SUMMARY OF LECTURE

Ethical decisions and decision-making in palliative and end-of-life care: Nursing involvement and implications for the future

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Num. de Identificação: 10533169
Data: 2024.08.16 17:16:31 +0100

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Detailed Summary of the Lecture about a topic within the scientific area or specialty of Health Sciences, Technologies and Well-Being: Nursing submitted to Universidade de Évora for the awarding of the Academic Title of Aggregated, as established by the Portuguese Decree-Law n.º 239/2007 of June 19th, line c) of Article 5th, updated by the Portuguese Decree-Law n.º 64/2023 of July 31st, and by the Universidade de Évora Circular Letter 2/2009 of March 13th.

Sumário pormenorizado da Lição sobre um tema dentro do âmbito do ramo do conhecimento ou especialidade de Ciências e Tecnologias da Saúde e Bem-Estar: Enfermagem submetido à Universidade de Évora para a atribuição do Título Académico de Agregado, conforme establecido pelo Decreto-Lei n.º 239/2007 de 19 de junho, alína c) do Artigo 5.º, atualizado pelo Decreto-Lei n.º 64/2023 de 31 de julho, e pela Circular n.º 2/2009 da Universidade de Évora.

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Sumário Executivo

Este documento constitui-se como o sumário pormenorizado da Lição sobre um tema dentro do âmbito do ramo do conhecimento ou especialidade de Ciências e Tecnologias da Saúde e Bem-Estar: Enfermagem submetido à Universidade de Évora para a atribuição do Título Académico de Agregado, conforme estabelecido pelo Decreto-Lei n.º 239/2007 de 19 de junho, alínea c) do Artigo 5.º, atualizado pelo Decreto-Lei n.º 64/2023 de 31 de julho, e pela Circular n.º 2/2009 da Universidade de Évora.

O tema escolhido é o seguinte: *Decisões éticas e processos de deliberação e tomada de decisão em cuidados paliativos e em fim de vida: Envolvimento dos enfermeiros e implicações para o futuro.*

Este sumário pormenorizado da Lição encontra-se redigido em língua inglesa, conforme previsto no Artigo 18.º do Decreto-Lei n.º 239/2007 de 7 de Junho.

Executive Summary

This document refers to the Detailed Summary of the Lecture about a topic within the scientific area or specialty of Health Sciences, Technologies and Well-Being: Nursing submitted to Universidade de Évora for the awarding of the Academic Title of Aggregated, as established by the Portuguese Decree-Law n.º 239/2007 of June 19th, line c) of Article 5th, updated by the Portuguese Decree-Law n.º 64/2023 of July 31st, and by the Universidade de Évora Circular Letter 2/2009 of March 13th.

The topic chosen for the Lecture is: *Ethical decisions and decision-making in palliative and end-of-life care: Nursing involvement and implications for the future*.

This detailed summary is written in English language, as foreseen in Article 18th of the 'Decreto-Lei n.º 239/2007 de 7 de Junho'.

1. Introduction

This Summary of the Lecture consists in a detailed description of the Lecture entitled *"Ethical decisions and decision-making in palliative and end-of-life care: Nursing involvement and implications for the future"* that I will present to Universidade de Évora for the awarding of the Academic Title of Aggregated, as established by the Portuguese Decree-Law n.º 239/2007 of June 19th, line c) of Article 5th, updated by the Portuguese Decree-Law n.º 64/2023 of July 31st, and by the Universidade de Évora Circular Letter 2/2009 of March 13th. The topic of the lecture fits within the scientific area or specialty of Health Sciences, Technologies and Well-Being: Nursing.

Ethical decisions and inherent decision-making processes are part of contemporary healthcare practices, particularly in palliative and end-of-life care. An ethical decision can be defined as the commitment to a course of action after evaluating and choosing among alternatives in a manner consistent with ethical principles and in a way intended to serve the interests and values of particular people. In palliative and end-of-life care, careful attention needs to be given to patients' quality of life and wellbeing. It is paramount to find the proper balance in terms of treatment and care provided to these patients to ensure that this is aligned with the patient's values, preferences and wishes, and promotes the patient's quality of life.

According to the World Health Organization,[1-4] palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening and/or life-limiting illnesses. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.[1-3] Palliative care is nowadays a crucial part of integrated, people-centered health services provision. Relieving serious health-related suffering is recognized as a global ethical responsibility.[4] Each year, an estimated 56.8 million people, including 25.7 million in the last year of life, are in need of palliative care.[1] Nevertheless, worldwide, only about 14% of people who need palliative care currently receive it.[1,3,4] In Portugal, a recent report from the Portuguese Health Regulatory Body highlighted that the number of beds in specialized palliative care inpatient units in Portugal was significantly lower than the numbers recommended by international associations, such as the European Association for Palliative care (i.e., 80 to 100 beds per 1.000.000 citizens).[5]

In 2018, the Lancet Commission on Palliative Care and Pain Relief Study Group,[6] hereinafter "the Commission", recommended the WHO definition of palliative care to be reviewed and revised to encompass health-system advances. The Commission recommended a definition that explicitly rejects any time or prognostic limitation on access to palliative care, includes complex chronic or acute, life-threatening, or life-limiting health conditions, and considers all levels of the healthcare system from primary to specialized care and all settings where palliative care can be delivered.[7] Consequently, the Commission treated palliative care as an essential component of comprehensive care for persons with complex chronic or acute, life-threatening, or life-limiting health conditions.[6] Palliative care should be practiced by all health and social care providers and provided by palliative care specialists, in any healthcare setting, including patients' own homes.[8]

Serious life-threatening and life-limiting illnesses impact quality of life, present an immense societal challenge, and place an enormous economic burden on society and health systems. Worldwide projections of serious health-related suffering requiring palliative care send alarming messages for global health. Knaul et al.[6] estimated that more than 25.5 million of the 56.2 million people who died in 2015, experienced serious health-related suffering. Moreover, it is estimated that 48 million people will die experiencing serious health-related suffering by 2060, compared with 26 million people in 2016. This dramatic increase means that the absolute number of world citizens in need of palliative care will almost double over the next four decades, with the fastest increases occurring in low-income countries, among older people, and people with dementia. Immediate global action to integrate palliative care into health systems is an ethical and economic imperative[9] and a global health challenge.

National and international investment in needed palliative care research is also neglected in comparison to other areas of medicine. According to the Lancet Oncology Commission,[10] only one in six respondents in a European survey expected their institutions to increase funding for palliative care service provision, and less than 1% of cancer research funding goes to palliative or end-of-life care studies in the UK, with most other countries being little or no better. Although international organizations launch research initiatives for palliative care, the funds devoted to it represent only a minimum proportion of the budget. It is also notable that palliative care, hospice, pain, symptoms, decision-making, advance care planning, end-of-life are all absent from common descriptors and keywords in funders search engines. What is left unsaid is what happens when the disease cannot be cured, or is only partially treated or managed, or the treatment itself results in temporary or permanent distress and disability. A European study found that one of the main barriers in palliative and end-of-life care were related to capacity and funding, environment and culture and knowledge transfer and dissemination. These areas are interrelated and should not be addressed in isolation.[11] Furthermore, it is necessary to train a sufficient number of clinician scientists within palliative care research and to give these scientists the possibility of permanent research posts in particular combined clinical and research posts after the research training period. National and international funding needs to continue, and successful collaboratives need to receive predictable, sustainable funding.[12]

Palliative care encompasses end-of-life care. Yet, end-of-life care is only a portion of palliative care that is directed towards the care of persons who are nearing the end of their lives.[13-15] In fact, evidence suggests that the early integration of palliative care in the disease trajectory of life-limiting illnesses can have a positive impact on patients' quality of life, the severity of the symptoms experienced and even prolongation of life.[16-19] More recently, the concept of timely palliative care has been introduced to better highlight the highly personalized and individualized approach that is required for the integration of palliative care, based on patients' needs and delivered at the optimal time and setting.[20,21] Aligned with this concept of timely palliative care, a recent study suggested the introduction of a stepped-care model, with palliative care visits occurring at key points in patients' trajectories, using a decrement in quality of life to trigger more intensive palliative care exposure and interventions.[22]

The timely integration of palliative care and the use of a triggers-based[20,21,23] and stepped-care model[22] do therefore not preclude its introduction at the end-of-life. In fact, identifying additional triggers to intensify palliative care near death is a potential next step to further optimize a stepped-care model[22] and ensure that patients who are at the end-of-life have access to palliative care. Among all the vulnerable patients in need of palliative care, those who are facing end-of-life are indeed the most fragile and vulnerable ones, and the ones whose voices are less heard. It is therefore paramount to ensure that health systems do not leave these patients at the end-of-life in the fringes without proper care.[24]

Palliative care is rooted in core ethical principles and values, such as autonomy, dignity, beneficence, non-maleficence, integrity, vulnerability, solidarity, solicitude and justice. It respects patients' choices, acts to promote and meet patients' wishes and preferences, and helps their families to deal with practical issues, including coping with loss and grief throughout the disease trajectory and in case of bereavement. Ethical challenges may occur, and ethico-clinical decisions need to be made throughout the disease trajectory, particularly at the end-of-life.

Ethical decisions in palliative and end-of-life care happen as a result of the fact that the purpose of treatment and care in these situations is, above all, to improve the patient's quality of life.[25] This may lead to the need to implement or increase certain treatments and to withhold or withdraw others that no longer provide any benefit or have become disproportionate.[26] Doubts on "what to do?" may occur sidelong with conflicts within the interprofessional health care team and between these professionals and the patients' family members, mostly because of different perspectives about the patient's best interest.[25]

Particularly at the end-of-life, care provided to patients and their families includes physical, psychological, emotional, social, and spiritual support for patients and their families. The goal of end-of-life care is to control pain and other symptoms so the patient can be as comfortable as possible.[27] This may lead to ethical challenges. According to the Council of Europe in their Guide on the decision-making process regarding medical treatment in end-of-life situations,[26] end-of-life situations are understood as those in which a severe deterioration in health, due to the evolution of a disease or another cause, threatens the life of a person irreversibly in the near future. In this context, ethical decisions at the end-of-life, also labelled as end-of-life decisions, refer to medical decisions and practices that may have a potential or certain life-shortening effect, implying a tension between providing life-prolonging treatment and promoting quality of life.[29-32]

The terms end-of-life, terminally ill, and terminal care are considered as synonymous and frequently used interchangeably. These concepts apply to patients with progressive disease with months or less of expected survival.[28] Actively dying is related to patients with days of survival. In these situations, transitions of care may occur, posing sometimes additional ethical challenges. "Transitions of care" are related to changes in the place of care, level of care, goals of care,[28] and sometimes even the care team responsible for care provision. Ethico-clinical decisions at the end-of-life might be difficult, challenging,[25,29,30,33,34] and surrounded by uncertainty, risk and asymmetry of information.[35,36]

This detailed summary of my lecture entitled *Ethical decisions and decision-making in palliative and end-of-life care: Nursing involvement and implications for the future* is organized in nine sections. First, in the introduction, I provide a brief overview on the main definitions and concepts related to the topic of this lecture, namely, ethical decisions, palliative and end-of-life care. This is followed by the presentation of the objectives of the session (second section) and the methodology (third section) used in its development. The fourth section provides a detailed description of the main ethico-clinical challenges, decisions, and decision-making processes in palliative and end-of-life care, focusing on some disputed/controversial issues and relating this topic with core ethical principles as vulnerability, autonomy and decision-making capacity. In the fifth section, a list of models and frameworks for ethical deliberation and decision-making in palliative and end-of-life care is provided, highlighting their commonalities and specificities, and discussing whether or not these models actually work in clinical practice. The sixth section focuses on nursing involvement in ethico-clinical decision-making in palliative and end-of-life care. An overview of the evidence is provided on this topic and recommendations are drawn to show what nurses can do to improve ethical decision-making in palliative and end-of-life care. Section seven presents the implications for nursing clinical practice, education, and research in the future. The last two sections, sections eight and nine, provide some concluding remarks and a thorough list of references, respectively.

2. Objectives

The purpose of this detailed summary of the lecture is to provide a comprehensive overview of what will be presented in the public defense for the awarding of the Academic Title of Aggregated, as established by the Portuguese Decree-Law n.º 239/2007 of June 19th, line c) of Article 5th, updated by the Portuguese Decree-Law n.º 64/2023 of July 31st, and by the Universidade de Évora Circular Letter 2/2009 of March 13th.

The objectives of this lecture entitled *Ethical decisions and decision-making in palliative and end-of-life care: Nursing involvement and implications for the future* are the following:

(i) To identify the main ethico-clinical challenges, decisions and disputed issues in the field of palliative and end-of-life care.
(ii) To explore these ethico-clinical challenges, decisions, and disputed issues in light of ethical principles, such as vulnerability and autonomy.
(iii) To present some models and frameworks that can be used in clinical practice to enhance ethico-clinical decision-making processes in palliative and end-of-life care.
(iv) To recognize the role of uncertainty, risk, and asymmetry of information when making complex ethico-clinical decisions in palliative and end-of-life care.
(v) To understand nursing involvement in ethical decision-making in palliative and end-of-life care, highlighting what nurses can do to improve shared decision-making
(vi) To draw implications for nursing clinical practice, education and research in the future.

3. Methodology

This lecture results from the integration of multiple methodological approaches. First, this lecture is based on lectures, scientific presentations, classes and courses that I have taught, over time, about ethical decisions and decision-making in palliative and end-of-life care, with a particular focus on nursing involvement and implications for the future. Second, a simultaneously broad and systematic literature review has been conducted, focusing on four core sets of search terms: ethics AND decision-making AND palliative care OR end-of-life care AND nursing. Finally, my own research and publications about the topic are included and introduced throughout the whole lecture, highlighting the contribution of my work to the development of this scientific field.

4. Ethico-Clinical Challenges, Decisions and Decision-Making in Palliative and End-of-Life Care

In this section, the main ethico-clinical challenges, decisions and disputed issues in the field of palliative and end-of-life care will be presented, taking into account their frequency and discussing the ones who are considered as disputed and controversial issues. The ethical principles of vulnerability and autonomy will be explored, focusing on the differences between individual and relational autonomy and on how vulnerability can influence decision-making capacity. The specific condition of cognitive impairment and how it influences ethical decision-making at the end-of-life will also be examined, particularly due to its major impact in terms of vulnerability, autonomy, and shared decision-making.

