End-of-Life Decision Making in Palliative Care and Recommendations of the Council of Europe: Qualitative Secondary Analysis of Interviews and Observation Field Notes

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Abstract

Background: End-of-life decisions (ELDs) are embedded in clinical, sociocultural, political, economic, and ethical concerns. In 2014, the Council of Europe (CoE) through its Committee on Bioethics launched the “Guide on the decision-making process regarding medical treatment in end-of-life situations,” aiming at improving decision-making processes and empowering professionals in making ELDs.

Objective: To analyze if end-of-life decision making in palliative care (PC) is consistent with this Guide and to identify if disputed/controversial issues are part of current ELDs.

Design: Qualitative secondary analysis.

Setting/Subjects: Four qualitative datasets, including 44 interviews and 9 team observation field notes from previous studies with PC teams/professionals in Portugal.

Measurements: An analysis grid based on the abovementioned guide was created considering three dimensions: ethical and legal frameworks, decision-making process, and disputed/controversial issues.

Results: The majority of the professionals considered the ethical principle of autonomy paramount in end-of-life decision making. Justice and beneficence/nonmaleficence were also valued. Although not mentioned in the Guide, the professionals also considered other ethical principles when making ELDs, namely, responsibility, integrity, and dignity. Most of the interviewees and field notes referred to the collective interprofessional dimension of the decision-making process. Palliative sedation and the wish to hasten death were the most mentioned disputed/controversial issues. The nature, limitations, and benefits of qualitative secondary analysis are discussed.

Conclusions: End-of-life decision-making processes made by Portuguese PC teams seem to be consistent with the guidelines of the CoE. Further research is needed about disputed/controversial issues and the actual use, effectiveness, and impact of ethical guidelines for end-of-life decision making on professionals’ empowerment and for all parties involved.

Keywords: advance directives; decision making; end of life; ethical guidelines; ethical principles; ethics; palliative care; palliative sedation; qualitative secondary analysis; wish to hasten death

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[†]Information on Project DELiCaSP, Project InPalIn, and Subproject ETHICS II of Project ENSURE is provided in the Acknowledgments. Accepted December 6, 2017.

Introduction

THE CIRCUMSTANCES of dying and death have changed over the last decades. Nowadays, people die more often due to chronic progressive diseases, frequently in old age. Evidence shows that most patients prefer to die peacefully, rather than receiving aggressive life-prolonging treatments.¹⁻⁶ Consequently, healthcare professionals are increasingly making end-of-life decisions (ELDs), which are an integrated dimension of contemporary palliative and end-of-life care.⁷⁻⁹

ELDs are medical decisions made at the end of life that may have a potentially life-shortening effect.^{10,11} Decision-making processes underlying ELDs are embedded in and foster clinical, ethical, sociocultural, religious, political, and economic concerns. Healthcare professionals perceive end-of-life decision making as complex, difficult, and stressful, and ELDs are associated with burnout and moral distress.^{9,12-15}

The importance of ELDs and inherent decision-making processes is paramount as they refer to the ethical and legal aspects of care. End-of-life situations are very often moments of high vulnerability, which can profoundly impact patients' ability to exercise autonomy. When the latter is compromised, and patients are unwilling or unable to take part directly in the decision-making process, discussions involving surrogate decision makers become essential.¹⁶⁻¹⁹ ELDs can also be considered as a quality indicator. This happens in terms of both outcomes (e.g., decision making and preferences of care) and processes (e.g., discussions with patient about goals of care).²⁰⁻²⁶

Several professional associations worldwide have developed guidelines aimed at improving end-of-life decision making.²⁷⁻³⁰ Nonetheless, there is a lack of evidence about the actual use and benefits of these guidelines³¹ and whether or not professionals follow them.

In 2014, the Council of Europe (CoE), through its Committee on Bioethics, launched the "Guide on the decision-making process regarding medical treatment in end-of-life situations" (hereinafter, the "Guide").³² The aims of this Guide are: to propose reference points for the implementation of the decision-making process underlying medical treatment in end-of-life situations; to bring together both normative and ethical reference works and elements relating to good clinical practices; and to contribute to the overall discussion on the decision-making process in end-of-life situations, particularly the complex circumstances encountered in this context.³² The Guide is applicable throughout the continuum of healthcare provision, in any context or place of care. It targets a broad audience of stakeholders who are or may be involved in end-of-life situations (e.g., healthcare professionals, patients, families, and associations).³²

Due to the variability in cultural, societal, and legal status across European countries, the Guide is not legally binding, assuming solely an advisory role. Little is known about its effective implementation and whether or not end-of-life decision-making processes in European healthcare systems are consistent with its framework and recommendations.

