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Issues and needs in end-of-life decision making: An international modified Delphi study

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Abstract

Background: end-of-life decision making is an important aspect of end-of-life care that can have a significant impact on the process of dying and patients' comfort in the last days of life.

Aim: the aim of our study was to identify issues and considerations in end-of-life decision making, and needs for more evidence among palliative care experts, across countries and professions.

Participants: 90 palliative care experts from nine countries participated in a modified Delphi study. Participants were asked to identify important issues and considerations in end-of-life decision making and to rate the need for more evidence.

Results: experts mentioned 219 issues in end-of-life decision making related to the medical domain, 122 issues related to the patient wishes and 92 related to relatives' wishes, regardless of profession or country ($p > 0.05$). In accordance, more than 90% of the experts rated the comfort and wishes of the patient and the potential futility of treatment as important considerations in end-of-life decision making, although some variation was present. When asked about issues that are in need of more evidence, 87% mentioned appropriate indications for using sedatives and effects of artificial hydration at the end of life. A total of 83% mentioned adequate communication approaches.

Conclusions: palliative care experts from different professions in different countries encounter similar issues in end-of-life decision making. Adequate communication about these issues is universally experienced as a challenge, which might benefit from increased knowledge. This shared experience enables and emphasizes the need for more international research.

Keywords
decision making, expert opinion, research priorities, palliative care, terminal care

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Introduction

End-of-life decision making is a sensitive but important aspect of end-of-life care that can have a significant impact on the process of dying and dying patients' comfort in the last days of life. Such decision making may involve withdrawing or withholding treatment, such as artificial nutrition (AN) and hydration (AH), or providing intensive treatment to alleviate suffering, for example by using opioids or sedatives. Some countries, such as the Netherlands and Belgium, allow the provision of life-ending drugs upon the explicit request of the patient.

To date evidence on the effects, either beneficial or harmful, of providing or not providing different types of treatment in the last days of life is limited.[1,2] Current research focuses mostly on practices and experiences or attitudes of physicians, nurses, patients, relatives or the general public and is often locally based. However, some international research has been conducted.[3] Hence, we know that the frequency of foregoing treatments, such as AH and AN,[4] and the manner of alleviation of severe suffering at the end of life[5,6] vary between countries. Many factors can contribute to this variation, such as cultural, legal and practice differences, for example in the organization of health care. Research has shown that European intensive care unit (ICU) physicians' primary consideration in decision making on withdrawing or withholding life support or actively shortening the dying process was the patient's medical condition, while quality of life, patient age and patient or family request were less important.[7] In the Netherlands, important considerations in decision making about anti-cancer treatment for end-stage cancer patients were found to be the chance of improvement, patient wishes, the degree of suffering and the chance of therapy being successful.[8]

Besides variation in end-of-life decision-making practices between countries, previous research has also shown differences between professions in attitudes regarding end-of-life decision making,[9] which are probably related to different responsibilities, roles and levels of involvement.

More insight in the international and interdisciplinary variety in end-of-life decision-making practices can contribute to international understanding and debate and to the identification of international research themes.[10] The aim of this study was therefore to get more insight into the most important issues and considerations in end-of-life decision-making processes. We asked palliative care experts from different countries and professions to identify the key issues they encounter when making end-of-life decisions, their considerations when making end-of-life decisions, and the extent to which they feel that more evidence on these issues is needed.

Methods

Design and population

A modified two-round digital Delphi survey was conducted. This study was framed within the European research collaborative OPCARE9, in which palliative care practitioners and researchers from nine countries are identifying areas for optimizing care for the dying. These countries are Argentina, Italy, Germany, the Netherlands, New Zealand, Slovenia, Sweden, Switzerland and the UK. Within OPCARE9, every country constructed a national reference group, a multidisciplinary group comprised of palliative care experts, known leaders in the field and volunteers. Convenience sampling was used to construct these reference groups. Using these national reference groups, a purposive strategy was applied to identify experts with an interest and involvement in end-of-life decision making. We aimed at including four physicians, three nurses, two other professional caregivers and one volunteer per country.

Data collection

Two structured questionnaires were developed. In these questionnaires, decisions on AH, AN and the use of sedatives were used as examples of topics for end-of-life decision making. A pre-Delphi survey among 114 experts in nine countries showed that they considered these topics as very important at the end of life. In the first questionnaire, we asked the experts which important issues they encounter when making end-of-life decisions on AH, AN and using sedatives, by using open questions. We also presented them with 43 statements on eight considerations when making such decisions. The eight considerations assessed were comfort of patient, relative and professional caregiver, the wish of patient and relative, the effect on length of survival, futility of the treatment and ability to die at home. Participants were asked to rate the importance of these considerations on a seven-point Likert scale, ranging from unimportant (1) to highly important (7). The second questionnaire explored the extent to which experts thought that research on the issues that were frequently mentioned in round 1 would be useful. They were asked to which extent they agreed with statements that decision making would significantly improve if there would be more knowledge and/or evidence-based guidance on these issues. They rated their agreement on a five-point Likert scale, ranging from 1 'totally disagree' to 5 'totally agree'. The background characteristics of the experts (country, profession, work setting, age and experience) were asked in both questionnaires.