4.1. Ethico-Clinical Challenges and Decisions in Palliative and End-of-Life Care

The main goals of palliative and end-of-life care is to alleviate suffering, optimize the quality of life until death occurs, and provide comfort and dignity in death.[13-15,28,37] However, achieving these goals is not always easy and decision-making processes are often complex, difficult and challenging.[25,30,38] The complexity of ethical decision-making processes in palliative and end-of-life care needs to be analyzed in context.[38] Multifaceted aspects need to be taken into account, such as changes or transitions in the goals of care, transitions in the context of care, transitions in the healthcare team responsible for care provision, ambiguity, asymmetry of information, uncertainty, risk, cultures, values and beliefs, and trying to reach consensus among various stakeholders (e.g., professionals, patients and families).[13,20,21,23,28,33,35-38]

Making ethico-clinical decisions requires a true commitment to a course of action after evaluating and choosing among alternatives in a manner consistent with ethical principles and in a way that it serves the interests and values of all those involved in the decision-making process. Because physicians, patients, and patients' family members have to make decisions about care and treatment options (e.g., transitions of care, place of care, prolonging the person's life with the support of medical technologies, forgoing treatments, intensifying pain and symptom control), face various ethical challenges in their practice, some of them related to end-of-life care.[25,26,29,31,33,37]

The terminology around ethical decisions and ethical decision-making in palliative and end-of-life care is sometimes confusing. According to a recent review, a common conceptual understanding of the term 'ethical challenge(s)' is lacking within empirical bioethical research.[39] Failure to use definitions of crucial concepts within empirical bioethics research potentially generates confusion and avoidable bias within research outputs, risking misleading ethical analyses, evaluations, and resulting recommendations. Indeed, several expressions, such as 'ethical issue', 'ethical problem', 'ethical dilemma', 'ethical challenge', 'ethical tension', 'moral dilemma', among others, have been used interchangeably.[39]

In an attempt to define the concept of 'ethical challenge', we provide a definition based on interviews conducted with healthcare professionals in Portugal. Based on our research, healthcare professionals providing palliative and end-of-life care define an 'ethical challenge' as the situation of being faced with the need to make an ethical decision that requires greater rational, emotional or procedural effort in order to be done successfully and therefore tests a person's and/or a healthcare team's ability to make a decision.[40] However, while there is a broad range of literature around various ethical challenges and ethico-clinical decisions in palliative care, there is little evidence systematizing and collating the range of ethical challenges that are encountered in palliative care clinical practice.[41,42]

Evidence suggests that healthcare professionals working in specialist palliative care report experiencing the following ethical challenges in their clinical practice: the application of ethical principles; delivering clinical care; working with families; engaging with institutional structures and values; navigating societal values and expectations; and the philosophy of palliative care.[42] This is of relevance and highlights the need to further research and better systematize ethical decisions in palliative and end-of-life care, which is a core focus of our own research. Based on the literature[37,42-58] and on our own empirical bioethics research,[25,30,40,59-63] the main ethical challenges in palliative care can be systematized as follows (Table 1).

Table 1. Main Ethical Challenges in Palliative Care

Main ethical challenges	Ethical principles and values
Human rights issues	Dignity and Value, Equality and Fairness (Equity, Justice), Autonomy, Healthcare, Respect
Attending to the suffering other	Dignity, Respect, Vulnerability, Solicitude, Beneficence, Non-maleficence
Prognostication	Autonomy, Dignity, Respect
Disclosing the diagnosis and/or the prognosis	Autonomy, Dignity, Respect
Truth telling	Autonomy, Dignity, Respect
Keeping promises	Dignity, Respect, Confidentiality, Trust
Access to specialist palliative care	Justice, Autonomy
Advance Care Planning	Autonomy, Dignity, Respect
Advance Directives	Autonomy, Dignity, Respect
Do-not-attempt cardiopulmonary resuscitation	Beneficence, Non-maleficence, Integrity
Treatment escalation	Beneficence, Non-maleficence, Integrity
Treatment refusal	Autonomy, Beneficence, Non-maleficence
Therapeutic obstinacy and medical futility	Non-maleficence, Vulnerability, Paternalism
Forgoing treatment / non-treatment decisions (withholding and/or withdrawing)	Beneficence, Non-maleficence, Integrity, Vulnerability
Integration, transition and continuity of care	Dignity, Beneficence, Non-maleficence, Integrity, Vulnerability, Justice, Privacy, Confidentiality
Place of care and place of death	Autonomy, Beneficence, Non-maleficence, Justice

Palliative sedation for refractory symptoms	Dignity, Beneficence, Non-maleficence, Integrity, Vulnerability
Palliative sedation for emotional and existential distress	Dignity, Beneficence, Non-maleficence, Integrity, Vulnerability
Wish the hasten death / wish to die	Autonomy, Dignity, Vulnerability, Respect, Trust
Euthanasia	Autonomy, Dignity, Vulnerability, Respect, Trust, Responsibility
(Physician) Assisted Suicide	Autonomy, Dignity, Vulnerability, Respect, Trust, Responsibility
Organ donation (after the patient's death)	Autonomy, Dignity, Integrity, Respect, Responsibility
Participation in research	Autonomy, Non-maleficence, Vulnerability, Solidarity
Digital health	Autonomy, Justice, Fairness, Confidentiality, Privacy, Trust
Work related problems (e.g., moral distress, burnout, compassion fatigue, post-traumatic stress disorder)	Professionals' Vulnerability, Responsibility

Decision-making in palliative care is a complex process, and it is particularly challenging to make decisions with, or for, patients who are near the end of their life.[37,52] Evidence suggests that the need to make ethical decisions (e.g., end-of-life decisions, communication about difficult issues such as life-threatening diagnosis and limited prognosis, family conflicts, human suffering and vulnerability) can be a source of considerable stress, emotional constraint and it is often associated with higher burnout levels and moral distress.[25,64-69] However, studies conducted specifically in palliative care show that, although perceived as stressful, emotionally demanding and challenging, ethical decisions were not significantly associated with burnout.[25,59,67-69] This can be explained by the interprofessional decision-making process followed by these teams, which promotes a sense of shared-decision and team-based empowerment.[25,59]

Clinical judgment and effective communication between healthcare professionals, patients and families, and also within healthcare teams, are essential ingredients in the ethics of care.[70] Illness with a long trajectory provides both the opportunity and the obligation for healthcare professionals to have ongoing conversations with patients and their families about their values, preferences, and wishes for present and future healthcare interventions. This ensure that treatment and care is truly aligned with their values, beliefs, and goals.[70] In palliative care, the establishment of a true ethics of care in the relationship established between healthcare professionals, patients and families, and within healthcare teams, is paramount to ensure the implementation of effective ethical decision-making process.[71]

In fact, when facing the need to make ethical decisions in palliative care, healthcare professionals have to establish a balance between patient empowerment, compassion and understanding with solicitude.[72] Compassion and solicitude are key concepts in the ethics of care approach in palliative care. In practical terms, they can be transferred into clinical practice in tangible ways, such as telling the truth while keeping hope alive, respecting as much as possible patient autonomy, and meeting patient's needs, particularly at the end of life.[72-75]

4.1.1. Disputed and Controversial Issues

In the context of palliative and end-of-life care, a disputed issue refers to an important ethical issue or a decision that people argue and disagree about. In their nature, disputed issues are controversial and, by their very nature, divisive.[76,77] Disputed issues arise from deep-rooted differences in ethical values, which makes the resolution of such disagreements extremely difficult.

According to the Guide on the decision-making process regarding medical treatment in end-of-life situations of the Council of Europe,[26] various disputed and controversial issues exist in palliative and end-of-life care. For example, the legal status and binding force of advance directives, the limits and contents of advance directives, the question of limiting, withdrawing or withholding artificial hydration and nutrition, the decision on sedation for psychological or emotional distress in the terminal phase of life, and the use of sedation with the secondary risk of shortening the time left to live are presented as disputed issues that warrant further debate, discussion and careful consideration.[26]

Advance Care Planning and Advance Directives

Advance Care Planning (ACP) is defined as the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate.[78,79] It is a process that guarantees the respect of the patient's values, preferences, and priorities about his/her future care, particularly at the end of life. ACP consists of multiple conversations between the patient, his/her family and the healthcare team. Over the past years, ACP has become particularly relevant due to the growing attention on patients' autonomy and decision-making capacity as it supports patients in aligning their medical care and treatment with personal values and preferences.[80,81] Communication is a key element for ACP. It is crucial to build a relationship, assess readiness, timing and methods to start a conversation about goals of care and preferences for the future, explore information needs, provide attention to family relationships, promote comfort, embrace a professional attitude, and prepare the patient and family beforehand in case the disease progresses into a stage with communication problems or severe cognitive impairment.[82-84]

Despite its relevance, ACP is not without challenges or controversies. In fact, in 2021, a highly controversial and disputed viewpoint addressed the main pitfalls associated to ACP.[85] According to this viewpoint, the success of ACP depends on eight steps: (i) patients can articulate their values and goals and identify which treatments would align with those goals in hypothetical future scenarios; (ii) clinicians can elicit these values and preferences; (iii) preferences are documented; (iv) directives or surrogates are available to guide clinical decisions when patients' preferences have not changed and they lose enough decisional capacity for their ACP views to become operative; (v) surrogates will invoke substituted judgment (make the decision the patient would make if they were able) and base their treatment decisions on the patient's prior stated preferences; (vi) clinicians will read prior documents and integrate patient preferences into conversations with surrogates; (vii) previously expressed wishes will be honored; and (viii) health care systems will commit resources and care delivery to support goal-concordant care.[85] While conceptually relevant, the latter do not reflect the complexity, uncertainty, emotionally laden and fluid reality of treatment and care choices near the end-of-life.[85] This poses relevant challenges to ACP and requires further attention and research to ensure proper communication and shared decision-making when there is an actual need to make an ethico-clinical decision, particularly at the end-of-life.

A major challenge related to ACP is also how to implement it systematically and continuously across sectors and disciplines in a way that supports a proactive yet person-centered approach rather than an approach with an exclusive focus on medical procedures.[86] Timely initiation of ACP is also challenging,[80,85] especially in patients with non-malignant conditions, such as organ failure, multimorbidity, neurodegenerative conditions, and dementia.[80,87-89] Moreover, existing ACP definitional frameworks apply to individuals with decision-making capacity, defying its application for persons with dementia or cognitive impairment. A definition of ACP in dementia was thus consensualized as a communication process adapted to the person's capacity, which includes, and is continued with, family if available.[90] Pragmatic boundaries regarding participation and time (i.e., current or end-of-life care) were identified as well as three interrelated issues of particular attention, namely: capacity, family, and engagement and communication.[90]

Another controversial issues inherent to ACP is that ACP may or not lead to the completion of Advance Directives (AD). Advance Directives (AD) are legal documents helpful to clinicians and family members for making critical decisions on behalf of the patient, whereas he/she might become incapable.[80,85,90-94] In fact, several nations have introduced specific regulations of ACP and ADs. However, their diffusion is accompanied by unforeseen limitations and issues, burdening their complete and systematic adoption.[80] The legal status of AD varies considerably according to each country's relevant statutory provisions.[26] Different perspectives have also been identified among healthcare professionals on how they perceive the use and relevance of AD in their clinical practice, particularly in palliative and end-of-life-care.[62,95-101] Patients' preferences may also change over time. The fact is that AD reflect the will of the person at the time that they are written,[26] and not necessarily at the time they are used. In ethical and legal terms, this poses additional challenges as discrepancies may exist between what is written and the last expressed wish of the patient at the time a decision needs to be made.

The regulation of AD, particularly in relation to ACP, also poses challenges related to the equity of access and the use of dementia-inclusive approaches and conversations to express patients' values.[102] The need for an evidence-based dementia-specific practice model that optimizes engagement and communication with people with fluctuating and impaired capacity and their families to support decision making and empower people to adjust their decisions if their goals or preferences change over time is paramount.[102]

In the debate on the extent to which AD should be binding, some argue that giving them binding force places all the responsibility for the decision on the patient.[26] Yet, if AD are not binding, clinicians assume responsibility for the decision, which is an approach in which the ethical principle of responsibility is assumed and implemented in its entireness and threefold dimension: retrospective, current, and future responsibility.[103] It should therefore be noted that, even in countries which explicitly recognize the binding force of advance directives, there is broad acceptance that there may be certain reasons authorizing doctors not to follow the patient's wishes.[26,62,101]

Artificial Hydration/Nutrition at the End-of-Life

One of the most disputed and controversial issues at the end-of-life refers to the use of artificial hydration and/or nutrition.[26,37] The question of the appropriate nature, in medical terms, of artificial nutrition and hydration at the end-of-life remains a matter of debate.[26] Some take the view that implementing or continuing artificial hydration and nutrition are necessary for the comfort of a patient in an end-of-life situation. For others, the benefit of artificial hydration and nutrition for the patient at the end-of-life, taking palliative and end-of-life care research into account, is questionable.[26]

Although the worldwide debate over the use of artificial nutrition and hydration remains controversial, according to the European Society for Clinical Nutrition and Metabolism (ESPEN) the scientific and medical facts are unequivocal.[104] Artificial nutrition and hydration are a medical intervention, requiring an indication, a therapeutic goal and the informed consent of the competent patient.[104] This is in line with the position of the Council of Europe for whom artificial nutrition and hydration are given to a patient following a medical indication and imply choices concerning medical procedures and devices (perfusion, feeding tubes).[26]

A dichotomous understanding and approach can be identified on this disputed issue, requiring ethical, legal, cultural, and emotional considerations, and taking associated risks and benefits into consideration.[105-108] On the one hand, in various countries, artificial nutrition and hydration are considered medical interventions. Therefore, the decision to withhold or withdraw such interventions can be done either based on the refusal of the treatment expressed by the patient or based on the identification of such intervention as disproportionate treatment by the healthcare team.[26] On the other hand, in other countries, artificial nutrition and hydration are not considered as a medical treatment or intervention which can be limited or withdrawn, but rather as a type of care that meets the individual's basic needs. Hence, forgoing this intervention or treatment cannot be done, unless the patient, in the terminal phase of an end-of-life situation, expresses his/her wish to that effect.[26]

Our own research suggests that, even within the same country, artificial hydration/nutrition at the end-of-life remains a disputed issue. In an embedded mixed-methods study conducted with healthcare professionals providing end-of-life care in different settings in Portugal, when asked about whether artificial hydration and/or nutrition could be forgone in certain conditions, differing views were identified.[109]

While this dichotomized approach clarifies the two most frequent and opposite positions that exist about this disputed issue, the reality is far more complex. Often, the decision of introducing artificial hydration and/or nutrition or not is based on multiple elements, such as: incomplete clinical information; uncertainty about the prognosis; strong and sometimes conflicting patient, family, and healthcare professional attitudes, perspectives, and judgments; patients' cognitive impairment or lack of capacity to make an informed decision; psychosocial factors; and perceptions of perceived benefits results in artificial nutrition/hydration being initiated in terminally ill patients; and diverse cultural and religious views.[109-111] Amid this complexity and uncertainty, decisions need to be made with the core objective of providing treatments and care that reduce suffering and improve quality of life.[105,106,111,112]

In palliative and end-of-life care, there is no one-size-fits all approach to nutrition care. The combination of medical conditions, patient, families and healthcare professionals' beliefs, and geographic and cultural influences create a unique situation for each individual patient.[113] This is particularly challenging and complex, requiring healthcare professionals working in palliative and end-of-life care settings to have specialized ethico-clinical and communication competencies[114] to properly manage this type of decisions.