The objectives of this study are: (1) to analyze if end-of-life decision-making processes performed by palliative care (PC) teams in Portugal are consistent with the ethical and legal framework and recommendations of the Guide and (2) to identify if disputed/controversial issues (e.g., palliative sedation, forgoing artificial hydration/nutrition, and wish to hasten death) are part of current ELDs.

Methods

Secondary analysis

A secondary analysis of qualitative data was conducted. This methodological approach consists in using existing data to find answers to research questions that differ from the ones asked in the original research.³³⁻³⁶

Selection of studies, interviews, and field notes

Transcripts of interviews and observation field notes from three previous studies (four datasets) with professionals working in PC in Portugal^{9,37-40} were selected for this secondary analysis. Although the main topics of research in the primary studies were burnout, advance directives (ADs), and home care interventions, issues concerning end-of-life decision making strongly emerged.^{9,37,38,40} The emphasis on ethical issues and frameworks for end-of-life decision making made these interviews and field notes a rich source for our current analysis. Table 1 shows the details of the primary studies.

Theoretical considerations and methodological rigor

Qualitative secondary analysis involves the reanalysis of preexisting primary data to investigate new questions.^{33-36,41} It maximizes the potential of existing data to their fullest use⁴¹⁻⁴³ and is considered to be ethical by minimizing further intrusion and research fatigue.^{33,41,44,45} This approach is seen as an important, valid, and expanding area of investigation.⁴⁶

Secondary analysis of qualitative data is feasible whenever the contextual information most relevant for the interpretation of the text is provided.^{33,47-49} In our study, this was completely reasonable and it was possible to complete a "supra analysis," which "transcends the focus of the primary study from which the data were derived, examining new empirical, theoretical, or methodological questions."^{33,48} Measures were taken to ensure the methodological and ethical rigor of the secondary analysis (Table 2).^{41,45,47-53} The Standards for Reporting Qualitative Research were followed as far as these apply to secondary analysis.⁵⁴

Ethics procedures

Ethical and informed written consents were available from the primary studies and were aligned with the objectives and scope of the secondary analysis.^{33,44,47-53} Approval for the secondary analysis was obtained from the Ethics Laboratory of the Instituto de Bioética [Ref.04.2015]. Transcripts and data were carefully coded to ensure the anonymity, privacy, and confidentiality of the participant professionals/teams, thus protecting them of any potential harm or further intrusion.^{55,56} Tables 1 and 2 provide detailed information on the ethical procedures.

Analysis

Forty-four transcripts of interviews and nine field notes were analyzed. An analysis-grid based on the Guide³² was created considering three dimensions: ethical and legal frames of reference for the decision-making process, decision-making process, and disputed and controversial issues. These dimensions were divided into categories and subcategories corresponding to the topics developed in the Guide³² (Appendix 1).

