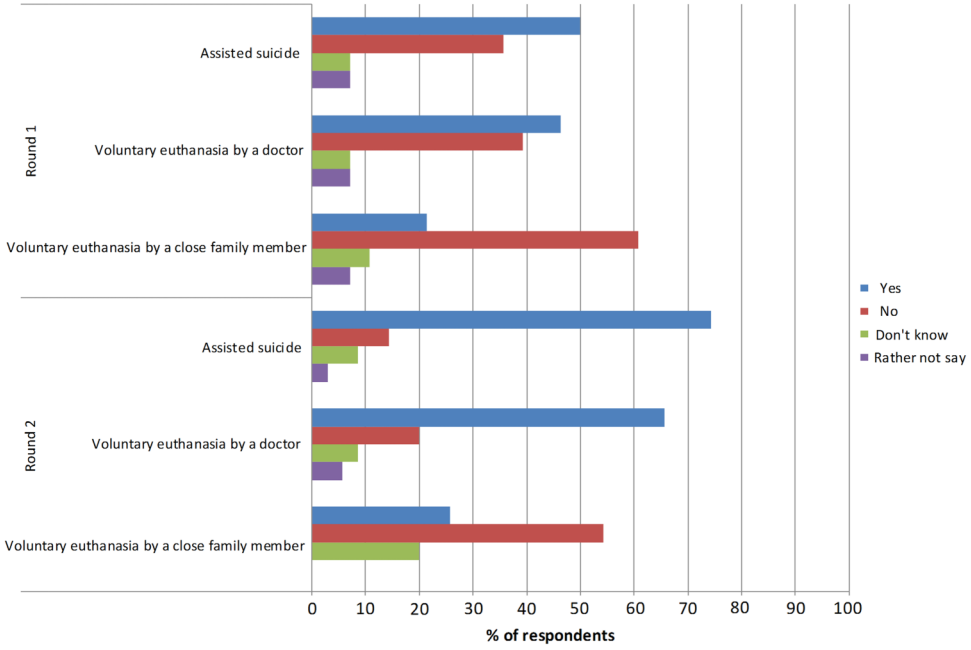

Figure 1 Respondent support for a change in the law.

The question with the single highest level of consensus was:

> What are the effects of carer burden on requests for assisted dying? (55.9%)

This was one of several highest level consensus questions specifically concerned with understanding how and why people make end-of-life decisions, and which factors influence those decisions:

> How do the views of people considering euthanasia/physician assisted suicide with a spectrum of conditions develop over time—especially those not near the end of life? (52.8%)

> What are the triggers for requesting assisted dying? (52.9%)

Table 4 Questions rated ≥7/10 by at least 50% of respondents

Primary theme	Proposed research question	Consensus (%)
Families and carers	What are the effects of carer burden on requests for assisted dying?	55.9
Arguments for and against assisted dying	Understanding better why some patient groups are strongly opposed to assisted suicide—what are their concerns, could these be mitigated?	54.3
Comorbidities	Given the progression of dementia, when should end-of-life care be discussed with the person with dementia and who should initiate this discussion?	53.3
Mental health, psychological and psychosocial issues	What are the triggers for requesting assisted dying?	52.9
Personal characteristics, experiences and decisions	How do the views of people considering euthanasia/physician assisted suicide with a spectrum of conditions develop over time—especially those not near the end of life?	52.8
International experiences/analysis of existing data	Does international experience confirm or lay to rest concerns that vulnerable individuals will be pressurised to avail themselves of assisted dying?	51.5
Personal characteristics, experiences and decisions	Why do people consider going to Dignitas—is it fear of dying, pain, control?	50
Personal characteristics, experiences and decisions	What would enhance a person's quality of life after diagnosis of a terminal illness, how do they define 'quality of life' and what are factors they take into consideration in assessing it?	50
Broader topics	How to operationalise concepts such as 'unbearable suffering'?	50
Moral, ethical and legal issues	The best alternative care pathways for 'end of life' (rather than depriving the patient food and drink and allowing them to starve)?	50

> Why do people consider going to Dignitas—is it fear of dying, pain, control? (50%)

> What would enhance a person's quality of life after diagnosis of a terminal illness, how do they define 'quality of life' and what are factors they take into consideration in assessing it (50%)