Palliative Sedation

Palliative sedation is defined as the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) to relieve the burden of otherwise intractable suffering in a manner ethically acceptable to the patient, their family, and healthcare providers.[26,115-117] It aims to alleviate or remove the patient's perception of an unbearable situation (such as unbearable pain or unappeasable suffering) when every available treatment adapted to this situation has been offered and/or administered but has failed to bring the expected relief. The aim of sedation is, therefore, not to shorten life. [26,115]

According to the Guide on the decision-making process regarding medical treatment in end-of-life situations of the Council of Europe,[26] palliative sedation is considered a disputed issues mainly for two reasons. First, due to its use not to relieve refractory physical symptoms (e.g., refractory dyspnea or refractory pain), but to alleviate psychological or existential suffering. The term refractory can be applied to symptoms that cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness.[115,118] Diagnostic criteria have been established for the designation of a refractory symptom and must the clearly perceived and identified by the attending physician before deciding upon a palliative sedation. These criteria include that the clinician must perceive that further invasive and non-invasive interventions are (i) incapable of providing adequate relief, or (ii) associated with excessive and intolerable acute or chronic morbidity, or (iii) unlikely to provide relief within a tolerable time frame.[115,118] Second, due to the secondary risk of life-shortening effect that palliative sedation might have, even if its aim is not to shorten life.[26]

The practice of palliative sedation is an important cornerstone of palliative therapy.[119,120] It is ethically grounded since it aims to provide the relief of refractory symptoms and unbearable suffering, which could not be controlled or relieved by other means. Yet, palliative sedation remains one of the most debated medical practices.[25,26,60,61,115,119] It is highly complex and requires many multiprofessional discussions, prudent application, broad clinical experience and good practice.[115,119]

Ethical considerations are also highlighted in the literature about palliative sedation and its controversies.[118-125] For instance, the principle of double effect,[120-123] the principle of proportionality,[118-124] the principle of therapeutic responsiveness,[121,123] the careful attention to ethical safety and safeguards when implementing a palliative sedation,[120,122,124] and the establishment of a relational ethics.[119,122,123,125,126] Albeit the impossibility to solve the disputed issues inherent to palliative sedation, the ethical principle of responsibility seems to be paramount when deciding upon sedating a patient at the end-of-life. This relates to the responsibility to (i) recognize how consciousness matters in (some) people's experiences at the end-of-life, including the experience of dying and death in relation with others,[121] (ii) alleviate refractory symptoms and recognize suffering as a core value in palliative and end-of-life,[6,24,115-117] (iii) participate actively in interdisciplinary collective ethico-clinical decision-making processes about palliative sedation,[122] and (iv) educate patients, families and non-expert healthcare professionals about the distinction between palliative sedation and other end-of-life decisions, such as euthanasia and assisted suicide.[125]

Euthanasia and Assisted Suicide

The controversies surrounding euthanasia and (physician) assisted suicide are so strong that in its Guide on the decision-making process regarding medical treatment in end-of-life situations of the Council of Europe, the Council of Europe deliberately chose not to include this end-of-life decision.[26] According to the European Association for Palliative Care (EAPC), euthanasia and physician assisted suicide are two of the most frequently debated and most sensitive ethical issues in the field of healthcare today.[127] Table 2 systematizes the definitions of euthanasia, (physician) assisted suicide and non-treatment decisions.[127,128]

Table 2. Definition of Euthanasia, (Physician) Assisted Suicide and Non-Treatment Decisions[127,128]

Terms	Definitions
Euthanasia	A physician (or other person) intentionally killing a person by the administration of drugs, at that person's voluntary and competent request.
Assisted Suicide	A person intentionally helping another person to terminate his or her life, at that person's voluntary and competent request.

Physician Assisted Suicide	A physician intentionally helping a person to terminate his or her life by providing drugs for self-administration, at that person's voluntary and competent request.
Non-Treatment Decisions	Withholding or withdrawing medical treatment from a person either because of medical futility or at that person's voluntary request.
Based on Radbruch et al.[127] and De Lima et al.[128]	

Based on these internationally consensualized definitions provided by international associations such as the European Association for Palliative Care[127] and the International Association for Hospice and Palliative Care,[128] decisions about euthanasia and (physician) assisted suicide clearly differ from other decisions, such as non-treatment decisions (withholding and/or withdrawing), voluntary stop eating and drinking, and palliative sedation.[127,128]

The terms of euthanasia and assisted suicide are often replaced by others, such as assisted dying or medical aid or medical assistance in dying (MAID), which increases the conceptual ambiguity surrounding the highly controversial and disputed issue of hastening death. In fact, replacing the terms of euthanasia and assisted suicide by "softer" ones, such as MAID corresponds to the use of euphemisms.[129-131] A recent article pinpoints to the fact this trend is deleterious because MAID's proponents do not consistently express the meaning and intent of the practice, and the phrase downplays the fact that a provider is participating in the act of death for a patient.[129] The use of this euphemism blurs the differences between providing high-quality palliative care and participating in the death of a patient prior to a natural death.[129] Unambiguous language and clear definitions should always be provided when referring to practices of euthanasia and assisted suicide.

Evidence suggests that, when using unambiguous language and clear conceptual definitions, there is a lower acceptance of euthanasia and assisted suicide among palliative care specialists.[132-135] However, there seems to be a trend towards a broader acceptance and societal normalization of the practices of euthanasia and assisted suicide, even in persons with advanced dementia or psychiatric conditions and in children or minors.[136-141] In Portugal, evidence suggests a large acceptance of the legalization of euthanasia and assisted suicide among medical students.[142] Moreover, our own research shows a large willingness in performing such practices, despite the perceived tension between the legalization and practice of euthanasia and assisted suicide and their ethical and deontological code as physicians.[143]

One of the basic principles of palliative care is that it neither hastens nor postpones death.[1-3] Therefore, international associations in the field of palliative care have been expressing and reinforcing their opposition against these practices.[127,128,144] Embedding euthanasia and assisted suicide in clinical palliative care practice risks giving it a spurious aura of benevolence and of being a best-interest procedure.[144] However, with the growth in the number of countries legalizing these practices, complete consensus on these topics seems to be unachievable due to incompatible normative frameworks and views that clash. Understanding and respecting alternative viewpoints are not the same as the ethical acceptance of either euthanasia or physician assisted suicide.[127]

A common denominator between those in favor and those against the practices of euthanasia and assisted suicide seems to be that both these opposites are unified in their focus and wish to provide 'safe and compassionate care for the dying person'.[145,146] This unifying stance may be the way forward to further reflect on the ethical implications of euthanasia and assisted suicide, regardless of their legal status, and also inherent to a wish for hastened death. The discussion should focus on optimal holistic care for patients and their caregivers, from a palliative care perspective.[127,144]

Wish to Hasten Death/Die

The expressions of a "wish to hasten death" or "wish to die" raise ethical concerns and challenges. While the wish to die is not considered a disputed issue per se, the wish to hasten death is perceived as such due to its association to euthanasia and assisted suicide. In 2016, an international consensus definition was proposed for the "wish to hasten death", where the terms "wish" and "desire" were used interchangeably.[147] The wish to hasten death was thus defined as a reaction to suffering, where the patient considers that accelerating death is the only way out.[148] This concept should be distinguished from the acceptance of impending death or from a wish to die naturally, although preferably soon.[147-150]

Several studies, including systematic reviews, have been performed about the wish to hasten death and/or desire to die.[148,149,152-155] These studies explain that the wish to hasten death is associated with various factors, such as physical symptoms, psychological distress (e.g., depression, fears, hopelessness), existential suffering (e.g., tiredness of life, loss of meaning of life), and/or social aspects (e.g., feeling like a burden to others).[147-151,156] Despite these various factors underlying a wish to hasten death or a wish to die, evidence suggests that this does not necessarily mean that patients want healthcare professionals to practice euthanasia or (physician) assisted suicide.[156] Instead, expressing a wish to hasten death is sometimes used as an extreme coping strategy against anticipated agony or as a way to alleviate psychological distress and regain a sense of control.[147-149,156] What many patients who express a wish to hasten death expect from their caregivers is for them to be open so they can share and explore their ideas, emotions and perceptions.[156] This is extremely relevant. On the one hand, it underscores the need for healthcare professionals to address and explore a wish to hasten death proactively, openly and compassionately. On the other hand, it highlights the need for a cautious approach when managing such expressions as they do not necessarily mean a true desire or request to end the patient's life. Ethical and communication competencies need to be fostered for healthcare professionals working in palliative and end-of-life care to be able to properly address this highly complex ethical challenge.

Expressions of a wish to hasten death or a wish to die are related to ethical principles such as autonomy, dignity and vulnerability.[148] Particularly in end-of-life care, these ethical principles are truly intertwined and need to be considered *prima facie*, as an obligation that needs to be fulfilled, unless it conflicts, in a specific instance, with another principle.[157] Respect for autonomy has been advocated as the ethical principle justifying the practices of euthanasia and assisted suicide. Nevertheless, although autonomy is always relevant as a *prima facie* principle, along with other prima facie principles, it has no more and no less weight than other ethical principles.[158]

A wish to hasten death can have multiple meanings and may be affected by several factors, such as physical symptoms, psychological/existential suffering, loss of dignity, and feeling a burden to others. While often not mentioned explicitly or with enough in-depth, these meanings relate to the ethical principles of vulnerability, dignity, and autonomy.[148] That is why healthcare professionals should address these topics compassionately and ethically, taking into account the unique perspectives of patients and family members as well as their own internal tensions.[148] Further research is needed, particularly using qualitative methods, to explore the meanings behind a wish to hasten death, their ethical contours, ethical reasoning, and implications for clinical practice.

4.2. Autonomy, Vulnerability, and Decision-Making in Palliative and End-of-Life Care

Autonomy and vulnerability are, among other ethical principles and values, paramount in palliative and end-of-life care.[25,37,60,61,63,67,160-162] Taking these ethical principles into account and reflecting on them critically is necessary to ensure that decision-making processes in palliative and end-of-life care are clinically and ethically sound.

Vulnerability generally refers to a state or condition of being susceptible to harm.[159,160] It often stems from physical, emotional, and psychological fragility and social factors undermining individuals' ability to protect themselves or express autonomy.[160] In the context of healthcare, vulnerability can manifest itself in many ways, including individuals' experiences of illness, injury, disability, and even emotional harm.[161] In some cases, the bioethical principles of vulnerability and autonomy seem opposite.[148] However, establishing a dichotomy between these two ethical principles drives to situations where both principles cannot be reconciled.[160] In fact, vulnerability ultimately leads to the establishment of relational autonomy, where vulnerability and autonomy do not stand in opposition to each other.[160]

4.2.1. Individual and Relational Autonomy

Autonomy is a foremost ethical principle in healthcare and a core principle in ethical decision-making in palliative and end-of-life care.[25,26,60,61,63,148,163,164] It recognizes that patients have the right to decide about their medical treatment and care, including accepting or refusing medical therapeutics, withdrawing life-sustaining treatment, or requesting medical aid in dying based on their values and goals.[26,37,60,61,148,163] Healthcare professionals should respect and support patients' autonomy by providing them with relevant information, ensuring their understanding, and involving them in the decision-making process.[26,60,61,148,165] Autonomy is a cornerstone of person-centered care. This is particularly visible in palliative and end-of-life care due to its relevance and implications, namely in terms of anticipating situations and decisions for the future in order to meet patients' wishes and preferences for care.[60,61,148]

Individual autonomy works from the assumption that patients are competent, have sufficient experience making healthcare decisions, have the ability to independently decide what kind of treatment and care they may want in the future and document these wishes in a meaningful way.[158,166] In real world clinical practice, this is rarely the case, putting emphasis on the need to establish a relationship that can help patients make informed and shared decisions. A relational approach is thus needed in which relational views of autonomy recognize that self-determination is both defined and pursued in a social context, and that this context influences the opportunities an agent has to express or develop autonomy.[166,167]

Relational autonomy acknowledges the reality of the person's illness within their "relational autonomy", rather than absolute self-determination, underscoring the importance of the patients' participation in their treatment decision making and end-of-life care.[168] It aims to maintain the essential aspect of autonomy, namely control over one's life, while, at the same time, incorporating insights of a socially embedded perception and reality.[148] This is particularly relevant in the context of palliative and end-of-life care.

Fostering relational autonomy includes navigating between the patient exercising his/her autonomy within a framework of relations, taking the patient's vulnerability into account while, simultaneously, shielding the patient from paternalistic practices.[148,169] Embracing a relational approach (i.e., relational autonomy)[148,170,171] and providing truly person-centered care, where fears about the future can be openly discussed and care plans can be defined together with the patient and his/her loved ones, are thus paramount when facing the need to make end-of-life decisions.