TABLE 1. DETAILS OF THE PRIMARY STUDIES

Country	Primary study title	Objectives	Participants	Methods	Participant and/or institutional consent	Funding
Portugal	Burnout em cuidados paliativos: uma perspectiva bioética [Burnout in palliative care: A bioethical perspective] (PhD thesis in Bioethics) ^{37,38}	To identify burnout levels among physicians and nurses working in Portuguese palliative care teams; To identify risk and protective factors of burnout among these professionals; To understand how these professionals prevent burnout; To understand the emotional impact of working in palliative care settings; To understand how burnout syndrome relates to making ethical decisions at the end of life.	Specialized palliative care teams (<i>n</i> =9) Professionals (physicians and nurses) working in specialized palliative care teams (<i>n</i> =92 for survey completion; <i>n</i> =20 for interviews).	Nationwide study. Mixed methods, including: Questionnaire with sociodemographic and professional variables Questionnaire of work-related experiences in the week and day before survey completion Maslach Burnout Inventory—Healthcare Services. Interviews (semistructured). Observation guide and field notes.	Written consent from all institutions and palliative care teams. Written consent from all participants who filled-in the survey and who were interviewed. Verbal consent for observations.	Fundação Grinenthal and Fundação Merck, Sharp and Dohme
Portugal	Advance directives: Portuguese palliative care professionals' views ³⁹	To identify and reflect on Portuguese palliative care professionals' perspectives of advanced directives and their relevance to end-of-life decision making.	Professionals (physicians, nurses, psychologists, and social care workers) working in specialized palliative care teams (<i>n</i> =14)	Interviews (semistructured)	Written consent from all participants who were interviewed.	No funding to declare
Portugal	Primary Home Care for Palliative and Terminal Patients near Lisboa: Nursing Practice and Hospital Palliative Care Team Support ⁴⁰	To identify the interventions conducted by nurses from primary care when caring for palliative and terminal patients at home. To identify the barriers in relation to primary care nursing practice in end-of-life care. To analyze the support given by hospital palliative care teams to those nurses who care for palliative and terminal patients at home.	Nurses providing home palliative care in primary care settings (<i>n</i> =10)	Interviews (semistructured)	Institutional approval from the Primary Care Center. Written consent from all participants who were interviewed.	No funding to declare

In the original study,³⁷ 9 palliative care teams were observed and 20 professionals (11 nurses and 9 physicians) were interviewed; publications based on the same study either included the interviews conducted both to physicians and nurses in a total of 20⁴ or included only the interviews conducted with nurses (11).³⁸

TABLE 2. RECOMMENDATIONS FOR THE REPORTING OF SECONDARY ANALYSES OF QUALITATIVE DATA AND MEASURES TAKEN

<i>Recommendation to ensure rigor in secondary analysis of qualitative data</i>	<i>Measure taken</i>
Information about the discursive context of interviewee's responses and observations. Information about the discursive history of interviewee's responses and observations. Information about background characteristics of interviewer, interviewees, and observed teams.	Detailed transcriptions of interviews and field notes, transcribed verbatim, fully available. Interviews and field notes fully available. The interviewer and observer of the primary studies (SMP) is one of the researchers involved in the secondary analysis. EF interviewed participants in the third study. SMP was familiar with the complete four datasets. Field-note summaries included information about the interviewees' gender, age, profession, years of professional experience, and years of professional experience in palliative care. These were available for all three studies and summarized to all the researchers involved in this study. Field notes resulting from observations included an observation grid with organizational aspects of each participant team. These characteristics are presented in Table 3.
Information about the place, time, and setting of interviews and observations. Information about the composition of the secondary dataset. Funding of the primary and secondary work.	Information included in the field-note summaries. These were made available to all the researchers of this study. Framework of the primary studies described in Table 1. Funding sources of the primary studies included in Table 1. The authors received no financial support for this qualitative secondary data analysis.
The relationship of each of the authors to the data.	One researcher from the original studies (SMP) was involved in the secondary analysis. SMP provided detailed information on contextual queries and was involved in the recoding of the data. This was conducted by SMP and PHM and validated by EF to ensure the reliability of the established codes.
Information about informed consent.	Ethics and informed consent available from the primary studies, as described in Table 1. As the secondary analysis focuses and goes further in the analysis of one of the objectives and dimensions that emerged in the primary studies (i.e., ethical decision making and its relation to burnout, advance directives, home palliative and end of life care in primary care settings), data were aligned with the aims of the consents obtained from the participants and teams in the primary studies. Furthermore, one of the researchers involved in the primary studies (SMP) thoroughly anonymized the data before performing the secondary analysis.
Rationale for approach used in secondary analysis and description of the analysis procedure.	Rationale and description provided in the methods section.
Information about how the data were managed.	Data were managed using QSR-NVivo 9 qualitative data analysis software in both the primary studies and the secondary analysis.
Information about how the rigor of the secondary analysis was established.	Details provided in this table.
Information about how the "fit" of the data was ascertained.	At least one of the researchers from the original study confirmed the fit of the resulting themes.
Details of limitations.	Limitations are outlined in the limitations section.