These questions imply a need for robust qualitative evidence about individuals' motivations, experiences and decisions, while another question identified the analysis of existing evidence from jurisdictions in which some form of assisted dying is already legal as an area of importance:

> Does international experience confirm or lay to rest concerns that vulnerable individuals will be pressurized to avail themselves of assisted dying? (51.5%)

One question raised a general methodological issue for end-of-life researchers:

> How to operationalise concepts such as 'unbearable suffering'? (50%)

Two consensus items touched on issues broader than simply obtaining good research evidence, raising questions about optimal planning and decision-making at the end of life:

> Given the progression of dementia, when end of life care should be discussed with the person with dementia and who should initiate this discussion? (53.3%)

> What are the best alternative care pathways for 'end of life' (rather than depriving the patient food and drink and allowing them to starve)? (50%)

Finally, one proposed research question was not concerned with understanding people at the end of life, but those who take a particular position on the issue of assisted dying:

> Understanding better why some patient groups are strongly opposed to assisted suicide—what are their concerns, could these be mitigated? (54.3%)

Relationship between respondents' views on assisted dying and their perceived importance of research questions

Figures 2–4 illustrate the relationship between respondent views on various forms of assisted dying and mean ratings for questions with ≥50% consensus. The pattern of scores in figure 2 suggests that respondents with no fixed position on assisted suicide (ie, 'Don't know') consistently gave higher ratings to the research questions than did respondents with a fixed position (ie, 'Yes' or 'No'). As might be expected, respondents with less certainty tended to value research evidence more highly.

The pattern of ratings was not consistent for all views on assisted dying (assisted suicide, doctor-assisted voluntary euthanasia, family-assisted euthanasia), though mean ratings tended to be slightly lower among respondents who were against any hypothetical changes in the law (figures 2–4).