In a beautiful piece, Miccinesi et al.[168] refer to the "peculiar beauty" of palliative care based on its ethical foundations embedded in relationships and support, in a so called "relational autonomy'' for the patient, included in a "care ethics'. Based on the words of Cicely Saunders,[172,173] the authors highlight that the only proper response to a person at the end-of-life is respect; a way of seeing and listening to each one in the whole context of their culture and relationships, thereby giving each his or her intrinsic value.[168,172,173]

Relational autonomy also embraces an understanding of all people as embodied, vulnerable, and potentially in need of care.[166] Vulnerability is inherent in all human beings as a result of our embodiment: our social, affective, and political nature, and our exposure to the natural environment. As such, we can all potentially suffer harm, including illness, death, injury, disability, loss, grief, rights abuses, oppression, and exploitation.[148,159,160,166] The concept of relational autonomy departs thus from the relational-oriented ethics of care and captures the need to frame the patient's autonomy within a responsible relationship with others.[174] According to ethics of care, human beings are vulnerable, deeply situated in relation to other people, and dependent upon one another.[174,175]

In fact, autonomy for the vulnerable patient can only be achieved by interaction and engagement, within a relationship, rather than abandoning the patient to decide for themselves. Although the conception of relational autonomy cannot solve all ethical issues and challenges, particularly in palliative and end-of-life care, relational autonomy is helpful for understanding healthcare professionals' extended responsibility to learn to know their patients through their life stories, and to enable them to frame the care according to the patients' most profound wishes and values.[174]

4.2.2. How increased Vulnerability can influence Decision-Making Capacity

Vulnerability is a touchstone in bioethics and a common denominator to both clinical and research ethics.[176,177] As a concept, vulnerability is defined as the susceptibility of being wounded or hurt, being a term of Latin origin, meaning *vulnus*, wound. This concept was introduced into the vocabulary of bioethics as a characteristic attributed to particular populations considered to be those most exposed to and poorly defended against maltreatment or abuse of others.[177] Substantial debates have been established to define who vulnerable people are and to minimize the risk they have of being exploited. Nevertheless, defining vulnerable persons or populations has proved to be more difficult than initially expected.[159,160,177]

Kipnis[178,179] was one of the first authors suggesting that vulnerability is inherent in situations and not persons or groups, thus challenging national and international guidelines for research that identify vulnerability as specific classes of people (e.g., persons with dementia). Specific categories of vulnerability can be identified as opposed to the institutionalized subpopulation focus (e.g., children, prisoners, pregnant women, persons with dementia or cognitive impairment).[178] This needs to be taken into account when considering, reflecting on, and discussing vulnerability in the context of ethico-clinical decision-making processes.[177] Table 2 systematizes and describes the different categories of vulnerabilities.

Table 3. Kipnis's[178,179] Categories of Vulnerability

Categories of Vulnerability	Description	Questions to be asked
Cognitive vulnerability	This category includes, for instance, persons with dementia, with certain types of mental illness, intellectual disability, older adults who are institutionalized in nursing homes, older persons with educational deficits and/or unfamiliarity with the medical language, persons at the end-of-life, particularly in the last days of life. People with these conditions are cognitively vulnerable and deserve special attention in ethico-clinical decision-making processes, particularly when assessing decision-making capacity and developing, implementing and evaluating the informed consent process.	• Does the person have the capacity to understand and decide to be treated or not? • Does the person have the capacity to provide an informed consent for a clinical intervention and/or treatment or for research?

Incapacitational and/or Juridic vulnerability	This category refers to the (in)capacitational and/or juridic vulnerability, which requires clinicians and researchers to take into account whether the person is competent to make a decision and provide informed consent or not, and the scope of the legal authorized representative's authority to make such decisions on behalf of the person. The main concern about (in)capacitational and/or juridic vulnerability is that uncaring or misguided legal authorized representatives or proxies, and enterprising clinicians and/or researchers that might subject vulnerable persons to disproportionate or to unwholesome interventions and/or research programs.	• Does the person lack the capacity to deliberate about and decide whether to participate in the study and/or to receive this treatment? • Is this person juridically declared as incompetent to make a decision? • Is the person liable to the authority of others who may have an independent interest in that participation?
Situational vulnerability	This category includes persons who cannot be sufficiently informed and/or who cannot complete effective deliberation within the available timeframe. A few examples can be given on this situation: patients receiving a very serious diagnostic or closed prognostic (e.g., dementia, neurodegenerative disease, advanced stage cancer), patients who are being submitted to an urgent surgery, or even patients who need to be sedated for a certain reversible reason.	• Is the patient in a situation in which medical exigency prevents the education and deliberation needed to decide?
Medical vulnerability	Some patients could be more vulnerable due to a set of different circumstances. Therefore, a patient can have additional vulnerability when he/she has a serious health-related condition for which there are no satisfactory treatments. Patients with palliative care needs are unquestionably in a situation of medical vulnerability, which might be exacerbated by their symptoms or needs. A few examples of persons with medical vulnerability: persons with dementia, with metastatic cancers, with Parkinson's disease, multiple sclerosis, or other life-limiting or life-threatening conditions.	• Has the person a serious health-related condition for which there is no satisfactory solution?
Allocational vulnerability	Very poor patients, and all the older patients who are in a socially devaluated or disadvantaged condition, can be identified as having this type of vulnerability. Often, allocational vulnerability influences people to express their agreement to participate, for example, in clinical trials due to the financial compensation that might result from their participation. Careful attention needs to be paid to prevent this.	• Is the patient seriously lacking in important social goods that will influence his/her decision?
Social vulnerability	As an example of social vulnerability, we can include persons with addictions, older patients, older migrants, migrants or refugees, homeless, prisoners and all those persons who might be in a socially disvalued or disadvantaged situation due to a social or demographic characteristic.	• Have this person's rights and interests been socially disvalued? • Does this person have a personal characteristic that puts her at risk of being socially marginalized?
Deferential vulnerability	This type of vulnerability refers to powerful social and cultural pressures. It is known, for example,	• Is the patient deferential behavior what masks an

	that some patients experience the “white coat syndrome” towards their medical doctors, or, in another scope, women or men who may find it hard to turn down requests from their spouses.	underlying unwillingness to decide?
Based on Kipnis[178,179] and Hernández-Marrero et al.[177]		

Combined vulnerabilities may occur and need to be considered when making ethico-clinical decisions as they have larger impact on decision-making than any individual vulnerability.[180] This is particularly relevant since someone with increased vulnerability or combined vulnerabilities is at risk of having his/her autonomy or dignity or integrity capable of being threatened. As the description of the different categories of vulnerabilities suggest, under certain or various circumstances, one’s autonomy (the capacity to make an informed, uncoerced decision), dignity (the right of a person to be valued and respected for their own sake), or integrity (the quality of being honest and having moral principles), can be in danger or lost.[60,61,63,181]

Establishing an ethics of care, embracing relational autonomy, acting with responsibility and acknowledging the impact of combined vulnerabilities is therefore crucial.[182,183] In clinical encounters, particularly in palliative and end-of-life care, compassion, sensitiveness, autonomy, integrity and respect are important notions, principles and values that need to be taken into account when caring for those who are more vulnerable. Vulnerability is not attributed solely to a person or group, but to a situation, which means that the person is viewed in context. By combining vulnerability as a context-related and situational concept with existing approaches of informed consent, the different ethical principles can be balanced and preserved at every step of the treatment, care and/or research process (if applicable).[159,163,169,177-179,183]

The complexity and diversity of meanings attributed to vulnerability makes this ethical principle difficult to address in clinical practice and research. In fact, vulnerability challenges the modern illusion of self-sufficiency and allows us to discover and invent life together.[184] However, if we can more accurately recognize vulnerable individuals, we can ultimately be better at empowering and involving them in ethico-clinical decision-making processes, protecting them from improper consent and avoiding cases where too much protection results in lack of access of appropriate treatment or research participation.[177,185]

Adequate and creative strategies need to be designed to empower those with vulnerabilities.[177] This is a major challenge for healthcare professionals, researchers, and ethicists. Overall, future research efforts should allow us to develop a more accurate understanding and identification about how vulnerability (and vulnerabilities) may influence decision-making capacity. It is also important to further develop effective instruments that will enable a better identification of vulnerabilities and the participation of vulnerable persons with one or multiple vulnerabilities in clinical care and research decision-making process, particularly in palliative and end-of-life care.[177]

4.2.3. Decision-Making Capacity: The Case of Patients with Cognitive Impairment

Patients at the end-of-life might experience cognitive dysfunction or decline, which can be attributed to a variety of factors (e.g., advanced age, opiate medication, symptoms such as delirium, brain metastasis).[186-189] Such dysfunction likely affects decisional capacity, which is a crucial consideration as the end-of-life approaches and patients face multiple choices regarding treatment, family, and estate planning.[186,187]

Cognitive impairment may have a negative impact on patients' capacity to provide consent to clinical care or research participation.[190,191] Nevertheless, to make ethically and legally valid medical decisions, patients must have decisional capacity.[191,192] From an ethical perspective, the requirement for decisional capacity reflects both a desire to protect the rights of capable patients to make their own choices and the imperative to protect incapable patients from the consequences of decisions reached without adequate mental capacity.[192]

The generally accepted legal and ethical standards for decision-making capacity fall into four categories: (i) understanding (i.e., the patient's ability to grasp the meaning of information communicated by the physician and other caregivers); (ii) appreciation (i.e., the patient's ability to appreciate the consequences of the situation, particularly the medical condition, need for treatment, when applicable, and the likely benefits and harms of each possible treatment); (iii) reasoning (i.e., the patient's capacity to weigh risks and benefits within/across treatment options and arrive at a decision that is consistent with their starting premise(s), their preferences and values); and (iv) communicating a choice (i.e., the patient's capacity to clearly indicate their preferred treatment and/or care option and maintain that choice for a sufficient period of time for it to be implemented).[190,191,193]

Patients with cognitive impairment (e.g., patients at the end-of-life, persons with dementia) are considered a vulnerable population without capacity to consent. The conditions associated with cognitive impairment cause great suffering to affected patients and their families.[177] Cognitive impairment is at times associated with partial or full impairment of the capacity to make decisions. When patients lose decision-making capacity, others must make surrogate decisions on their behalf.[194] In the context of palliative and end-of-life care, advance care planning (ACP) and advance directives (AD) are often used (despite being considered as disputed and controversial issues, as discussed above), surrogate decision-makers are involved in ethico-clinical decision-making processes, and approaches such as supported decision-making are sometimes implemented.[177] A surrogate decision-maker is someone who is chosen (by the patient prior to losing decision-making capacity) or assigned (based on legal statute) to speak for the patient and represent their values, goals, and wishes when they cannot speak for themself.[26,85,90,177,194] Supported decision-making refers to scenarios where decisions are made by both with the person with cognitive impairment or limited decision-making capacity and another person or persons who provide different levels and types of support.[177] The core ethical principle underlying supported decision-making is autonomy, emphasizing its relational nature.[166,167,170,171,177]

Improving clinical care for persons with cognitive impairment, particularly at the end-of-life, depends on shared decision-making processes that require the mobilization of various features, such as ACP, AD, proxy decision-making, supported decision-making. In fact, evidence suggests that, despite its challenges, the use of proxies is the most common strategy used in healthcare decision-making involving persons with cognitive impairment.[195] Besides, decision aids (e.g., videos, visual images or other non-conventional information aids) for people with impaired decision-making capacity (e.g., persons with cognitive impairment, persons with dementia) have been described to improve decision-making capacity, particularly in clinical research.[195-198]

Research is needed to further improve both the quality of life and the quality of care provided at this particularly vulnerable moment. It is known that assessing medical interventions or care provision requires some measure of treatment or care effect, which is particularly complex to implement in persons with cognitive impairment.[191] Therefore, despite its major ethical challenges, research involving persons at the end-of-life, particularly those who are cognitively impaired, is needed.[176,177,195]

Cognitive impairment is, at times, associated with partial or full impairment of the capacity to consent to research. This both limits the ability of the individual to consent personally to research participation, and also increases pressure upon Institutional Review Boards and investigators to place additional safeguards for the appropriate participation of cognitively impaired individuals in research. Special protection is to be given to persons who do not have the capacity to consent, and this calls indeed for protection. Nevertheless, it should not prevent research participation. In fact, excluding vulnerable patients or those who lack capacity to consent from participating in relevant research that could potentially improve the quality of life and the quality of care of these patients could suggest that society is failing in its obligation to improve high-quality, evidence-based healthcare due to misguided paternalism.[176,177]

Persons with impaired decision-making capacity require special attention and ethical considerations and procedures during recruitment and participation in research. When substitute consent is necessary, state laws generally provide a range of options, including proxy consent and advance directives.[177] However, our own research suggests that healthcare professionals working in palliative and end-of-life care in Portugal still use a protective paternalist style, often preventing persons with cognitive impairment (e.g., persons with dementia) from participating in relevant research.[197] Fundamentally, a shift must be made away from misguided protectionism or paternalism towards promoting appropriate inclusion of adults lacking capacity in order to honor society's obligation for equitable health care for all.[198]

5. Enhancing Ethico-Clinical Decision-Making in Palliative Care

Clinical practice in palliative care is characterized by the need of making ethico-clinical decisions, particularly at the end-of-life.[25,29,37,40,60,61] End-of-life situations are situations in which a severe deterioration in health, due to the evolution of a disease or another cause, threatens the life of a person irreversibly in the near future, posing the need to make ethico-clinical decisions.[25,26,29,40] Often, these decisions are difficult and challenging; so, the so-called “ethical challenges” emerge.[39,42] Despite its ubiquity, there is no consensualized definition of this expression. Various terms are used interchangeably, such as “ethical challenges”, “ethical problems”, “ethical issues”, “ethical dilemmas”.[39,40,42]

Even though there is a wide range of ethical decisions that need to be made in palliative and end-of-life care, there is no unique model or guideline to help professionals and teams in making difficult, complex, and/or challenging decisions. Several models and guidelines for ethical decision-making at the end-of-life coexist[199] and can be a relevant aid for healthcare professionals and teams. They can help stimulate the process and the discussions around disputed and controversial issues, facilitating professionals to follow a well-informed and shared decision-making model in order to meet patients’ values, wishes and preferences.

5.1. Ethical Decision-Making Processes: Models and Frameworks

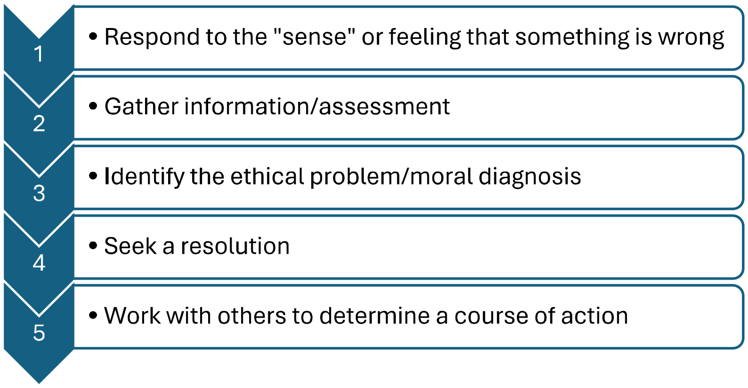
In the bioethics and clinical literature, various models and frameworks can be identified to aid healthcare professionals when navigating through complex ethical decision-making processes.[199-201] Typically, these ethical frameworks are normative and fall broadly into four approaches: (i) Actions are judged by their consequences, trying to balance the possible good and bad effects of decisions; (ii) actions must respect rights and duties (deontology); (iii) actions are based on virtues (i.e., personal characteristics, such as honesty, prudence, courage, compassion, forgiveness and generosity) that form the basis of professional practice; and (iv) actions are based on communication and relationship-based ethics, suggesting that the right action is the one resulting from the exchange of information, perspectives, and views of all stakeholders involved.[202] A recent review identified at least seventeen different frameworks for complex decision-making in older patients, which could be divided in two categories: with or without a step-by-step plan.[199] Another study expanded the use of frameworks or models to other healthcare specialties, identifying a total number of 55 ethical decision-making models across seven healthcare professional groups and 22 sub-fields.[201]

In the following subsections, I am presenting and systematizing a selection of five different frameworks that can be used in complex ethical decision-making process in palliative and end-of-life care. The choice for these five different frameworks is based on the fact that they represent best practices in inter-professional resolution of ethical problems in clinical practice with a focus on the tools needed for all members of the team, including nurses, to communicate with each other. All these five models embrace an interdisciplinary, collective, dialogical, communicational, and thought-provocative approach that makes them useful both in the clinical context and in education.