Adapted from Evans et al.⁵⁰

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A thematic analysis^{33,42,44,48,49} was used, considering the definitions of the ethical principles and recommendations for the decision-making processes described in the Guide.³² First, a deductive analysis based on these dimensions, categories, and subcategories was performed, validating each time they emerged in the text. Second, an inductive approach was conducted, allowing the identification of categories beyond those expressed in the Guide.³²

Results

Characteristics of the participants

The interviewees were aged between 26 and 56 years, the majority was female, nonmarried, had >10 years of professional experience, and worked in a PC team for <5 years. The teams were heterogeneous, geographically dispersed, and had regular interdisciplinary meetings (Table 3).

TABLE 3. CHARACTERISTICS OF THE INTERVIEWEES AND TEAMS

<i>Characteristics of the interviewees (n = 44)</i>	<i>No. of professionals</i>
Age, years	
21–30	11
31–40	24
41–50	6
51>	3
Gender	
Male	12
Female	32
Marital Status	
Married	14
Nonmarried	30
Profession	
Physicians	9
Nurses	32
Social Care Worker	1
Psychologist	2
Years of professional experience	
<5	7
6–10	15
11–15	14
16>	8
Years of experience working in palliative care	
<5	21
6–10	12
11–15	7
16>	4
<i>Characteristics of the observed teams (n = 9)</i>	<i>No. of teams</i>
Typology	
Inpatient unit	5
Hospital support team	1
Home care team	3
Location	
North	1
Centrum	2
South	6
Professional groups within the team	
Physicians	9
Nurses	9
Psychologist (full time)	2
Psychologist (part-time)	6
Social Care Worker (full time)	1
Social Care Worker (part-time)	3
Other, by request (including Psychologists, Social Care Worker)	9
Interprofessional, interdisciplinary team meetings	
Daily meetings, for regular discussion and care planning	2
Weekly/biweekly meetings, for the evaluation and discussion of more complex cases	8
Monthly/biannual meetings, for the implementation of activities for teambuilding, teamwork, and burnout prevention	4
Regular, but not systematized, depending on the patients' and/or team needs	5

Ethical and legal frames of reference for the decision-making process

Our analysis provided insights on the ethical principles most valued by the professionals/teams when making ELDs. All three principles mentioned as ethical reference for the decision-making process in the Guide³² emerged clearly.

Autonomy, which begins with the recognition that the person has the legitimate right and the capacity to make personal choices,^{32,57–59} was the most valued ethical principle raised by the interviewees and teams. Thirty-three out of the 44 interviewees referred to autonomy, its relevance and implications, namely in terms of anticipating situations and decisions for the future. Seven out of nine field notes mentioned the importance given by the observed teams to autonomy.

Justice as equitable access to healthcare^{32,57,58,60,61} was the second ethical principle arising in our analysis. This principle was mentioned in 28 interviews and in 7 field notes. Justice was mostly mentioned by professionals working in inpatient units, for whom the right to guarantee equitable access to PC was a major concern. Justice as a process of care includes support for family carers.³² It also emerged quite expressively in our analysis.

Finally, the ethical principle of beneficence/nonmaleficence, defined as the dual obligation healthcare professionals have to seek to maximize the benefit and to prevent as much as possible any potential harm,^{32,57,58} was also valued by the participant professionals/teams. This principle emerged in five field notes and was mentioned by seven professionals during their interviews, referring mostly to situations identified as disproportionate and for which a treatment needed to be limited.

The inductive analysis of the existing qualitative data allowed us to identify three other ethical principles, beyond those mentioned in the Guide,³² namely: (1) The principle of responsibility, which refers to the competence, conscientiousness, and prudence healthcare professionals should embrace in their daily practice, being accountable for their actions.^{62,63} Responsibility was considered by six interviewees as a relevant feature to pursue when making ELDs. (2) The principle of integrity that was mentioned by three professionals and in three field notes, enhancing the holistic perspective of palliative and end-of-life care, the coherence of life, which is remembered from experiences and can be told in a narrative.⁶⁴ (3) The principle of dignity, recognized as an intrinsic quality of personhood.⁶⁵ Dignity was valued in five interviews and in two field notes as the core ethical principle and inherent human attribute to be promoted in PC.

Decision-making process

Our analysis showed that the following parties were commonly involved in the decision-making process: patient, family members, care team, and other stakeholders (e.g., clinical ethics committees). Family members were the most mentioned parties. The inclusion of the patient and family members together in the decision-making process was mentioned in 24 interviews and 7 field notes.