The questionnaires were written in English and distributed electronically. The first questionnaire was sent between October 2009 and November 2009, and the second between May 2010 and June 2010. For both questionnaires reminders were sent in the case of non-response within three weeks.

Statistical analysis

All issues mentioned in response to the open question were labelled, categorized and counted. We used the analysis of variance (ANOVA) to compare the number of issues mentioned in different domains between countries and professions, for those domains which met the requirements. Likert scores on the importance of considerations were dichotomized

Table 1. Profile of respondents in the first and second round of the Delphi study.

	Round 1	Round 2
Response rate % (*n*)	76% (*n* = 68)	60% (*n* = 54)
Age (mean, SD)	45.8 (8.5)	47.9 (7.9)
Profession		
Physician	46% (31)	52% (28)
Nurse	25% (17)	33% (18)
Other caregiver[a]	29% (19)	15% (8)
Setting		
Hospital	27% (18)	26% (14)
Hospice	31% (21)	32% (17)
PCU	34% (23)	33% (18)
Other	8% (5)	9% (5)
Country		
Argentina	16% (11)	18% (10)
Italy	15% (10)	9% (5)
Germany	12% (8)	6% (3)
New Zealand	12% (8)	13% (7)
Slovenia	3% (2)	4% (2)
Sweden	15% (10)	16% (9)
Switzerland	7% (5)	9% (5)
The Netherlands	9% (6)	15% (8)
United Kingdom	12% (8)	11% (6)
Expertise	Mean (SD)	Mean (SD)
Years working in palliative care	11.1 (7.1)	12.4 (6.8)
Attending deaths per year	159 (146)	120 (111)

[a]Other caregivers were social workers, psychologists, spiritual caregivers, occupational therapists, volunteers and a dietician.
PCU: palliative care unit

(1–4 'not important' and 5–7 'important') and the percentage of scores in either consideration was calculated. Likert scores on the potential of research to contribute to the quality of end-of-life decision making were also dichotomized (1–3 'not important, 4–5 'important'). Differences between countries and professions in percentage of respondents who thought that specific considerations and research needs were important were tested using the non-parametric Fisher's Exact Test. For statistical analyses, we used SPSS software (SPSS PASW 17 17.0.2 ENG, WinWrap Basic, Polar Engineering and Consulting).

Ethical considerations

This study was evaluated by nine ethics committees in all beneficiary countries, as part of the whole project OPCARE9. No ethical objections were raised.

Results

Response

In the first round the response rate was 76% ($n = 68$) and in the second round 60% ($n = 54$). The mean age of the experts was 45.8 years in the first round and 47.9 years in the second round. All professions were represented as planned (Table 1). All countries were represented and the distribution of professions per country did not differ in either round. Almost all experts were working in institutions and they had an average experience in palliative care of 12 years.

Issues in end-of-life decision making

The experts mentioned 552 issues that they encounter when making end-of-life decisions: 189 related to AN, 182 related to AH and 181 related to the use of sedatives at the end of life. The issues mentioned could be categorized into nine domains. Most issues were related to the medical domain, followed by issues related to addressing patients' wishes, addressing relatives' wishes and to multidisciplinary team decision making. Issues in the cultural and legal domains were least often mentioned. The number of issues mentioned per domain did not differ between professions or countries.

Considerations in end-of-life decision making

According to the experts, the most important consideration in end-of-life decision making is the comfort of the patient, for all three types of decisions, followed by the potential futility of treatment and the wishes of the patient (Table 2). The least important considerations were the comfort of professional caregivers and the (expected) effect of treatment on postponing death or foreshortening life. The importance of these considerations was rated similarly by all professions. There were significant differences between countries: futility of treatment was least often rated as an important consideration in the UK (overall $p < 0.05$) and enabling people to die at home was most often rated as important in Argentina and least often in Sweden (overall $p < 0.01$).

Need for more guidance in end-of-life decision making

Table 3 shows the percentage of experts who thought that end-of-life decision making could significantly improve if there were more evidence-based guidance. Of the experts, 87% (totally) agreed with the statement that more evidence-based guidance on 'optimal strategies for communication with the patient' could improve end-of-life decision making, and 83% agreed with a comparable statement on communication with relatives. Other important research themes were indications for using sedatives at the end of life (87% of the experts), the effects of (de)hydration at the end of life (83% of the experts) and the dosage of sedatives to use at the end of life (80% of the experts). No differences between countries were found in the rating of the importance of more evidence for the different themes. There were some differences between professions: the effect of dehydration on quality of life was more often considered important by physicians and nurses than by other caregivers (overall $p < 0.05$) and

Table 2. Percentage of respondents rating considerations in end-of-life decision making as important.