5.1.1. The Five-Step Model for Ethical Decision Making developed by Amy M. Haddad

In a seminal work entitled "The Anatomy and Physiology of Ethical Decision Making in Oncology",[203] Amy M. Haddad proposes a five-step normative decision-making model to help health care professionals arrive at sound ethical judgments. The five steps provide the structure for the decision-making process and are linear; that is, they should be carried out in the order listed in Figure 1.[203]

Figure 1. The Five-Step Model for Ethical Decision-Making, Haddad[203]



1 • Respond to the "sense" or feeling that something is wrong

2 • Gather information/assessment

3 • Identify the ethical problem/moral diagnosis

4 • Seek a resolution

5 • Work with others to determine a course of action

The steps in this model outline a process, a way of making judgements about what ought to be done in a particular ethically complex situation.[203] Table 3 shows that, inherent to each step, various questions can be posed to work towards a justifiable solution.

Table 4. Five-Step Model for Ethical Decision-Making and inherent Questions

Steps of the Model	Questions to be asked
Step 1	Do these emotional signs or does this "sense" really indicate that an ethical problem is in progress? What is it that makes you react to this case? Was it the patient suffering? Was it something else? With whom do you identify yourself most in the case?
Step 2	What is the medical condition of the patient? Do we know the full medical history, the diagnosis and the prognosis? What treatments have already been provided and what were their effects? What is the patient's probable life expectancy and general condition with or without that specific proposed treatment, intervention or care? What are the risks and the side effects of such treatment, intervention or care? Does the patient fully understand his/her condition? How does he/she feel about it? Does the patient have the capacity to

	make a decision and/or consent? What are the patient's wishes? Do we know these wishes? Do the family members understand the patient's condition? What do they think about the condition and proposed treatment, intervention or care? How do the family members feel about the situation and decision? What are the views of other individuals (e.g., the patient, his/her family members, the various members of the interdisciplinary healthcare team, other relevant stakeholders) involved in the case? How do these views compare and contrast?
Step 3	What is the ethical problem? What is the ethical or the moral diagnosis of the situation? What are the ethical principles, values, rights, or duties that are in conflict? What values does the patient hold concerning the situation? What are the values of the family and/or other stakeholders involved in the decision-making process? Do these values conflict with each other?
Step 4	What are the potential courses of action? What are the ethical justifications for each potential course of action? What are the implications of each potential course of action?
Step 5	Who should be part of the team or group to resolve the ethical problem? Do we have any additional resources that can be mobilized for the decision-making process?
Based on Haddad[203,204] and Veatch et al.[205]	

Although this model embraces a stepwise approach, ethical decision-making is more than just following steps. As suggested by the multiple and complex questions inherent to each step, ethical decision-making, particularly in palliative and end-of-life care, involves an appreciation of the complexity of the situation and of the components of each step such as what really comprises gathering information and how the steps relate to each other.[205] This framework includes ethical principles to systematically analyze and resolve ethical problems in particular cases. This normative model for ethical decision making provides a guideline and stepwise approach for systematic reflection that will lead to clear articulation of an ethical problem and a justifiable resolution.[203-205]

5.1.2. Moral Case Deliberation

Most ethical frameworks found in the literature are step-by-step plans that can be followed chronologically during moral case deliberations.[199] Moral case deliberation (or ethical case deliberation) refers to the process in which everyone concerned by the decision is considered a valid moral agent, obliged to give reasons for their own points of view, and to listen to the reasons of others.[207] The goal of this process is not the reaching of a consensus but the enrichment of points of views with others, increasing, in this way, the maturity of the decision, in order to make it more wise or prudent.[207] Moral case deliberation provides group-wise, structured reflection on dilemmas from practice.[208-212] In practical terms, moral case deliberation is organized as collaborative meetings where a group of healthcare professionals jointly reflects on a concrete moral question, issue or dilemma.[208-216]

During these meetings, a structured conversation, often led by a trained facilitator, occurs, helping to clarify which moral or ethical principles and values conflict with each other and need to be resolved.[199,207-214,216] Most practical questions concern "What should we consider as the morally right thing to do in this specific situation?" and "How should we do it rightly?". In addition, more philosophical or conceptual questions are also discussed. For instance, "What is respect?" and "What does understanding mean?".[208-216] Moreover, in these meetings, three central, often co-existing, goals of moral case deliberation are: (i) to reflect on the case and to improve the quality of care within that case; (ii) to reflect on what it means to be a good professional and to enhance professional's moral competencies, (iii) to reflect on institutional or organizational issues and improve the moral quality of care at that level.[208,210-214,216]

Various examples of moral case deliberation are described in the bioethics literature. Their key principles are: (i) considering experience as a starting point for moral reflection; (ii) taking into account variations related to interpretations and appreciations of facts by the participants of moral case deliberations plus the conclusions allied by them; (iii) linking the values and norms of the participant to concrete facts in the case; and (iv) using dialogue as a process and product in which knowledge and practical wisdom emergence and fleshed out by learning by doing.[213,214] In simple terms, moral case deliberation is based on the assumption that group reflection increases insight into ethical issues.[207,215] Table 4 provides the description of a ten-step moral case deliberation model widely used and described in the literature.[208-216]

Table 5. Moral Case Deliberation (MCD) – A Ten-Step Model[208,210-214,216]

Steps of the Model	Description of the Step and inherent Questions
Step 1. Introduction	Presentation of the aim and procedure of the MCD. • *Questions:* What is MCD? What is the aim of the meeting for the participants? What are the mutual expectations (e.g., open and honest communication)? What are the steps used in this method? What is the occasion and context of this MCD?
Step 2. Presentation of the case	This step focuses on the experience of the case presenter who describes the concrete personal situation in which a moral issue is at stake. • *Questions:* What is the specific moment within the timeline of the case, in which he/she experienced most strongly his/her moral dilemma - 'the moment of heat' of the case? What are the facts of the situation at that moment? What feelings did he or she experience that can be useful to better understand the moral discomfort?
Step 3. Formulating the moral question and the dilemma	In this step, the underlying moral question is made explicit by the case presenter. • *Questions:* What is at stake for you in this situation? What worries you? What makes you feel uneasy? What are the concrete actions you could choose for in this situation? In a dilemma, there are always two options which mutually exclude one another. Each of the actions has negative consequences. Formulating explicitly the negative consequences of each of the two options makes clear what is at stake for the case presenter.
Step 4. Clarification in order to place oneself in the situation of the case presenter	The fourth step aims to foster a clear understanding of the situation, so that the participants can put themselves in the shoes of the case presenter. The aim of clarification is to (re)construct as clearly as possible the situation presented by the case owner in order to investigate the moral dilemma. • *Questions:* How would I answer the moral question if I were in his/her situation? How do I justify my own answer? Within MCD, participants try to answer the dilemma of the case presenter. Participants have to ask themselves what they think should do in such a

	situation. The clarification in this step does not aim at getting insight into what other people think about the case, but to better understand the dilemma experienced by the presenter, and to prepare the participants to put themselves in his/her shoes.
Step 5. Analyzing the case in terms of perspectives, values and norms	This step serves to gain insight in the complexity of the case. Participants investigate the values and norms of the stakeholders involved, and jointly construct a perspectives, values, and norms diagram. That means that the participants make a list of the relevant perspectives (stakeholders), and for each perspective investigate what are important values related to the dilemma, and what action should be done to realize a specific value (this we call a norm). In case the group seems to overlook an important stakeholder, value or norm, the facilitator can verify this by asking questions to the participants. • *Questions:* Do you think that X would be a relevant perspective which should be included? Is there any other relevant perspective that can bring in other important values related to the case? The analysis of the perspective of the case presenter will entail values and norms which either support choice A or choice B. Not all stakeholders need to have values and norms which go in both directions. Some will have a clear preference for one of the options and experience no dilemma themselves. Only values and norms related to the dilemma or moral question are relevant here. The values and norms are not formulated in general; they are always formulated in relation to a perspective and expressed in the way they are concretely experienced by the stakeholder under consideration. Thus, the values are not derived from moral theory, but from lived experience.
Step 6. Looking for alternatives	The aim of this step is to have a brainstorm in order to get a view on possible courses or actions which lie be yond the dilemma. The focus is on stimulating creative out-of-the-box thinking (not on the desirability or feasibility of the alternatives). • *Questions:* Did we explore all possible alternatives? Is there any other potential solution we did not think of? Is there any other stakeholder that we could ask for advice? Some of the alternatives mentioned might be useful later, when participants answer the moral dilemma question for themselves and reflect on their underlying considerations.
Step 7. Making an individual choice and making explicit one's considerations	The aim of this step is to have the participants formulate their personal views, values and norms in relation to the case. The moral justification they give is a personal viewpoint on what is morally right, including the moral arguments why they conceive this specific answer or action as morally right. Later on, in the MCD process, every moral justification of the MCD participants can be further explored and criticized in order to further learn from each other's reasoning. The aim of this step is not to give advice to the case-presenter ('you should do this'), but to examine one's own thinking concerning the central moral question in the case. • *Questions:* What is my individual choice? What do I think about the central moral question in the case? The participants chose between option A and B, or an alternative (either mentioned in step 5, or not) including the main value or norm that motivates their choice. Here, referrals to existing normative frameworks (like policies, laws or professional codes) can also be mentioned. Furthermore, each of them reflects on the value and norm which cannot be realized, but is still important, and in need of repair. Each participant also makes explicit what he or she needs to repair the so-called 'moral damage' which is often an inherent feature of a moral dilemma.

Step 8. Dialogical inquiry	In this step, similarities and differences between the individual considerations are examined. Sometimes, two participants make a different choice in the dilemma based on the same value. On the other hand, participants may choose the same option in the dilemma based on different values or norms. Identifying similarities and differences may lead to a better understanding of one another and a better insight in what is important in the specific case. • *Questions:* What are my values? How do they influence my choice? Thus, the participants reflect on their own values and learn to see the relevance of other positions. In dialogue, they may reach a new and richer view of the situation. A dialogue is distinguished from a discussion. In a discussion, the participants try to persuade each other that their own position is superior. In a dialogue the participants focus on understanding and examining each other's viewpoint. A dialogue requires a critical yet constructive attitude of listening and asking questions.
Step 9. Conclusion	In this step, the participants are invited to sum up conclusions and make a plan for action. • *Questions:* What was the initial moral question? What insights have been reached? Reaching consensus is not necessary; the conclusion can also be that there is a plurality of ideas which lead to questions what this plurality means for daily practice and how to deal with it. In case one idea or participant is dominant, the facilitator might ask questions to encourage critical reflection among the participants. This may open the dialogue again and lead to new ideas and conclusions. Sometimes, conclusions should be understood as preliminary conclusions because a referral to an external expert or another perspective is needed after the MCD sessions.
Step 10. Evaluation	Evaluation is important in order to learn from positive and negative learning experiences regarding the process and the result of the moral deliberation. • *Question:* What did everyone learn from this experience and process? What are the positive aspects? What are the negative ones? What can we do differently or better? This may lead to changes concerning the skills, attitudes and procedure next time, taking into account limitations experienced.
Based on Weidema et al,[208] Haan et al,[209] Abma et al,[210] Weidema et al,[211] Svantesson et al,[212] Stolper et al,[213] Widdershoven et al[214] and Janssens et al.[216]	

Based on the work of Widdershoven and colleagues,[208,210-214,216] a recent and more simplified moral case deliberation model is being developed. This is a four-step low-threshold instrument that fosters ethical reflection for professionals working in palliative care.[217] These four steps are an acronym of the name of the instrument, 'CURA'.[217,218] The first step, 'Concentrate', is about focusing on the situation at hand, and about zooming in on the moral doubts of caregivers. The second step, 'Unrush' is devoted to reflection on emotions. The third step, called 'Reflect', ventures into what is of value of those involved in the situation. The fourth step, 'Act', focuses on relating moral judgment to concrete action.[218] This instrument is specifically developed for nurses caring for patients with palliative care needs. According to a recent feasibility study, the instrument itself is considered feasible and low-threshold and might help to deal with morally difficult situations in practice.[219]

As a matter of fact, moral case deliberation has been applied in various clinical settings, assuming slightly different versions and steps. Regardless of the specific model or the number of steps implemented in practice, moral case deliberation follows an inductive learning approach through a dialogical moral inquiry in which participants develop not only knowledge but also skills, attitude and character.[209,213] The dilemma method, which is a specific conversation method used in moral case deliberation, is useful for supporting healthcare professionals in and helping them how to reflect on their own moral issues in clinical practice.[213] Evidence suggests that moral case deliberation can be useful for healthcare professionals to better recognize the moral dimension of their daily clinical practice, to become more able to distinguish various perspectives, to increase team's cohesion and mutual understanding, to reason in a systematic manner, and to improve care.[199,207-216]

5.1.3. The Framework for Ethical Decision-Making – Markkula Centre for Applied Ethics at Santa Clara University

Making good ethical decisions requires a trained sensitivity to ethical issues and a practiced method for exploring the ethical aspects of a decision and weighing the considerations that should impact our choice of a course of action. Having a method for ethical decision making is therefore essential. When practiced regularly, the method becomes so familiar that healthcare professionals and teams work through it automatically without consulting the specific steps. The more novel, difficult, and complex the ethical challenge or problem is, the more healthcare professionals need to rely on discussion and dialogue with others. Only by careful exploration of the ethical problem, aided by the insights and different perspectives of others, is it possible to make good ethical choices in such situations.[220]

The framework for ethical decision-making developed by the Markkula Centre for Applied Ethics at Santa Clara University is intended to serve as a practical tool for exploring ethical dilemmas and identifying ethical courses of action. It is composed of five dimensions, each divided in multiple questions that can facilitate self-reflection, collective discussions and decision-making processes. Table 6 systematizes this framework, introducing its inherent questions and ethical lenses (i.e., the perspectives or frameworks through which individuals view and make ethical decisions).

