13. Bioethical frameworks in end of life care decision-making

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The medicalisation of dying and death and increasing access to high-technology interventions at the end of life have led to multiplying ethical challenges and complex decision-making processes in end of life care. Nowadays, people die more often due to chronic progressive diseases, frequently in old and very old age, and institutionalised (Dattani et al. 2023; Fong 2019; Martins Pereira et al. 2018; Martins Pereira et al. 2015; Morgan et al. 2020). Globally, serious health-related suffering will increase most rapidly among older people, which will be driven by rises in deaths due to cancer and dementia (Sleeman et al. 2019), posing relevant ethical challenges.

The medicalisation of death, defined as a dying process facilitated or prolonged by medical intervention (Hetzler and Dugdale 2018), has enabled patients to live longer. Yet, from historical, sociological, and even medical perspectives, the medicalisation of death has transformed the inherently humane nature of dying and death into a highly technical process, often perceived as a failure. Although the COVID-19 pandemic contributed to a shift in the trends of place of death (O'Donnel et al. 2021; Teasdale et al. 2024; Tong et al. 2023), the truth is that, over the last decades, dying and death in people's own homes and surrounded by their loved ones has diminished, replaced by death in hospitals or other institutions and surrounded by strangers (Gustafson et al. 2023; Wiltshire et al. 2024; Wachterman et al. 2022).

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 (Council of Europe 2014). Evidence shows that, in these end of life situations, most patients prefer to die peacefully, rather than receiving aggressive life-prolonging treatments (Becker et al. 2017; Coret and Martimianakis 2023; Cottrell and Duggleby 2016; Emanuel and Emanuel 1998; Fleming and Farquhar 2016; Kehl 2006; Martins Pereira et al. 2018; Zimmerman 2012; Zimmermand and Wennberg 2006). Healthcare professionals are increasingly making complex ethical decisions at the end of life. These so-called end of life decisions are nowadays an integrated dimension of contemporary palliative and end of life care, mostly due to the need to change the purpose of treatment and focus on improving patients' quality of life (Hernández-Marrero et al. 2019; Hernández-Marrero et al. 2016; Rietjens et al. 2012; Raijmakers et al. 2011; Martins Pereira et al. 2018).

End of life decisions are medical decisions made at the end of life that may have a potentially life-shortening effect (Council of Europe 2014; Deyaert et al. 2014; Chambaert et al. 2008; Martins Pereira et al. 2018; Miccinesi et al. 2005; Onwuteaka-Philipsen et al. 2006). It is therefore not surprising that decision-making processes underlying end of life decisions are embedded in, and foster, clinical, ethical, sociocultural, religious, political, and economic concerns (Martins Pereira et al., 2018). End of life decision-making frequently involves a complex and sometimes challenging balance of clinical, cultural, social, ethical, religious, and economic considerations (Akdeniz et al. 2021; Cain et al. 2018; Coret et al. 2023). The importance of end of life decisions and inherent decision-making processes is therefore paramount, as they not only refer to the ethical aspects of care but also foster the establishment of various legal frameworks.

End of life situations are very often moments of high vulnerability, which can profoundly impact patients' ability to exercise autonomy (Martins Pereira et al. 2018). When autonomy is compromised, and patients are unwilling or unable to take a direct part in the decision-making process, discussions involving surrogate decision-makers become essential (Shanley et al. 2017; Wendler 2017; Fetherstonhaugh et al. 2017; Schildmann et al. 2015). The use of advance care planning, the timely discussion of patients' values and preferences, the shared definition of goals of care, the presence of advance directives, the need to set up priorities and decide upon the escalation or not of certain treatments, and the allocation of resources can increase the complexity inherent to these decision-making processes.

Doubts can occur on what to do: What is the best course of action in this specific situation? Simultaneously, when trying to answer these questions, conflicts within the interprofessional healthcare team and between these professionals and the patient's family members may happen. This happens mostly because of the different perspectives these stakeholders may have around what they consider to be the patient's best interest.