Decision-making processes were characterized by collective and interprofessional approaches. This was noticeable in 22 interviews and 6 field notes.

Disputed and controversial issues

The analysis also highlighted disputed/controversial issues, namely: palliative sedation, different types of forgoing treatment decisions, and the patient's wish of hastening death.

TABLE 4. RESULTS FROM THE SECONDARY DATA ANALYSIS, BASED ON THE “GUIDE ON THE DECISION-MAKING PROCESS REGARDING MEDICAL TREATMENT IN END-OF-LIFE SITUATIONS”³²

<i>Dimension of the “Guide”</i>	<i>Categories</i>	<i>No. of professionals (n=44)</i>	<i>No. of teams^a (n=9)</i>	<i>No. of quotes</i>
(1) Ethical and legal frames of reference for the decision-making process	Principle of autonomy ^a	33	7	84
	Principle of beneficence and nonmaleficence ^a	7	5	18
	Principle of justice—equitable access to healthcare ^a	28	7	64
	Principle of responsibility ^b	6	1	11
	Principle of integrity ^b	3	3	7
	Principle of dignity ^b	5	2	7
	Challenges and difficulties related to cognitive impairment (e.g., dementia) and the ethical principle of autonomy ^b	1	0	3
(2) Decision-making process	Parties involved (including patient, family members, care team, other—clinical ethics committee) ^a	24	7	58
	Deliberative process and decision making (including collective dimension—phases—collective discussion, evaluation of the decision-making process) ^a	22	6	48
(3) Disputed and controversial issues	Palliative sedation ^a	4	3	9
	Limiting, withdrawing, withholding artificial hydration/nutrition ^a	3	1	5
	Limiting, withdrawing, withholding mechanic ventilation ^b	5	0	7
	Patient’s wish of hastening death ^b	5	1	8

^aDeductive analysis, included in the Guide.

^bInductive analysis, not included in the Guide.

Further details of our analysis can be found in Table 4. Quotations from interviews and field notes illustrating our findings are presented in Table 5.

Discussion

The ethical principle most valued by PC teams in Portugal is autonomy, followed by justice in relation to the accessibility to PC. Another relevant finding was that these teams include the family in the process of care, meeting the ethical principle of justice in a broader sense. The decision-making process was characterized by a collective approach, appearing to be consistent with the Guide.³²

The primacy of autonomy and the relevance of justice in PC

According to our findings, autonomy is paramount in the decision-making process followed by Portuguese PC teams. This principle was present in a large majority of interviews and field notes. This is not surprising, as autonomy is considered to be of foremost relevance in PC.^{9,66–70}

Furthermore, there is a major concern in assessing patients’ preferences, anticipating situations, and planning care in advance. This can be considered a quality indicator in end-of-life care.^{20–26,67,68}

According to the recommendations of the Guide, the decision-making process concerning care and treatment at the end of life should acknowledge the ethical principle of autonomy.³² Respect for autonomy encompasses the recognition of the right and capacity of making personal choices,

requiring the exercise of free and informed consent.^{32,57–59} Shared decision-making processes are the recommended model of communication between healthcare professionals and patients, especially when pertaining to preference-sensitive clinical decisions, as those concerning ELDs for terminally ill patients.^{68,71} The Guide³² also highlights the relevance of advance care planning, which implies an understanding of patients’ previous wishes and preferences in light of and balance with their current condition and capacity to exercise autonomy.

The use of ADs under the form of written living wills also emerged in our analysis. Although at the time of the interviews, ADs were still neither legally binding nor fully established in Portugal, PC teams integrated them, when available (e.g., when caring for U.S. citizens living in Portugal), in the decision-making process at the end of life. AD was perceived as a relevant guidance for decision making at the end of life.^{39,72}

The ethical principle of justice, one of the major principles in the Guide,³² was also emphasized in the interviews and field notes included in our analysis. The access to specialist PC provision at the end of life was one of the main concerns expressed by professionals. As mentioned elsewhere,^{73,74} although Portugal is considered to have a generalized provision of PC, access is still characterized by a set of inequalities (e.g., geographic, financial, diagnostic treatment, and age related).⁷⁴ It is therefore not surprising that professionals working in PC units highlighted these issues as they did not feel capable to respond to all patients’ needs. To meet the challenges posed by end-of-life situations, it is a priority