Table 6. Framework for Ethical Decision-Making developed by the Markkula Centre for Applied Ethics at Santa Clara University[220]

Steps of the Framework	Questions to be asked	Ethical Lenses
Identify or recognize the Ethical Issues	1. Could this decision or situation be damaging to someone or to some group, or unevenly beneficial to people? 2. Does this decision involve a choice between a good and bad alternative, or perhaps between two "goods" or between two "bads"?	

	3. Is this issue about more than solely what is legal or what is most efficient? If so, how?	
Get the Facts	4. What are the relevant facts of the case? What facts are not known? 5. Can I learn more about the situation? Do I know enough to make a decision? 6. What individuals and groups have an important stake in the outcome? 7. Are the concerns of some of those individuals or groups more important? Why? 8. What are the options for acting? 9. Have all the relevant persons and groups been consulted? 10. Have I identified creative options?	
Evaluate Alternative Actions	11. Ask various questions using different *ethical lenses*	
	Which option best respects the *rights* of all who have a stake?	*The Rights Lens*: To respect others' rights and dignity
	Which option treats people *fairly,* giving them each what they are due?	The *Justice Lens*: social justice (structuring the basic institutions of society), distributive justice (distributing benefits and burdens), corrective justice (repairing past injustices), retributive justice (determining how to appropriately punish wrongdoers), and restorative or transformational justice (restoring relationships or transforming social structures as an alternative to criminal punishment).
	Which option will produce the most good and do the least harm for as many stakeholders as possible?	The *Utilitarian Lens*: the ethical action is the one that produces the greatest balance of good over harm for as many stakeholders as possible.
	Which option best serves the *entire community* and not just some of its members?	The *Common Good Lens*: mutual concern for the shared interests of all members of a community.
	Which option leads me to act as the sort of *person I want to be*?	The *Virtue Lens*: ethical actions ought to be consistent with certain ideal virtues that provide for the full development of our humanity.
	Which option appropriately takes into account the *relationships, concerns, and feelings* of all stakeholders?	The *Care Ethics* Lens: Care ethics is rooted in relationships

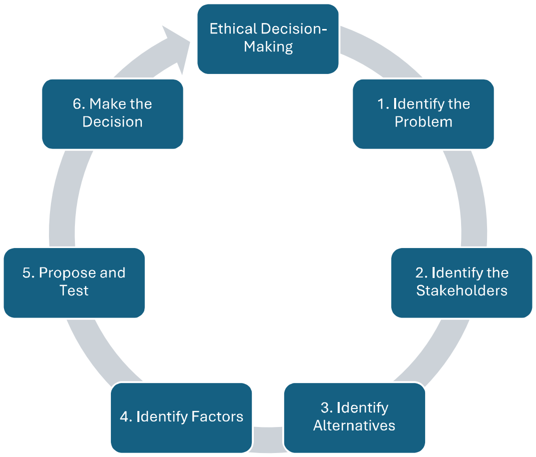
		and in the need to listen and respond to individuals in their specific circumstances, rather than merely following rules or calculating utility. It privileges the flourishing of embodied individuals in their relationships and values interdependence.
Choose an Option for Action and Test It	12. After an evaluation using all of these lenses, which option best addresses the situation? 13. If I told someone I respect which option I have chosen, what would they say? 14. If I had to present my option to a public audience, would I do it? 15. How can my decision be implemented with the greatest care and attention to the concerns of all stakeholders?	
Implement Your Decision and Reflect on the Outcome	16. How did my decision turn out? 17. What have I learned from this specific situation? 18. What, if any, follow-up actions should I take?	
Based on Markkula Centre for Applied Ethics at Santa Clara University[220]		

As described in Table 5, multiple ethical lenses can be mobilized and help answering some core questions when making complex ethical decisions. Each of these questions and approaches can help healthcare professionals and teams determine what standards of behavior can be considered ethical. However, using these ethical lenses is not without challenges in itself. In fact, when answering each one of the questions, different stakeholders might not agree on the same core set of rights, on what constitutes a common good, or not even on what constitute a “good” or a “bad” action. The apparently basic question on “what is ethical” might be answered in completely distinct ways. Nonetheless, trying to answer this wide range of questions and exploring ethical challenges using these various lenses can provide healthcare professionals and teams with relevant information that can be used to determine what is ethical in a particular circumstance.[220]

5.1.4. A Framework for Ethical Decision-Making by Michael McDonald – The W. Maurice Young Centre for Applied Ethics, University of British Columbia

As other centers dedicated to applied ethics and bioethics, The W. Maurice Young Centre for Applied Ethics at University of British Columbia developed and uses a specific framework for ethical decision-making.[221] This model has further been elaborated and applied in clinical practice.[222] One of the key features in the practical application of this model in clinical practice is its deep consideration about the context of decision-making process. The model provides a stepwise structured reflection on ethical issues, questions and challenges that raise from clinical practice. In practical terms, through this model, healthcare professionals are able to consider the context of decision-making, giving particular consideration to the combination of the following four intertwined aspects: Clinical issues, Patient preferences, Quality of life or death, and Contextual features. Moreover, it considers the healthcare professional as an active agent in the decision-making process and therefore puts emphasis on not only the rational but also the emotional aspects of the decision-making process. A series of questions are raised throughout the process to increase individual and collective awareness. This ethical decision-making framework is also built as a stepwise model that follows five steps, as illustrated in Figure 2.

Figure 2. A Framework for Ethical Decision-Making - University of British Columbia[221,222]



Each step illustrated in the figure above entails several sub-steps, features and questions that aid the decision-making process. Table 6 provides and overview of these steps, its goals, features and guiding questions.

Table 7. Framework for Ethical Decision-Making - University of British Columbia - Steps, Goals, Features and Guiding Questions[221,222]

Steps of the Framework	Goals	Features	Guiding Questions
1. Identify the problem	To collect information To identify the problem	• Be alert; be sensitive to morally charged situations. • Look behind the technical requirements. • Use ethical resources and moral intuition. • Identify what you know and don't know. • Gather information from the patient, family, other healthcare providers.	• What is the ethico-clinical problem? • What decisions have to me made? • What are the clinical issues (i.e., diagnosis, prognosis, goals of treatment, probabilities of success)? • How can the patient benefit from care and how can harm be avoided? • What are the patient preferences (i.e., preferences for treatment

		• Decisions may have to be made before a full story is known. • State the case briefly with as many of the relevant facts and circumstances as you can gather within the decision time available • Identify clinical issues • Explore patient preferences • Describe the goals of care Discover the contextual features	care, prior preferences, AD, capacity to consent)? • Is the patient's right to choose being respected to the extent possible in ethics and law? • What are the prospects in terms of quality of life and death (e.g., prospects for a return to the patient's normal life, biases that might prejudice the evaluation of the patient's quality of life, self-perceived prospect, plans or rationale to forgo treatment, plans for comfort or palliative care)? • What are the contextual factors in this situation (i.e., chapter in the patient's life, family/cultural/religious issues influencing treatment decisions, problems in allocation of resources, influence of clinical research or teaching)?
2. Identify the stakeholders	To identify who are the decision-makers To identify who should be involved in the decision-making process	• Be alert to (potential) conflict of interests • Consider the context of decision-making	• Who are the decision-makers? • Who is affected by the decision? • Who should be involved in the decision-making about this problem? • Who should be consulted?
3. Identify alternatives	To identify feasible alternatives To explore the potential consequences of each alternative	• Specify feasible alternative • State the live options at each stage of decision-making and ask what likely consequences are of various decisions. • Always take into account good or bad consequences for all affected persons. • Be honest. • Encourage others to be honest.	• What are the alternatives? • What are the potential consequences for the patient, family, healthcare team, institution? • Are there any consequences for other affected people?
4. Identify factors	To identify relevant ethical values and principles that can guide the decision	• Identify and explore ethical principles, such as autonomy, non-maleficence, beneficence, justice, fidelity, vulnerability, integrity, dignity. • Take into account moral models • Use ethically informed sources, including policies, source materials, professional norms and codes of conduct	• What are the relevant values and principles that will guide the decision-making? • Have promises been made? • Will this harm somebody? • Are we treating others fairly? • Are we being faithful to professional and institutional roles? • Are we living up to the trust relationships that we have with others?

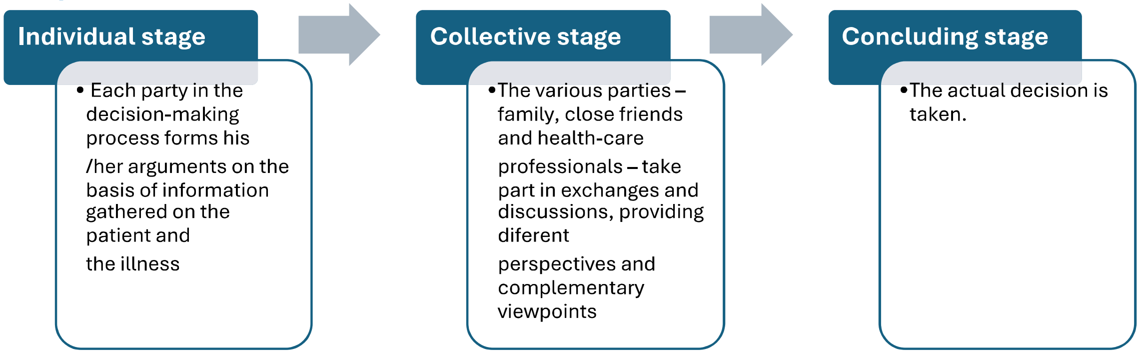
		• Explore the ethical context • Identify personal judgements (yours, your associates' ones, your trusted friends or advisors) • Organize procedures for ethical consultation (e.g., formal case conferences, consult ethics committees, liaise with ethics consultant)	
5. Propose and test	To identify the best option	• Identify the alternative that best fits the relevant values and principles • Find the best consequences overall • Propose a resolution • Select the best alternative • Perform a sensitivity analysis • Be critical • Consider the impact on ethical performance of others	• What is the best option, all things considered? • Is the proposed resolution acceptable for all stakeholders involved? • Would anything alter your decision? What would alter your decision? • Are you setting a good example? • Would a good person do this? • What if everyone in these circumstances did this? • Will this remain trust relationship with others? • Does it still seem right?
6. Make a decision and take action	To identify what needs to be done about the decision	• Finalize the decision • Accept responsibility for the decision and commit to it • Document the decision, the decision-making process, and the communication process • Communicate the decision to all stakeholders • Implement the decision • Evaluate the outcome	• What is the decision? • Who will be accountable for the decision? • Where will the decision and the decision-making process be documented? • Who will the decision be communicated to? • What are the required actions/steps and resources to implement the decision? • Who and how will the decision be evaluated and what will be the indicators of success?
Based on Framework for Ethical Decision-Making by Michael McDonald, University of British Columbia [221,222]			

5.1.5. Guide on the Decision-Making Process regarding Medical Treatment in End-of-Life Situations of the Council of Europe

The Guide on the decision-making process regarding medical treatment in end-of-life situations (hereinafter Guide) elaborated by the Council of Europe is another relevant framework and guide that was developed with the aim of improving decision-making processes and empowering professionals in making end-of-life decisions.[26] The specific aims of this Guide are: (i) to propose reference points for the implementation of the decision-making process underlying medical treatment in end-of-life situations; (ii) to bring together both normative and ethical reference works and elements relating to good clinical practices; and (iii) to contribute to the overall discussion on the decision-making process in end-of-life situations, particularly the complex circumstances encountered in this context. 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).[26]

In terms of structure, the Guide is organized into two dimensions. On the one hand, it presents the ethical and legal frames of reference for the decision-making process; on the other hand, it provides a framework for the decision-making process. The basic principles on which the decision-making is rooted are: (i) The patient should always be at the center of any decision-making process; (ii) the decision-making process takes on a collective dimension when the patient is not willing or able to participate in it directly; (iii) in principle, the collective decision-making process in end-of-life situations is made up of three main stages: individual stage, collective stage, and concluding stage (Figure 3); and (iv) patients and, where appropriate, any other people concerned (legal representatives, attorneys and persons of trust or even their family members and friends) must always have access to the information corresponding to their role in the decision-making process.[26]

Figure 3. Stages of the Decision-Making Process according to the Guide of the Council of Europe[26]



Individual stage

- Each party in the decision-making process forms his /her arguments on the basis of information gathered on the patient and the illness

Collective stage

- The various parties – family, close friends and health-care professionals – take part in exchanges and discussions, providing diferent perspectives and complementary viewpoints

Concluding stage

- The actual decision is taken.

The Guide summarizes the principles that could be applied to decisions on medical treatment when a severe deterioration in health, due to the evolution of a life-limiting or life-threatening disease, threatens the life of a person irreversibly in the near future.[26] It recognizes that, in those situations, the main purpose on any medical treatment is palliative, focusing on the quality of life or, at the very least, the control of symptoms that may impair the quality of the end of a patient's life.[15,20,21,24,26,144,168,223] The Guide calls attention to the need to take patients' wishes into consideration, actively involving patients in the decision-making process.[26] In fact, the Guide is a form of quality procedure in which the core focus is to guarantee respect for patients who may be particularly vulnerable.[26,223]

In a series of Portuguese studies, evidence suggests that end-of-life decision-making processes made by palliative care teams seem to be consistent with the guidelines of the Council of Europe.[26,60,61,109] Our research showed that the following parties were commonly involved in the decision-making process: patient, family members, and healthcare team. Other stakeholders (e.g., clinical ethics committees) were involved in an ad hoc and needs-based basis, not often meeting clinicians' expectations or practical needs. Family members were the most mentioned parties involved in the decision-making processes. Decision-making processes were characterized by collective and interprofessional approaches.[60] As recommended in the Guide, autonomy is indeed a highly valued ethical principle in end-of-life care and decision-making processes in palliative care.[60,61,109] Particularly nurses expressed major concerns in assessing patients' preferences, wishes, and promoting advance care planning.[61] According to our research, and although the Guide of the Council of Europe does not explicitly mention the role and involvement of nurses in end-of-life decision-making,[26] nurses working in palliative care in Portugal are highly involved in end-of-life decision-making.[61]

In another recent Portuguese study, a collective decision-making process with the patient at the center was valued by most participants, although they recognized the need for a more inclusive approach (e.g., involving clinical ethics committees or clinical ethics advisors as part of the decision-making process).[109] This reinforces the collective and inclusive approach recommended in the Guide of the Council of Europe.[26] This latter study also found that, although healthcare professionals rated the importance, applicability and transferability of the Guide as being very important, applicable and transferrable to their clinical practice, they do not use it in their day-to-day practice.[109] In fact, the reality is that healthcare professionals tend to use more clinical decision tools, clinical guides, clinical protocols or clinical algorithms rather than ethico-clinical decision-making frameworks or models, which require advanced ethical knowledge, competencies, team effort, time and its true embeddedness into their daily clinical practice.[109]

5.2. Decision-Making under Uncertainty, Risk and Asymmetry of Information

The need to make ethical decisions in palliative and end-of-life care, particularly end-of-life decisions, requires healthcare professionals and teams, as well as patients and family members, to embrace ethico-clinical decision-making processes under uncertainty, risk, and asymmetry of information.[35,36] Ethical decision-making often requires some level of uncertainty and risk to solve problems. Ethical decision-making can be complex and difficult processes because healthcare professionals have different roles, have differing clinical responsibilities, have different ethical values, and might perceive the same situation differently.