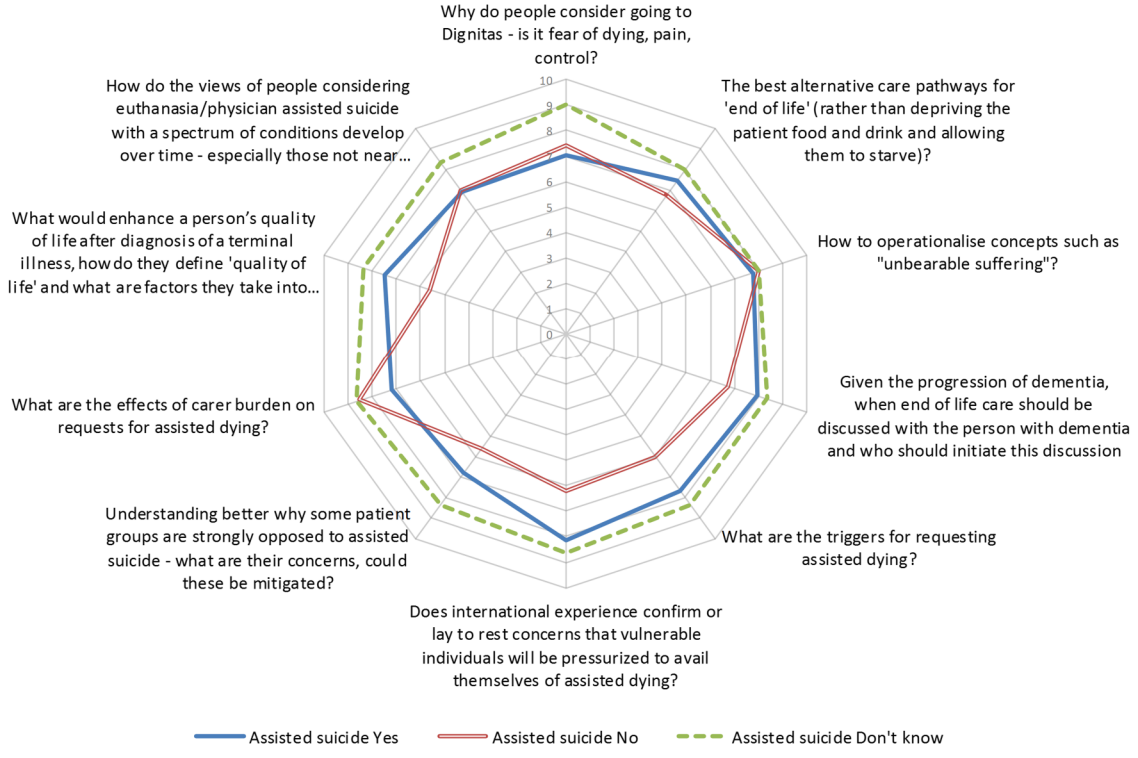

Figure 2 Relationship between respondent views on assisted suicide and mean rating for highest consensus questions.

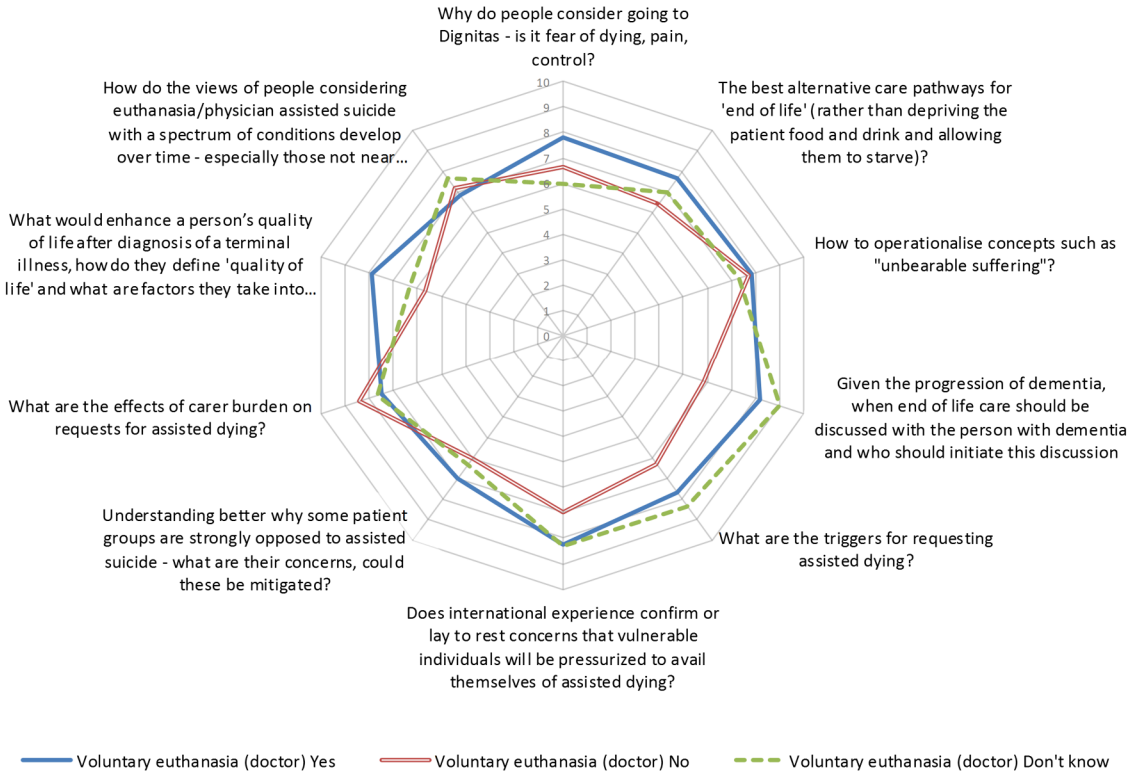

Figure 3 Relationship between respondent views on doctor-assisted voluntary euthanasia and mean rating for highest consensus questions.

Discussion

To the best of our knowledge, this is currently the only attempt to identify the main areas of uncertainty and subsequent research priorities to inform the ongoing debate around assisted dying. All research questions were generated and refined by a group of interested parties from both sides of the debate, most of whom considered themselves to be very knowledgeable about the topic.