TABLE 5. QUOTATIONS (ONE PER CATEGORY) FROM THE SECONDARY DATA ANALYSIS ON END-OF-LIFE DECISION MAKING IN PALLIATIVE CARE AND THE “GUIDE ON THE DECISION-MAKING PROCESS REGARDING MEDICAL TREATMENT IN END-OF-LIFE SITUATIONS”³²

<i>Dimension of the “Guide”</i>	<i>Categories</i>	<i>Examples of quotations emerging from the secondary analysis</i>
(1) Ethical and legal frames of reference for the decision-making process	Principle of autonomy ^a	“(…) we did whatever this patient wanted and allowed us to do. (…) sometimes I felt that we could have done more, providing some additional treatment or procedure; we could not and we did not do it as the patient did not want it and we respected his wish” (Interview 1, Nurse, Home Care Team).
	Principle of beneficence and nonmaleficence ^a	“(…) considering the condition of the patient and the disproportion of the treatment, we had to decide upon withdrawing the treatment (…).” (Interview 11, Physician, Inpatient Unit).
	Principle of justice—equitable access to healthcare ^a	“This unit has several organizational constraints. (…) a physician said: It breaks my heart and frustrates me a lot not being able to admit this patient in our unit, but we don’t have any bed available (…) there is no other specialized palliative care team in this region” (Field-notes 3, Inpatient Unit).
	Principle of responsibility ^b	“(…) working in this field has increased my sense of responsibility, obliging me to further study... so that I can feel more secure when facing the need of making an end-of-life decision... so that I can be able to make better and more correct decisions...” (Interview 2, Physician, Hospital Support Team).
	Principle of integrity ^b	“(…) deciding at the end-of-life is a type of work that requires a global holistic assessment of the person, considering all his/her dimensions (…) this is one of the ideological foundations of palliative care (…) a concrete expression of the patient-person in all his/her integrity. We can only understand, treat, and care for that person and make good decisions at the end of life if we approach that person throughout all his/her dimensions... in all his/her integrity” (Interview 5, Physician, Inpatient Unit).
(2) Decision-making process	Principle of dignity ^b	“Above anything, we (…) promote their dignity to the fullest and to the very end (…).” (Interview 26, Social Care Worker, Hospital Support Team)
	Challenges and difficulties related to cognitive impairment (e.g., dementia) and of autonomy ^b	“In patients with dementia, for instance, it is quite challenging to meet their preferences... many of them do not have a living will and we depend on other people to assess what they would have preferred in that situation... tricky... difficult...” (Interview 25, Physician, Hospital Support Team)
(3) Disputed and controversial issues	Parties involved ^a	“(…) all the decisions we need to make, we make them together with them [family] (..) it is always a shared decision” (Interview 13, Nurse, Inpatient Unit).
	Deliberative process and decision making ^a	“(…) all professionals expressed their perspective and shared their assessment and view about the situation, participating in the discussion and decision making” (Field-notes 4, Inpatient Unit).
	Palliative sedation ^a	“Those decisions are commonly related to... palliative sedation, for example...” (Interview 18)
	Limiting, withdrawing, withholding artificial hydration/nutrition ^a	“(…) the team discussed ethical issues (..) one case of artificial nutrition” (Field-notes 3, Inpatient Unit).
	Limiting, withdrawing, withholding mechanic ventilation ^b	“The question of withholding or implementing mechanic ventilation to a patient always raises lots of doubts, questioning...” (Interview 26, Social Care Worker, Hospital Support Team)
	Patient’s wish of hastening death ^b	“The team discussed a very complex situation... a patient said that he wanted to die and asked if they could give him something for that...” (Field-notes 3)

^aDeductive analysis, included in the Guide.

^bInductive analysis, not included in the Guide.

to broaden access to PC regardless of how it is organized.³² This recommendation is of foremost relevance in Portugal.

One important finding in our study was the relevance given to the care for family members. This is consistent with the Guide, in which providing support for family members ensures the fulfillment of the ethical principle of justice by guaranteeing the access to healthcare to all those who are affected by a life-threatening disease.³²

The decision-making process: a collective approach

In this study, the decision-making process concerning ELDs involved healthcare professionals, patients, and family members. An inclusive approach was used and all potential stakeholders participated in the decision-making process. Including the patient in the decision-making process and assuming a deliberative model of relationship between healthcare professionals and patients seem most appropriate.^{75–77} Moreover, this approach is considered as a quality indicator in PC,^{20–22} showing consideration and respect for patients' autonomy.