Clinical decision-making is part the daily practice of clinicians. They need to integrate a huge variety of clinical data while facing conflicting pressures to decrease diagnostic and/or prognostic uncertainty, to minimize risks to patients, to disclose information, and to manage limited healthcare resources. In straightforward or common situations, clinicians often make such decisions reflexively; diagnoses are made by recognizing patterns, and testing, treatment and care are initiated based on customary or protocolized practice. In more complex cases, a structured and analytical methodology may be a better approach to decision-making. Even when pattern recognition provides the most likely diagnostic or course of action possibility, analytic decision-making might be useful to confirm the diagnosis, prognosis and courses of action. These analytic methods may include the application of the principles of evidence-based medicine, use of clinical guidelines, and use of various specific ethico-clinical decision-making frameworks and models.[224-226]

Healthcare professionals are active agents in both clinical and ethical decision-making processes. It is therefore crucial to consider not only the rational elements of decision-making processes, but also their emotional aspects. In fact, "doing ethics" and making ethico-clinical decisions are not just rational cognitive processes where normative models or analytical methods are followed and applied.[203,224-226] In other words, the reality is that ethico-clinical decision-making processes are strongly influenced by personality, cognitive biases, values, cultural factors, social influences, emotions, and trust. These psychological factors can affect and modulate the use and outcomes of normative guidelines or models used in ethical decision-making.[202-205,227]

When making clinical decisions, healthcare professionals sometimes tend to exhibit several types of unconscious errors (cognitive errors). Studies suggest that these types of unconscious cognitive errors are more frequent than having lack of clinical knowledge or information, which can also influence ethico-clinical decision-making processes. Being aware of common types of cognitive errors can help clinicians recognize and avoid them in their clinical practice and decision-making processes. The most common cognitive errors are: (i) Availability error, when clinicians choose the first thing that comes to their mind, often based on their previous experience and memory of a case that was dramatic; (ii) Representation error, when clinicians focus on the presence or absence of classic manifestations of a disease or condition without taking into account their prevalence or the evidence; (iii) Premature closure, when clinicians jump to and hold on to a presumptive diagnosis or course of action, failing to consider other possibilities or alternatives; (iv) Anchoring errors, when clinicians steadfastly cling to an initial impression even as conflicting and contradictory data accumulate; (v) Confirmation bias, a "cherry-picking," when clinicians selectively accept clinical data that support a desired hypothesis and ignore data that do not; (vi) Attribution errors, when decisions are based on negative stereotypes that can lead clinicians to ignore or minimize the possibility of serious diseases or conditions; and (vii) Affective errors, that involves letting personal feelings (positive or negative) about a patient affect decisions.[228] In sum, reflective practice and cognitive bias awareness may help clinicians move toward adaptive expertise and help them improve their clinical accuracy in decision-making.[224,229]

Particularly in palliative and end-of-life care, emotions are indeed an inherent part of ethical decision-making. Hence, they should be explored in ethico-clinical decision-making processes.[227] Aristotle's view on emotions is relevant for ethics in the ethics reasoning and reflection in five ways: (i) Emotions may inform us why a moral issue or a moral question emerged; (ii) Emotions may inform us how the facts of the case are interpreted and valued; (iii) Emotions may urge us to investigate whether the way we express the emotion is morally right, justified and balanced according to the characteristics of the person and the facts of the situation; (iv) We can reflect upon the thoughts that are connected with emotions in order to investigate their reliability; and (v) We can examine whether we exhibit the right excellence or disposition regulating the emotion.[227,230] In fact, in practical terms, emotions play a role in the actual clinical case or ethical problem that needs to be solved in clinical practice, in the moral judgments and decision-making within that case, and in the process of discussing the case within the healthcare team.[231]

In situations of ethico-clinical decision-making surrounded by uncertainty, risk and asymmetry of information, emotions are often experienced as burdensome.[232,233] Psychological factors, such as bounded rationality (i.e., the limited capacity to understand all the aspects of a problem or situation at once), projection (i.e., the unconscious attribution of one's own feelings, attitudes, or desires to others, which may obscure meaningful communication about what is truly beneficial for the patient), and mixed motives or competing demands (i.e., when a person is influenced by more than one pressure, such as respecting a patient's autonomy and fulfilling one's obligations to benefit the patient, resulting in a sense of uncertainty often leading to anxiety and stress), can block the use of normative guidelines, frameworks and models for ethical decision-making.[200] As an example, evidence suggests that clinicians’ close ties to their patients might play an unexamined role in their reluctance to initiate palliative care.[232] In cases characterized by uncertainty, physicians' emotional investment in their patients and patients' families might unduly promote decisions to continue aggressive treatment rather than transition to comfort care and palliative care.[232] Through the process of reflecting upon emotions and associated thoughts, one learns to relate to the emotions and the immediate appeal they make on us. This results in a situation in which emotions do not *linea recta* guide us, and our free space and critical thinking increases.[35,36,231]

As a matter of fact, it can be inferred that normative models and frameworks of ethical decision-making sometimes do not fully consider the effects and impact of cognitive, emotional, psychological and sociocultural factors in making individual, group, shared and organizational decisions. For instance, in shared decision-making processes, healthcare professionals usually discuss the nature of the decision, describe treatment alternatives, discuss the pros and cons of the choices, assess patient and family understanding, elicit patient values and preferences, discuss the family's role in the decision-making process, assess the potential need for input from others, explore the context of the decision, and elicit the patient and the family's opinions about the treatment decision.[234,235] What is often missing is to explore patient, family, and healthcare professionals’ emotions, address potential cognitive errors and biases, and discuss uncertainty. Moreover, evidence shows that prognostic uncertainty is a prevalent source of distress among hospitalized patients with advanced cancer at the time of initial palliative care consultation, also affecting the assessment of patients’ quality of life.[234,235] That is why, in real-life situations, shared decision-making regarding end-of-life care choices will always be in some way ‘incomplete’, as clinical experts’ advice can effectively bias patients’ choices.[236-241]

6. Nursing Involvement in Ethical Decision-Making in Palliative and End-of-Life Care

Nurses are the largest professional group in healthcare[61,242-246] and those who spend more time close to patients, thus making more decisions.[61,247] When caring for patients at the end-of-life, nurses are at the patient's bedside during the dying process, developing trusting relationships, establishing confidential conversations with the patient and family members, gaining an in-depth understanding of the patient's values, wishes and preferences, building therapeutic relationships, obtaining a unique perspective on the patient's condition and life, and providing vital emotional support.[61,248-251] It is therefore not surprising that nurses are key players in ethical decision-making processes in palliative and end-of-life care. In fact, nurses act as information brokers, advocates, and mediators in ethico-clinical and end-of-life decision-making processes.[248]

Evidence from several countries shows large variations in nurses' involvement in end-of-life decision-making.[25,60,61,65,114,252] These variations occur due to cultural contours and also because of the specificities of the legal and regulatory frameworks of nursing practices in these countries.[60,114,253,254] Nurses' characteristics (e.g., education about end-of-life decisions and previous involvement in end-of-life decision-making) also seem to be determinant factors for their involvement in end-of-life decision-making.[61,252-254] Furthermore, it seems that there are also major contextual differences in the association between the need of making end-of-life decisions and the increasing vulnerability among healthcare professionals, including nurses, resulting in the development of work-related problems (e.g., burnout and moral distress).[61,65,67-69,255-257] Working in intensive care units, for instance, more than doubles the likelihood of developing burnout when compared to working in palliative care units.[69] Moreover, making end-of-life decisions was identified as a determinant factor of burnout in intensive care units[65,69] although not in palliative care units.[25,59,67-69,71] In fact, evidence suggests that nurses working in hospitals experience a higher level of moral distress when they are involved in life-prolonging treatments because of the patient's advanced disease condition and their own lack of involvement in decision-making processes about these treatments.[255,256] In these situations, moral distress is often characterized by feelings of powerlessness and frustration.[255,257,258]

A recent systematic review highlighted the multifaceted and complex ethical challenges that nurses encounter in providing end-of-life care.[252] Four overarching themes emerged: (i) the centrality of communication and decision-making and patient involvement in decision-making; (ii) the ethical dilemmas inherent in end-of-life care practice, including the balancing of ethical principles, such as autonomy, beneficence and relational aspects; (iii) the integration of palliative care principles and the alignment with patients' values; and (iv) the need for educational and organizational support to equip nurses with ethical competencies and coping strategies. These themes underscore the interdependent nature of ethical issues, palliative care practices, and the pivotal role of nurses in shared decision-making in palliative and end-of-life care.[252]

6.1. Shared Decision-Making in Palliative and End-of-Life Care

Shared decision-making is a process by which a healthcare choice is made jointly by the healthcare professional/team and the patient and is said to be the core of patient-centered care.[259-261] Shared decision-making can also be considered as an interpersonal, interdependent process in which healthcare professionals, patients and their caregivers relate to and influence each other as they collaborate in making decisions about a patient's health condition, treatment and care.[259] Despite its potential, shared decision-making has, in reality, not yet been widely adopted in clinical practice.[261] Moreover, evidence suggests that patient involvement behaviors in shared decision-making appears to be low.[261,262]

In a seminal work about shared decision-making,[263] the following minimum characteristics of shared decision-making were identified: (i) Shared decision-making involves at least two participants, the clinician and the patient; (ii) both parties (clinicians and patients) take steps to participate in the process of treatment decision-making; (iii) information sharing is a prerequisite to shared decision-making (although shared decision-making is not limited to information sharing); and (iv) a treatment decision is made and both parties agree to the decision (although mutual acceptance does not always indicate a shared decision-making process).[263] This work was mostly centered around the physician-patient relationship and the involvement of other healthcare professionals in the shared decision-making process was only slightly mentioned.[263-265] In more recent studies about the concept of shared decision making in medical encounters, nine essential elements that could be translated into specific behaviors were identified: (i) define and explain the healthcare problem, (ii) present options, (iii) discuss pros and cons (e.g., benefits, risks, costs), (iv) clarify patients' values and preferences, (v) discuss patient ability and self-efficacy, (vi) present what is known and make recommendations, (vii) check and clarify the patient's understanding, (viii) make or explicitly defer a decision, and (ix) arrange a follow-up.[33,259-261]

Although the concept of shared decision-making is widely used in the healthcare literature, there seems to be an absence of a commonly agreed operational definition of the construct.[265,266] Consequently, multiple approaches are used when referring to its definition and evaluation.[265,266] In an attempt to sketch an ethically rooted description of the construct, Chambers[265] proposed the following definition: "Shared decision-making occurs when two autonomous and uncoerced agents both commit to actions that neither has reason to want to change based on their understanding of anticipated outcomes given the situation at hand and of the intended actions of the other party".[265] This tentative definition is framed based on two elements: *deciding* and *sharing*. As a matter of fact, shared decision making is not something that one person or agent does; it is a relationship between two agents, one that either may block but neither can impose.[265]

In a shared decision-making process, the common problem to be solved must be broad enough to cover the realistic alternatives of two or more parties. That is what *sharing* means. Commitment to an action is based on choosing between alternative outcomes or hoped for conditions, considering what could be expected given the combination of what is known about the situation and the value of each potential outcome. The various agents bring their interpretations of the facts and their own values to the table. That is what a *decision* is. The relationship in shared decision-making is created because each party must consider the other's intentions. Although each party has its own set of facts and values, they interact.[265,266] A relevant feature of shared decision-making is that it goes beyond sharing information.[265-267] It is the decision that is shared, not only the information. A decision is a commitment to action with an intent to bring about a better future than what could be expected pursuing an alternative or taking no action.[265]

Some studies have shown an association between shared decision-making and patient outcomes.[261] These positive outcomes are related to the communication between healthcare professionals and patients, which can have an impact on affective-cognitive outcomes (e.g., knowledge, understanding, satisfaction, trust, less decisional conflict), behavioral outcomes (e.g., treatment decisions, adherence to recommended treatments and adoption of health behaviors), and health outcomes (e.g., quality of life, self-rated health and biological measures of health).[261,268,269] Nevertheless, one of the challenges in measuring the outcomes of shared decision-making relies precisely on what a patient considers and reports to be a shared decision, making it difficult to identify its associated factors in practice.[269] What is however unquestionable is that patients increasingly report a desire to engage in shared decision-making, which remains an important process to promote patients' involvement, autonomy, rights and satisfaction.[269,270]

Shared decision-making is particularly relevant for preference-sensitive and value-laden (i.e., heavily influenced by personal opinions and values) decisions, where there is clinical equipoise, that is, no "right" or "wrong" answer based on a universally agreed upon good outcome.[263,267] In these cases, the decision depends on patients' preferences and values and requires: (i) the exchange of information about baseline disease prognosis, treatment choices, and likely outcomes; (ii) the exchange of information about patients' goals and preferences in light of these treatment choices; and (iii) healthcare professionals to help patients to "weigh" what choice is best based on their preferences and values.[264-267,271] This is why, internationally, shared decision-making is seen as a hallmark of good clinical practice, an ethical imperative,[269,272] and as a way of enhancing patient engagement and activation.[273] There is indeed an ethical imperative to respect the agency of individuals, offer information, collaborate, and support deliberation when difficult decisions arise.[272] In other words, shared decision-making recognizes, respects and implements relational autonomy. It does so by acknowledging the need to support autonomy, by building good relationships, by respecting individual decision-making capacity and competence, and by interdependence on others.[263] As mentioned earlier, relational autonomy is indeed a cornerstone and grounded ethical principle of palliative care,[160,168,172-174] reason why the use of shared decision-making approaches is not surprising in this context.