In this chapter, first, we will reflect on how bioethics and end of life care ethics emerged in response to, on the one hand, the technological developments that have not only expanded life expectancy but also the number of treatments aimed at curing diseases and improving persons' quality of life, and, on the other hand, to the anthropological issue of the medicalisation of dying and the increasing high-technology interventions that are provided to persons at the end of life. Second, an overview of ethical issues and decision-making processes in end of life care is provided. Third, a brief review of existing studies about the role of bioethics in end of life care is presented. Finally, throughout the chapter, an in-depth reflection is developed on how healthcare professionals can promote a more holistic approach to end of life care, focusing on health and human integrity from an existential perspective rather than simply prolonging life.

MEDICALISATION OF DYING AND ETHICAL DILEMMAS IN END OF LIFE CARE BIOMEDICAL SETTINGS

Modern medicine has unequivocally altered the process of dying and the anthropological understanding of death (Sallnow et al. 2022). This has required a redefinition of ethical boundaries, particularly in the realm of end of life care. Throughout history, illness, pain, and suffering have been constant companions of humanity. These experiences can shake our beliefs and leave us with deep emotional wounds that require appropriate responses. Whether we are dealing with grief, dying, or death, vulnerability can have a profound impact on individuals, groups, communities, and societies. We must acknowledge this reality and work together to find effective solutions to help us heal, care for each other, and move forward.

Biologically, we comprehend death. Yet, the real experience of dying remains unknown. In the presence of a lifeless body, what constitutes life? The subject is missing, as their presence would indicate vitality. This question emphasises the ambiguity of life and death and reminds us that life is a valuable gift that must never be taken for granted.

In Western societies, for example, after someone passes away, people often refer to the deceased person as a body rather than by the person's name. Usually, the following expressions are used: 'bring the body', 'take care of the body', 'dress the body', 'lower the body into the grave', and so on. This highlights the mystery of death, which will always remain inconceivable to us because it is humanly impossible to know what it is like to be dead. A dead consciousness is contradictory and therefore unknowable. The Greek philosopher Épicure, who lived in the fourth century BC, once wrote to his disciple Ménécée a famous axiom that still resonates with many people today. He argued that 'death, the most terrible of all evils, is nothing to us since it does not exist for as long as we are alive. And when death eventually arrives, we will no longer exist to experience it' (Épicure, in Hutchinson, 1994).

Throughout history, humans have been searching for ways to live more, better, and, if possible, forever. In 'The Epic of Gilgamesh', a Sumerian poem that dates back more than 4,000 years, the main character is afraid of dying and sets out on a futile journey to find immortality. After the death of his dear friend Enkidu, Gilgamesh becomes obsessed with the idea of immortality. He goes on a journey to find Utnapishtim, the only ancestor who survived a great flood, hoping that he can reveal to him the secret of eternal youth. Gilgamesh eventually finds the plant at the bottom of the sea, but a serpent steals it from him before he can take it. Disappointed, Gilgamesh returns to his city of Uruk, realising that he cannot escape the inevitability of death. This quest for eternal life is also present in the biblical myth of Genesis, with two trees planted at the centre of the Garden of Eden: the tree of knowledge and the other one of life (Genesis 2:8–9). Beyond these mythical and religious scripts, the desire for immortality in the field of medicine can be traced back from ancient times up to the present. From Greek mythology (Echeverry 2012; Sellman 2023) to modern music (for example, Queen's 'Who Wants to Live Forever?'), the desire for immortality has been constantly present and represented in multiple ways.

Yet, as we all know, death is both inevitable and universal, making the quality of dying and death, and maintaining the quality of life for those who are dying and for those caring for them a public health issue that, like any other public health issue, poses ethical challenges (Albers et al. 2015). In fact, the four characteristics of public health (it is a public or collective good; it involves a particular focus on prevention; it often entails government action; and it involves an intrinsic outcome orientation) are interrelated with ethical challenges (Faden et al. 2019). Many real-world challenges in public health require an ethics approach and consideration around ethical principles and the associated legitimacy standpoints in order to provide an adequate analysis of what is ethically at stake (Faden et al. 2019).