Family involvement is also relevant,^{32,78–84} as it allows a better understanding of patients' wishes, especially in those cases where a lack of capacity and ability to make decisions may prevent patients to express their preferences. Considering the Portuguese cultural context and the relevance given to family care provider's role, the consultation and involvement of family members in the decision-making process is particularly relevant in view of their emotional ties and intimacy with the patient.³² The request of the patient and/or family for care or treatment at the end of life can be considered a culturally determined factor, being one that most differs among countries.^{85–87} At this level, decisional capacity, probably because of its interaction request, seems to be a determinant.^{19,85}

Another important finding was that decision-making processes embraced a collective approach. Ethical deliberation at the end of life was interdisciplinary, allowing the participant teams to search for a consensus and shared decision. This is aligned with the Guide, according to which this collective approach aims at reaching a consensus once all involved parties have put forward their own perspective and arguments.³²

It is relevant to mention that our analysis included transcripts of interviews conducted with nurses and physicians. Nurses, however, are not explicitly mentioned in the Guide.³² Despite the close relationship commonly established between nurses and patients at the end of life, evidence from several countries worldwide (e.g., Belgium, Netherlands, Portugal, South Africa, Brazil, and Australia) shows a large variation in the involvement of these professionals in the decision-making process concerning ELDs.^{9,14,88–92} These variations occur not only due to cultural differences but also because of the specificities of the legal and regulatory frameworks of nursing practices in these countries. There is indeed a large diversity in the recognition, roles, competencies, educational background, and professional regulation of nursing across Europe. In Portugal, for instance, PC is included as part of mandatory undergraduate nursing curricula, including a significant component on ethical issues.⁹³

Disputed and controversial issues

Palliative sedation was the most relevant disputed issue for PC teams in Portugal. The debates around this topic result

mostly from (1) the use of sedation not to relieve physical refractory symptoms but to alleviate psychological and existential suffering and (2) the risk of life-shortening effect.⁹⁴ Sedation is considered to be a relevant and necessary therapy in the case of selected PC patients who have refractory distress, requiring caution and prudent practice.⁹⁴ As we noticed, professionals working in Portuguese PC units highlighted the complexity of making this type of decision. The use of available guidelines, for example, those provided by the European Association for Palliative Care⁹⁴ can be particularly useful.⁹ Nevertheless, a recent study highlighted the need for development and implementation of guidelines on palliative sedation.⁹⁵ This implies further discussion to reach consensus that can inform practice.

Interestingly, the concern “how to respond to a patient who expresses the wish of hastening death?” was only mentioned in five interviews and in one field note. A recent study emphasized that a patient's desire to hasten death may mean that this patient is asking the caregivers to listen to and respect his/her wish, although he/she may not expect the caregivers to understand this as an order to actually hasten death.⁹⁶ This constitutes an ethical challenge for excelling care and highlights the need for conceptual clarification and discussion, keeping clinical, societal, and ethical debates open.

Strengths, limitations, and further research

This study begins to address the paucity of research on cross-country and culturally sensitive guidelines on end-of-life decision making as those provided by the CoE.³² Nevertheless, a remark needs to be done about the nature of this study. Secondary analysis of qualitative data is embedded in several risks, which not only constitute its scenery but also can be considered as a limitation. Measures were taken to overcome this and to ensure validity and reliability (Table 2). Moreover, by exploiting the potential of a rich source of qualitative data and information, this study embraces an ethical dimension and diminishes the risk and burden of research fatigue. Finally, as the original studies were solely conducted with professionals/teams, our study only considers their perspective and the observed practices. It does not provide information on the patients, families, and other stakeholders' perspectives. Further research, including other settings and primary data collection, is therefore needed.