Considerations in end-of-life decision making	Physicians	Nurses	Other caregivers	Total	Difference professionals	Difference countries
	% important	% important	% important	% important	*p*-value	*p*-value
Comfort of patient	100	100	100	100	n.a.	n.a.
Futility of treatment	90	81	100	90	0.30	<0.05
Wishes of patient	83	100	93	90	0.17	0.13
Enable patients to die at home	79	75	57	73	0.33	<0.01
Comfort of relatives	30	41	50	38	0.45	0.43
Wishes of relatives	28	32	36	31	0.93	0.21
Possible effect on length of survival	11	0	15	9	0.42	<0.05[a]
Comfort of professional caregivers	7	18	0	9	0.23	0.39

Dichotomized scores on a seven-point Likert scale (1–4 = not important, 5–7 = important).

[a] Little relevant differences between countries, although statistically significant, due to very low % of experts who rated this consideration as important.

multidisciplinary team decision making was more often considered important by nurses (overall $p = 0.01$).

Discussion

This study shows that palliative care experts from different professions in nine countries encounter similar issues in end-of-life decision making. Important issues were often related to the medical domain, such as uncertainty about the effects of (de)hydration and appropriate indications for the use of sedatives, and to communication, such as how to address patients' and relatives' wishes and how to inform those involved. The most important considerations for all professions, when making end-of-life decisions, were the comfort and the wishes of the patient and the potential futility of treatment. Improved knowledge regarding appropriate indications for using sedatives, the effects of AH at the end of life and adequate communication approaches was identified as contributing to better end-of-life decision making.

It is important to emphasize that the term 'end-of-life decision' is surrounded by some confusion. In the early 1990s this term was predominantly used for decisions in the patient domain, involving advance care planning and gaining insight into the values of the patient. A significant amount of research on *medical* end-of-life decision-making practices focused on decisions in which the physician aims at or takes into account a life-shortening effect.[3,11–16] In this international collaborative, the term 'end-of-life decisions' was defined as a broad concept that included all decisions that may have a significant impact on how, where and when patients die. A preparatory survey, utilizing this definition over 100 experts in all participating countries, identified decisions on medical issues such as AH, AN and use of sedatives as the important end-of-life decisions.

Our study has both strengths and limitations. To assess issues, considerations and needs related to end-of-life decisions, a large international expert panel was used. The experts were selected within the nine beneficiary countries of the OPCARE9 consortium. It is not possible to determine if the panel is representative of the population of palliative experts. Nevertheless, the presence of different professions and the average length of palliative care experience (12 years) suggest that our panel represents a broad and experienced group. The response was satisfactory, namely 76% in the first Delphi round and 60% in the second. It is important to note that almost all experts worked in an institutional setting, which makes it difficult to generalize our results to home care settings. In addition, the participants were predominantly physicians and nurses, because they were more inclined to respond. This partly explains the emphasis on medical issues.

This study shows that palliative care experts from different countries share experiences regarding issues and considerations in end-of-life decision making. The fact that these shared opinions regarding the importance of patient comfort, futility of the treatment and patients' wishes in end-of-life decisions making do not seem to involve similar practices[3] may be related to the fact that evidence-based end-of-life care is still evolving. Therefore practices can only result from the limited objective data informed by experience and humanistic considerations.

We also identified some variation between countries and professionals. 'Enabling the patient to die at home' was least often rated as an important consideration in end-of-life decision making in Sweden. This finding coincides with a relatively low rate of about 21% home deaths (of all non-sudden deaths) in Sweden.[17] This consideration may

Table 3. Percentage of respondents agreeing that more evidence on end-of-life decision making issues could improve end-of-life decision making.