New research ideas are frequently generated by research professionals who have an interest in a topic area. While researchers may be able to identify gaps in the evidence, they may not be best placed to determine which areas are most urgently in need of further research. Approaches such as the James Lind Priority Setting Partnerships aim to tackle treatment uncertainties by consulting a wider range of participants in order to identify research priorities. Such partnerships consist of at least one patient/carer organisation and at least one clinician organisation.[21]

This Delphi consultation incorporated a diverse set of experiences, including those of health and social care professionals, researchers, campaigners, patients and carers from a predominantly UK setting. Consequently, the research priorities identified here may more closely reflect those of value to wider society. For example, researchers might be interested in analysing data collected in jurisdictions where assisted dying is legal. However, while research questions about cross-country comparisons were most commonly suggested by panel members, only one of these emerged among the highest priority questions based on consensus score.

The results raised a number of important questions about end-of-life issues that were broader than just the topic of assisted dying. For example, clear definition and measurement of concepts such as 'quality of life' and 'unbearable suffering' in this setting are fundamental to understanding end-of-life issues, yet the panel of experts considered the evidence to be lacking in this area. The National Institute for Health Research (NIHR) 'palliative and end of life care Priority Setting Partnership' (PeolcPSP) has looked at end-of-life issues more broadly and identified a set of unanswered questions around provision and access to palliative care and the benefits of advance care planning that complement those identified in the current exercise.[22] Some issues—such as concerns about how to listen to and incorporate patient preferences—overlap with the priorities identified here. Interestingly, the PeolcPSP also received a number of comments and questions outside its intended scope.

The overall level of consensus as defined in this study was relatively low (4–56%). However, wide variation in second round scores between items suggested that respondents were able to distinguish pertinent research questions from untestable hypotheses and statements of opinion. Therefore, it seems that most respondents understood the aim of the project and were focused on identifying areas of uncertainty that would benefit from empirical investigation. Further, it seems that the consensus threshold

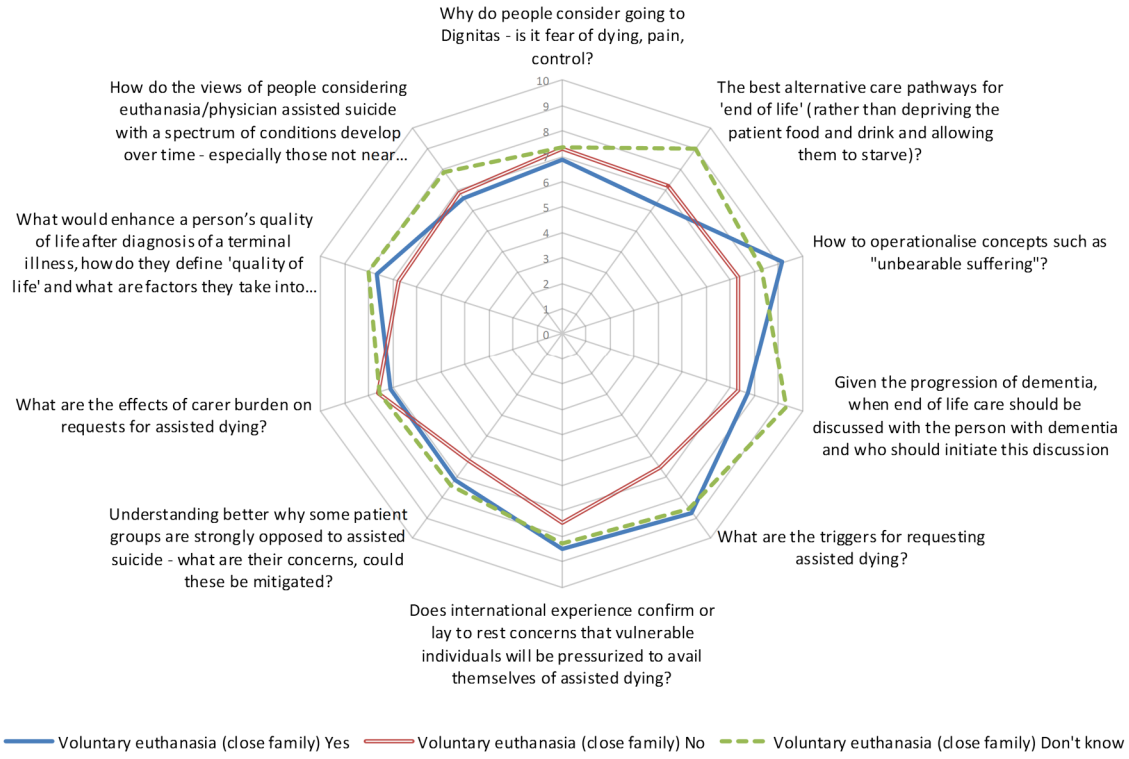

Figure 4 Relationship between respondent views on family-assisted voluntary euthanasia and mean rating for highest consensus questions.

applied here (at least half the respondents giving ≥7 points) was able to identify the highest priority questions.