According to Veatch and Guidry-Grimes (2020), four levels of moral or ethical discourse can be identified: (i) Meta-ethics, which is an attempt to understand the metaphysical, epistemological, semantic, and psychological presuppositions and commitments of moral or ethical thought, talk, and practice; (ii) Normative ethics, which can be organised into three theories – the action theory (what are the principles for a right action?), the value theory (what things are good or valuable?), and the virtue theory (what character traits are good to have?); (iii) Rules and rights, which often refer to codes of ethics and/or codes of conduct; and (iv) Casuistry, which refers to the analysis of paradigmatic cases where one or more people disagree on the best course of action. Consideration of these levels of moral or ethical discourse is paramount as they are deeply intertwined and can be used to make ethical decisions. Establishing a deeper connection across these levels of moral or ethical discourse involves integrating the goals, procedures, risks, and implications of scientific endeavours with an understanding of the fundamental ontological nature, the axiological value of reality and discovery, and the nature of human and interpersonal relations.

Modern healthcare systems have medicalised death (Clark 2002), which has significant implications for how individuals perceive and navigate through the care and dying process. By treating death as a medical act that requires intervention and treatment, rather than considering it a natural part of life, patients are often encouraged to view their end of life experiences through a lens of medicalised care. In this context, experiencing a life-limiting disease and nearing the end of life might often be lived as a failure by both healthcare teams and patients and their families. The medicalisation of dying and death has bioethical implications that need to be considered carefully. This shift in paradigm impacts not only patients' expectations for aggressive interventions and technology to extend their lives, but it also influences decision-making related to end of life care. Consequently, patients and their families often face difficult decisions when considering treatments that may have limited benefits and high burdens. These challenges can lead to ethical issues and implications, emotional distress, and conflicts (Hetzler et al. 2018; Sutherland 2019).

In situations where someone is terminally ill, putting too much emphasis on medical interventions can hurt patients' quality of life and increase suffering. This can lead to physical discomfort, emotional strain, and an overall diminished sense of well-being. It can also affect communication between patients, families, and healthcare professionals (Endacott et al. 2016; Hold 2017; Ventura et al. 2013; Voltz et al. 2022). Sometimes, discussions about goals of care and end of life preferences can take a backseat to other more aggressive and high technological medical procedures. Given the complexities of medicalised dying, it is crucial to consider the ethical implications that arise. These include the need to balance between preserving life and maintaining quality of life, respecting patient autonomy and values, and promoting a patient-centred approach that prioritises comfort, dignity, and the fulfilment of patient wishes (Kelly et al. 2002; Martins Pereira et al. 2018; Houska and Loučka 2019). By doing so, we can ensure that end of life care is provided compassionately and humanely and upholds the values of patients (Akdeniz et al. 2021; Borges et al. 2024; Kennedy 2016).

One of the main challenges here is balancing the desire to extend life through advanced medical interventions with the equally important goal of maintaining or improving the quality of life for patients at the end of life. The decision of when to switch from curative treatments to palliative care can be emotionally and ethically complex and requires careful consideration of patients' values and preferences. The growing availability of advanced medical treatments has led to concerns about administering disproportionate interventions that provide little or no benefit to patients at the end of life. This highlights the importance of carefully assessing the suitability of continuing with such interventions and prioritising patients' comfort and dignity (Hetzler et al. 2018; Sutherland 2019).

The medicalisation of dying and the widespread use of high-tech interventions in biomedical settings have created significant ethical challenges in end of life decision-making worldwide (Clark 2002; Hetzler et al. 2018; Houska and Loučka 2019; Kelly et al. 2002; Martins Pereira et al. 2018). When death is seen as a medical crisis to be managed and overcome by medical means, it can result in a greater emphasis on curative treatments rather than on palliative care and comfort measures. This approach has contributed to a rise in ethical challenges that involve balancing goals of care, respecting patients' autonomy, providing high-quality compassionate care, and promoting well-being that aligns with patients' preferences and values (Delgado 2021; Hetzler et al. 2018). Patient autonomy is a critical aspect affected by the medicalisation of dying. It empowers individuals to make well-informed decisions about their care, including choices about end of life treatments and care (Beauchamp and Childress 2019).