Decision making on AN/AH/sedatives in the last days of life could substantially improve if there would be more general knowledge and/or evidence-based guidance on…	Physicians	Nurses	Other caregivers	Total	Difference professionals	Difference countries
	% agree	% agree	% agree	% agree	*p*-value[a]	*p*-value[a]
… optimal strategies for communication with patients	86	94	71	87	0.32	0.82
… for what indication to use sedatives	93	78	88	87	0.28	0.47
… optimal strategies for communication with relatives	85	89	63	83	0.32	0.67
… the effect on quality of life of dehydration[b]	89	89	50	83	<0.05	0.33
… what dose to use for sedation[c]	79	83	75	80	0.90	0.45
… diagnosing dying	82	67	88	78	0.44	0.93
… what medications to use for sedation[c]	82	72	75	78	0.67	0.38
… the side effects	75	83	50	74	0.25	0.91
… the effects on quality of life	75	72	63	72	0.77	0.52
… how to improve multidisciplinary team decision making	56	94	63	70	0.01	0.59
… the impact of cultural perception	67	72	63	68	0.85	0.99
… relatives' perceptions	71	53	75	66	0.42	0.43
… ethical considerations; respecting autonomy of patients	54	72	83	64	0.33	0.27
… legal aspects of making decisions	56	67	75	62	0.59	0.91
… patients' wishes	61	56	63	59	0.93	0.55
… ethical considerations; possible shortening life of patients	44	67	75	57	0.23	0.47
… reasoning behind patients' wishes	57	47	63	55	0.75	0.83
… the effects on patients' length of life	57	44	63	54	0.70	0.45
… relatives' wishes	29	38	50	35	0.52	0.95

Dichotomized scores on a five-point Likert scale (1–2 = agree, 3–5 = disagree).
AN: artificial nutrition, AH: artificial hydration
[a]*p*-values are based on Fisher's Exact Test, [b]statement only on use of artificial hydration at the end of life, [c]statement only on using sedatives at the end of life.

also be of less importance in Sweden, due to the high availability of technical devices in palliative home care in Sweden. Hence, decision making about AH or AN is not a determinate of place of care and dying. In Argentina, where approximately 59% of all people die at home,[18] it was most often mentioned as an important consideration.

This Delphi study also assessed the extent to which experts believed evidence-based guidance in end-of-life decision making would be helpful. This practice-based identification of research themes is not only useful and feasible, but it also may increase ownership of the future research results and the likelihood of these results influencing clinical practice.[19] Stakeholders in many fields are already involved in identification and prioritization of research themes, and increasingly so in palliative care.[10,20–22] However, this mostly national involvement of stakeholders in end-of-life research is still insufficient. Recently an international study identified 'lack of culture for research in palliative care services' and the 'disconnection in understanding between clinician and researcher' as important barriers in end-of-life research.[23] Using an international, multidisciplinary expert panel, our study may contribute to improving involvement in end-of-life research. In addition, our findings regarding the need for evidence-based guidance in end-of-life decision making are in line with previous research: communication has been shown to be considered as an important theme for end-of-life research by patients and their relatives too.[10]

Conclusion

In conclusion, we found a large degree of international and interdisciplinary consensus on important issues and considerations in end-of-life decision making. Communication with terminally ill patients and their relatives is a challenge that could benefit from more evidence, together with appropriate indications for and effects of end-of-life therapies. This international and interdisciplinary consensus underlines the possibility of and need for more international research.

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Conflict of interest

None declared.

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Appendix. Number of issues in end-of-life decision making as mentioned by 68 experts from nine countries[a].

Domain	Physicians *n* = 31	Nurses *n* = 17	Other caregivers *n* = 19	Sub themes
Medical issues	115	56	48	(Unknown) effect of therapies on quality of life, (unknown) effect on life expectancy, side effects (oedema, nausea, vomiting, death rattle, dyspnoea, dry mouth), refractoriness of symptoms, how to control symptoms (pain, delirium, insomnia, agitation, anxiety), appropriateness of treatment, diagnosing of dying, no guidelines, which dose of medication, balance between relief of distress and ability to communicate, alternatives for using sedatives
Patient wishes	47	33	42	How to know patient's values and true wishes, patient's perception of treatment aims, patient's wish to die, how important is patient's consent for treatment
Relatives wishes	38	25	29	Distress of family that patient will starve/is thirsty, family knowledge/expectations of hydration/nutrition, family resistance to doing 'nothing', family concerns about hastening death, how important are wishes of family/proxy, relatives' perception of treatment aims, relatives unable to cope
Decision-making issues	4	7	13	Communication, lack of (professional) agreement, multidisciplinary team discussion, acute settings, how to inform patient and relatives, advance care planning, conflicts, who should decide, consciousness level of patient (capacity)
Caregivers wishes	20	9	4	Multidisciplinary team views, perception of professionals on issues around hastening death, distress among professionals that patient is thirsty, lack of knowledge on use of sedatives, fear of using sedatives
Ethical issues	13	3	5	Ethical aspects, autonomy, how not to harm, medical vitalism (pro-life), shortening life, euthanasia or symptom management, double effect
Practical issues	13	10	5	Economic issues (health insurance), treatment possible at home, registration of drugs for specific indication, funding for drugs, emotional overload professional team
Cultural issues	5	3	0	Role of nutrition in culture, social cultural problems, societal ignorance of sedatives
Legal issues	4	0	1	Decision-making capacity of patient with low consciousness, worries about legal status of using sedatives

[a] The experts could mention more than one issue; in total 552 issues were mentioned.