The response rate to the Delphi (~25%) was relatively low but compares favourably to other surveys that have recruited doctors.[23 24] A low response might have been expected, given the onus on respondents to formulate their own research questions; the level of time and effort required for this may have been a barrier for participants who might otherwise have responded to a simple 'tick box' questionnaire. However, a fundamental objective of this process was to obtain research questions from experts and other interested parties, rather than have them imposed by researchers. Similar future surveys should consider engaging participants as early in the process as possible, and attempt to sustain participant enthusiasm to overcome such barriers. Alternatively, questions might be initially generated through interviews or focus groups.

Over 90% of respondents were based in the UK, with the remainder from elsewhere in Europe. There were no respondents from other regions, in particular the US states where assisted dying legislation has been enacted. This would raise concerns about possible unrepresentativeness if the identified high-consensus questions related specifically to medicolegal issues. However, the highest consensus questions identified here relate to how and why people make end-of-life decisions, which are more likely to be of universal concern. Nevertheless, we acknowledge that the relative emphasis placed on such questions may partly depend on cultural context.

Whereas large sample sizes are important for questions of precision, the aim of the Delphi exercise was to identify consensus among a diverse group of interested individuals. In this case, obtaining an appropriate sampling frame is perhaps more important. As well as including participants from a variety of professions, we approached groups and individuals with opposing opinions on the subject of assisted dying. While respondents from both sides of the debate contributed to both stages of the survey, there was a slight predominance of respondents in favour of assisted dying. Very few of the religious groups that we approached responded to the survey, so this may have had an influence on the ratings (ie, through under-representation of antiassisted dying opinion), and might partly explain high importance ratings for the question 'Understanding better why some patient groups are strongly opposed to assisted suicide—what are their concerns, could these be mitigated?'. However, the other highly rated questions do not appear to have an overtly proassisted or antiassisted dying stance, but rather address important areas of uncertainty. The distribution of scores did not show a clear influence of prior stance on question ratings: a slight tendency for lower scores among those respondents against a change in the law was observed, though for most questions, the scores did not differ greatly. It is plausible that people who consider the current legal position to be adequate are less likely to believe there is a need for research than people who are unsure or favour a change in the law.

Recommendations for future research

The logical next step would be to address the priority questions identified from this process. This should be carried out in the first instance by examining the existing evidence to further refine the design of any future research. There is some available evidence relevant to some of the questions identified here (eg, on views of patients and carers),[25] but a number of questions have not been addressed directly or systematically. Before undertaking any new primary research, one or more systematic reviews of the existing evidence focusing on the themes and questions identified here may be worthwhile. For example, a review of qualitative evidence specifically concerned with the influence of dementia on patient and carer views related to assisted dying would be of value. Although lower priority, this may be supplemented by a systematic review of the international evidence to determine the fate of vulnerable people in jurisdictions with legalised forms of assisted dying, which remains an area of major contention. A well conducted systematic review could provide an impartial and comprehensive overview of the evidence, making explicit its relative strengths and weaknesses in relation to the well-worn arguments in this area. If uncertainties still remain, the review could make clear and precise recommendations about where new primary research is needed.

CONCLUSION

This consultation revealed a number of important uncertainties around the debate on assisted dying and end-of-life issues more broadly. Eighty-five unique research questions were suggested by a broad range of interested parties with high levels of topic expertise. Research questions with the highest levels of consensus were predominantly concerned with understanding how and why people make end-of-life decisions, and which factors influence those decisions. Dissemination of these findings alongside a focused examination of the existing literature may be the most effective way to bring objective research evidence into the ongoing debate around assisted dying.

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