Conclusions

The ethical deliberation and decision-making process followed by Portuguese PC teams seem to be consistent with the “Guide on the decision-making process regarding medical treatment in end-of-life situations.”³² Professionals working in these teams emphasize the foremost relevance of autonomy when facing the need of making ELDs. Relevance is given to the ethical principle of justice in terms of accessibility to PC and inclusion of the family in the process of care. Other ethical principles (responsibility, integrity, and dignity) were also valued. The inclusive and collective approach used during the decision-making process, aiming at reaching a consensus, was highlighted. Palliative sedation was the most mentioned disputed/controversial issue.

Although this guide is not legally binding and is broad enough to be applicable across all the culturally diverse

European countries, it stimulates the debate about disputed and controversial issues. Since it has been developed by one of the most relevant regulatory structures in Europe, it should be considered as a gold-standard guide for end-of-life decision making in this region. Research is needed on cross-country operationalization of the analysis grid created in this study and on the actual implementation and impact of the Guide in clinical practice, education, and research.

Acknowledgments

Fundação Grünenthal and Fundação Merck, Sharp and Dohme (2007/2011 and 2016/2018). Project DELiCaSP: Decisions in end-of-life care in Spain and Portugal. Project DELiCaSP aims to provide a culturally sensitive and rational framework on end-of-life decisions (ELDs). The objectives are to (1) describe and compare ELDs, (2) understand the decision making of ELDs and analyze if this process is aligned with the “Guide on the decision-making process regarding medical treatment in end-of-life situations” launched by the Council of Europe in 2014, and (3) implement the use of this guide in specific care settings investigating its contribution to the decision-making process. Project InPalIn: Integrating Palliative and Intensive Care. Research members of project InPalIn: Sandra Martins Pereira, Pablo Hernández-Marrero, Carla M. Teixeira, and Ana Sofia Carvalho. Project InPalIn is funded by Fundação Grünenthal and Fundação Merck, Sharp and Dohme. Subproject ETHICS II of Project ENSURE: Enhancing the Informed Consent Process: Supported Decision-Making and Capacity Assessment in Clinical Dementia Research. This subproject is cofunded by ERA-NET NEURON II, ELSA 2015, European Commission, and Fundação para a Ciência e a Tecnologia (FCT), Ministério da Ciência, Tecnologia e Ensino Superior, Portugal.

Author Disclosure Statement

No competing financial interests exist.

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(Appendix follows →)

APPENDIX 1. ANALYSIS GRID ON END-OF-LIFE DECISION MAKING

<i>Dimension of the “Guide”</i>	<i>Categories (deductive analysis based on the “Guide”)</i>	<i>Subcategories (deductive analysis based on the “Guide”)</i>	<i>No. of professionals^a</i>	<i>No. of teams^b</i>	<i>No. of quotations</i>	<i>Examples of quotations</i>
(1) Ethical and legal frames of reference for the decision-making process	Principle of autonomy	Free and informed consent Prior information Anticipate possible future decisions Advance directives/living will				
	Principle of beneficence and nonmaleficence	Balance between benefits and harms & obligation of not dispensing disproportionate treatment Disproportionate treatment to be limited—identification of situations assessed by PC professionals as being disproportionate				
	Principle of justice—equitable access to healthcare	Available resources distributed as fair as possible and right to guarantee equitable access to PC Equity—absence of discrimination Support for family carers Broaden PC—foster PC approach among healthcare professionals—need for				
(2) Decision-making process	Parties involved	Patient Family members Care team Other—clinical ethics committee				
	Deliberative process and decision making	Collective dimension/phases—collective discussion Phases—evaluation of the decision-making process				
(3) Disputed and controversial issues	Palliative sedation	—				
	Limiting, withdrawing, withholding artificial hydration/nutrition	—				
<i>Dimension of the “Guide”</i>	<i>Categories (inductive analysis not including in the “Guide”)</i>	<i>Subcategories (inductive analysis not including in the “Guide”)</i>	<i>No. of professionals^a</i>	<i>No. of teams^b</i>	<i>No. of quotations</i>	<i>Examples of quotations</i>
(1) Ethical and legal frames of reference for the decision-making process						
(2) Decision-making process						
(3) Disputed and controversial issues						

This analysis grid was created for this study based on the “Guide on the decision-making process regarding medical treatment in end-of-life situations” developed by the Council of Europe³² and it can be used both for primary and for secondary data analysis.

^aIndividual-level analysis.

^bTeam-level analysis; No. of teams in which this dimension was observed; this column is based on observations only.
PC, palliative care.