In fact, a qualitative study on ethical decision-making in palliative care, in which the topic of shared decision-making in clinical practice was explored,[274] suggests that the concept is used to refer to various aspects that are part of palliative care philosophy and practice, such as communication, family involvement in the decision-making process, advance care planning, and provision of goal concordant care. Yet, no clear definition of shared decision-making was provided. Although shared decision-making was often presented as a core element and feature of palliative care clinical practice or as way to overcome ethico-clinical challenges and improve end-of-life care, professionals rarely systematized shared decision-making practices and interventions or evaluated its outcomes.[274] This is in line with previous studies showing that implementing shared decision-making in palliative care clinical practice requires the clarification of conceptual confusion, the inclusion of the members of the interprofessional team (e.g., nurses) in the shared decision-making process, and the adaptation of the approach to ambiguous and existential situations that often arise in palliative care.[275]

6.1.1. What can Nurses do to promote Shared Decision-Making?

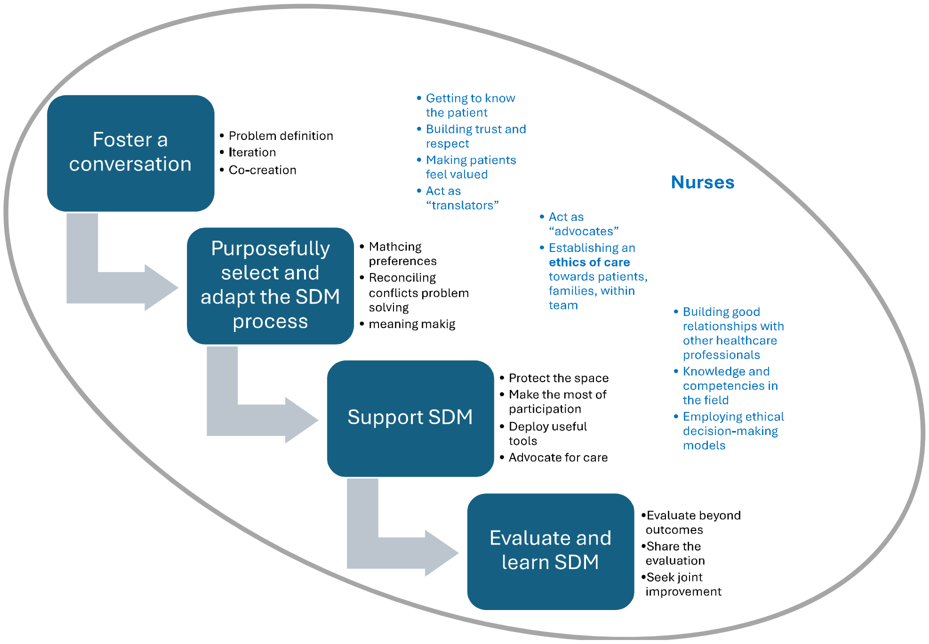
Nurses can have a prominent role when facilitating shared decision-making, particularly in palliative and end-of-life care.[274,275] In fact, an interdisciplinary collaboration and approach to shared decision-making is increasingly considered to be of great importance.[251,276] In an ideal situation, physicians, patients, close relatives and nurses are involved in a shared decision-making process to strengthen and support each other in order to arrive at high-quality decisions that are aligned with the patient's preferences, wishes, and values.[251,274] Patients and nurses often have close and frequent contact, and patients may therefore be open to sharing important information about their thoughts, concerns, emotions, wishes and preferences with nurses.[61,114,242-247,251,276] This information might concern personal preferences that patients might not feel comfortable sharing with their physicians during their relatively brief contact moments, where the emphasis is on medical or clinical information. Furthermore, nurses can strengthen the process of shared decision-making by acting as intermediaries between patients and physicians and as patients' advocates.[61,248,249,251]

A review about shared decision-making for nursing practice provided a comprehensive understanding of shared decision-making between the nurse and the patient.[277] The following categories of shared decision-making between nurses and patients were identified: (i) Communication and relationship building, taking individual characteristics into account, building trust and respect, exchanging information via interpersonal and intrapersonal communication, and taking contextual aspects into account (e.g., the specific healthcare context or service) which may facilitate or hinder the shared decision-making process; (ii) Work towards shared decision-making, with a main focus on assessment (i.e., getting to know the patient), finding balance within uncertainty and equipoise and between the nurse and the patient to arrive at a shared decision, teaching-learning (i.e., providing information to the patient and finding creative strategies to make this information understandable) and identifying the decision point (i.e., reaching the shared decision, which is not the end point in itself but signals the need for the patient to take action and carry out the decision); and (iii) Action for shared decision-making, including taking action on the decision and returning to the agent to re-evaluate the decision.[277] What is relevant to take into account is that shared decision-making is a comprehensive process that takes place between the nurse and the patient, taking its complexity into account and embracing shared decision-making as an ongoing process that does not end with the decision.[277]

The international literature is scarce in what refers to the implementation of shared decision-making processes in real world clinical practice. As highlighted above, even from a conceptual point of view, the expression shared decision-making is often used to refer to various other elements of healthcare provision (e.g., communication, advance care planning). In an attempt to systematize shared decision-making as a method of care, Montori et al.[278] proposed a simple four step model: (i) foster a conversation, (ii) purposefully select and adapt the shared decision-making process, (iii) support shared decision-making, and (iv) evaluate and learn shared decision-making. What makes this simple four step model potentially relevant for (nursing) clinical practice is that, as for shared decision-making, it should not be considered as an add-on. In reality, healthcare professionals, including nurses, are already engaging patients in conversations to work through a "shared" plan of action because that is what is required to formulate the best treatment and care plan. Every moment shared with each patient (e.g., for physicians it can be every consultation; for nurses it can be every nursing care encounter) is an opportunity to get care right for that person - intellectually, practically and emotionally -, using shared decision-making as a method of care.[278]

In practical terms, Figure 4 provides a graphical illustration on nursing involvement in a shared decision-making process based on and adapted from Montori et al's[278] proposed model and Truglio-Londrigan et al's[277] review. The light blue text in the figure for nurses results from my own analysis and interpretation of how nurses can be integrated in the shared decision-making model.

Figure 4. Nursing involvement in a shared decision-making (SDM) process



Based on and adapted from Montori et al.[278], Truglio-Londrigan et al.277. The light blue elements for nurses results from my own analysis and interpretation of how nurses can be integrated in the SDM model.

However, this role of nursing involvement in shared decision-making is not always embraced, enacted and implemented. This is due to existing misperceptions, self-perceived efficacy and competencies, and organizational clinical practices and cultures. To facilitate their contribution, nurses can enhance the shared decision-making process by checking the decision quality and by complementing and facilitating shared decision-making.[279] In fact, evidence suggests that nurses might experience varying degrees of influence on decision-making, particularly in what refers to end-of-life decisions. Different points of contact in the disease, treatment, and care trajectories exist at which nurses could enact an active role and be involved in shared decision-making processes.[279] For this to happen, some pre-conditions need to be considered, namely: (i) the transfer of information among nurses and between nurses and other healthcare professionals; (ii) a culture where there is a positive attitude to nurses' involvement in decision-making; (iii) a good relationship with physicians; (iv) knowledge and skills; (v) sufficient time; and (vi) a good relationship with patients.[279] In fact, there is still a need to further invest in developing nurses' knowledge, communication and ethical competencies about patient participation and their own role in shared decision-making processes in palliative care.

Nurses are often seen as partners and advocates for patients with palliative care needs and this important role needs to be acknowledged.[61,272,280] Moreover, nurses account for the majority of the multiprofessional healthcare team, and they are the healthcare professional group that spends more time close to patients and make more decisions.[61,242-247,272] This provides them with many opportunities to embrace an active role and participate in shared decision-making processes with patients and other healthcare professionals.[281] As a matter of fact, nurses can play the role of “advocates” and “translators” by conveying medical terms and clinical information to the patient and their family members in an easy-to-understand manner.[272,278-282] Moreover, nurses are recognized for embracing an ethics of care as the core of their professional conduct and practices. Caring and nursing are so intertwined that some conceptual nursing models are rooted in the concept and practice of caring (e.g., Jean Watson's caring theory).[283-285] Other nursing conceptual models are also aligned with the concept and practice of shared decision-making. For instance: (i) the promotion of autonomy and self-care advocated by Dorothea Orem, which explicitly clarifies a purpose for nursing practice, namely, to promote or restore the individuals' ability to self-care and the explanatory power of an action through the acquisition of skills to achieve autonomy and self-determination;[286,287] (ii) the identification and response to patients' needs, as postulated by Virginia Henderson, including the need to communicate with others about their emotions, needs, fears and opinion;[288,289] and (iii) the focus on helping patients navigate through transitions that often increase patient vulnerability as developed by Alaf Meleis.[290,291] In the latter, the goal of nursing interventions is to facilitate a healthy transition process as well as healthy outcome responses. Interventions can involve providing expertise, identifying milestones, modeling the role of others, providing resources and rehearsal opportunities and debriefing,[290,291] which is aligned with the relational autonomy required in shared decision-making.[61,274]

Therefore, engaging in active listening with patients and family members, which is part of nursing theoretical models, nursing care and nursing clinical practice, positions nurses well to promote shared decision-making processes. Through their ethical sensitivity, empathy and communication, nurses can have a major role in helping patients feeling seen, understood, and making their voices heard, exploring and understanding their thoughts, fears, desires and wishes, and involving them actively in shared decision-making as part of person-centered care.[272,277-285] In practical terms, for nurses, this implies that they should focus on aspects such as building a good relationship, acknowledging patients' feelings and circumstances, and empowering patients to feel knowledgeable, valued and heard. This way nurses will certainly have an active role in increasing patients' motivations, enhancing patients' capacity to participate in shared decision-making.[285]

7. Implications for the Future of Nursing Clinical Practice, Education and Research

Ethical decisions and decision-making in palliative and end-of-life care is a highly complex topic, which requires nursing involvement, practice, education and research. Based on this detailed summary of my lecture, various implications for the future of nursing clinical practice, education and research can be drawn.

Table 8. Implications for Nursing Clinical Practice, Education and Research

Implications for Nursing Clinical Practice, Education and Research
Implications for Nursing Clinical Practice
Nurses are relevant key players in the provision of palliative and end-of-life care, regardless of the specific context in which they conduct their clinical practice.
Nurses need to embrace an active role and involvement in ethico-clinical decision-making processes.
Ethical frameworks and models are useful to guide nurses in their clinical care encounters and interactions with patients and family members.
As members of multi-professional teams, nurses can have an active role in facilitating and participating in team meetings focused on implementing and using ethico-clinical decision-making models in clinical practice.
Uncertainty, risk and asymmetry of information need to be acknowledged as part of nursing clinical practice, particularly in clinical contexts characterized by clinical uncertainty.
Nurses need to hold their role of patient “advocates” and “translators”, fostering and participating more actively in shared decision-making processes.
Implications for Nursing Education
More and better knowledge is needed on the different types of ethical decisions, particularly on the various disputed issues, in palliative and end-of-life care. These topics should be introduced at undergraduate and post-graduate nursing education programs.
Considering the complexity inherent to ethical decision-making in palliative and end-of-life care, nursing education should integrate multidisciplinary modules. This would contribute to close the gap between healthcare disciplines.
Nurses need to further develop their ethical competencies, including their ethical sensitivity and ethical applied knowledge. Education about nursing ethics, particularly on ethics in palliative and end-of-life care, should be pragmatic and oriented towards the applicability of theoretical, conceptual and philosophical topics into clinical practice.
Although the development of nursing as a discipline is relevant, nursing education needs to acknowledge the nowadays complexities of healthcare needs, services, organizations, and systems. Therefore, multi and interdisciplinary approaches are needed to foster education in these highly complex topics, such as ethical decision-making in palliative and end-of-life care.
On the job-training, in terms of continuous education, should be promoted on existing ethico-clinical decision-making models and their application into day-to-day clinical practice.
Implications for Nursing Research
More research is needed on the actual role and involvement nurses have or can have in ethical decision-making in palliative and end-of-life care. Considering the complexity of this area, this type of research should be interdisciplinary and inter-sectoral.
Considering the lack of consensualized definitions about shared decision-making, particularly in palliative and end-of-life care, its operationalization in clinical practice, and the role of nurses in its implementation, further research is needed on this topic.
Further research is needed on the applicability and usability of ethico-clinical decision-making frameworks and models in nursing clinical practice.

8. Concluding Remarks: Take home messages

This Summary of the Lecture provides a detailed description of the Lecture entitled *"Ethical decisions and decision-making in palliative and end-of-life care: Nursing involvement and implications for the future"* that I will present to Universidade de Évora for the awarding of the Academic Title of Aggregated, as established by the Portuguese Decree-Law n.º 239/2007 of June 19th, line c) of Article 5th, updated by the Portuguese Decree-Law n.º 64/2023 of July 31st, and by the Universidade de Évora Circular Letter 2/2009 of March 13th. The topic of the lecture fits within the scientific area or specialty of Health Sciences, Technologies and Well-Being: Nursing.

The choice for this topic is intertwined with my career path in nursing clinical practice, education and research, as well as with my publication and research record. The latter is partially introduced throughout this detailed summary whenever appropriate.

As concluding remarks, I would like to suggest the following take-home messages,

- Ethical decisions and inherent decision-making processes are part of contemporary healthcare practices, particularly in palliative and end-of-life care.
- Palliative care is rooted in core ethical principles and values, such as autonomy, dignity, beneficence, non-maleficence, integrity, vulnerability, solidarity, solicitude and justice. It respects patients' choices, acts to promote and meet patients' wishes, values, and preferences, and helps families to deal with practical issues, including coping with loss and grief throughout the disease trajectory and in case of bereavement.
- It is paramount to find the proper balance in terms of treatment and care provided to patients with palliative care needs to ensure its alignment with patients' values, preferences, wishes, promoting patients' quality of life.
- Nurses are the largest professional group in healthcare and those who spend more time close to patients, thus making more decisions. They are key players in ethical decision-making processes in palliative and end-of-life care.
- There is a large amount, variety, and complexity in the type of ethical decisions that need to be made in palliative and end-of-life care.
- Ethical decision-making frameworks and models exist and can help nurses and other healthcare professionals in making complex, challenging and difficult ethical decisions, particularly in palliative and end-of-life care.
- Nurses, and other healthcare professionals, need to further develop their ethical sensitivity and ethical competencies to participate actively in shared decision-making processes and ensure person-centered care for patients at the end-of-life and their loved ones.
- Considering the increase in palliative care needs and in providing complex healthcare interventions, healthcare systems need to adapt. Therefore, further interdisciplinary and intersectoral education and research is needed on this highly relevant and complex topic.

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