Caring for someone with a serious illness can be challenging not only for patients but also for families and caregivers. They may have to make extremely complex and difficult treatment decisions, which can be emotionally taxing. With so many options available, decision-making requires careful ethical reflection, in-depth discussion, and consideration. Balancing patients' interests and preferences with the perspectives of families and healthcare professionals can sometimes lead to ethical challenges (Gracia 2001, 2003; Kalsi et al., 2020; Quill and Miller 2016).

The shift towards a more medicalised approach to dying has resulted in death being viewed through medical lenses. This approach can sometimes come at the expense of patients' quality of life and their personal preferences. Sometimes, it may even overshadow the natural aspects of the dying process (Sallnow et al., 2022; Cain et al. 2018). In recent years, medical technology has come a long way, giving us more options for treating illnesses, prolonging life, and improving quality of life. However, this also raises important ethical questions. For example, the use of too many diagnostic tests or treatments can be perceived as inappropriate and can constrain healthcare resources. This is especially true when it comes to incurable illnesses, where decisions about treatments can be difficult for patients, families, and healthcare professionals. Ultimately, it is up to healthcare systems to act ethically and equitably when it comes to allocating limited resources (Fritz 2021; Munthe et al. 2021; Ford et al., 2000).

Balancing the advantages and potential risks of medical treatments, respecting patients' autonomy, and guaranteeing that care aligns with individuals' values and preferences are some of the complex issues at stake. These challenges are further complicated by conflicting medical objectives, patient desires, family expectations, cultural beliefs, and societal norms, requiring careful consideration of multiple, interrelated, and even conflicting ethical principles and effective communication. To address these challenges, a holistic approach is necessary, integrating ethical reflection, open and honest communication, and an unwavering commitment to patient-centred care that upholds individual autonomy, dignity, and values in palliative and end of life care (Cain et al. 2018; Quill and Holloway 2012).

ETHICAL CHALLENGES AND DECISION-MAKING IN END OF LIFE CARE

The main goal of palliative and end of life care is to alleviate suffering, optimise the quality of life until death occurs, and provide comfort and dignity in death (Akdeniz et al. 2021; Hui et al. 2013, 2014; Krau 2016; Rome et al. 2011). Achieving these goals is not always easy, and decision-making processes are often complex, difficult, and challenging (Hernández-Marrero et al. 2016; Martins Pereira et al. 2015; Watts 2012). 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, including healthcare professionals, patients, families, and care partners (Akdeniz et al. 2021; Hernández-Marrero and Martins Pereira 2023; Hui and Bruera

2020; Hui et al. 2014, 2022; Hurst et al. 2007; Martins Pereira 2022; Ribeiro et al. 2024; Rome et al. 2011; Watts 2012).

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 respects the interests and values of all those involved in the decision-making process. Because physicians, patients, families, and care partners have to make decisions about care and treatment options, they face various ethical challenges, some of which are related to end of life care (Akdeniz et al. 2021; Council of Europe 2014; Deyaert et al. 2014; Hernández-Marrero et al. 2016; Hurst et al. 2007; Rietjens et al. 2012).

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’ is lacking within empirical bioethical research (Schofield et al. 2021). 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 to be done successfully and therefore tests a person’s and/or a healthcare team’s ability to make a decision (Martins Pereira and Hernández-Marrero 2023). However, while there is a broad range of literature around various ethical challenges and ethico-clinical decisions in palliative care, there is little evidence systematising and collating the wide range of ethical challenges that are encountered in palliative care clinical practice (Clark et al. 2018; Schofield et al. 2021).

Healthcare professionals working in specialist palliative care report experiencing various 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 (Quill and Miller 2016). This highlights the need to further research and better systematise ethical decisions in palliative and end of life care. See Table 13.1.

Decision-making in palliative and end of life care is a complex process (Akdeniz et al. 2021; Emanuel and Scandrett 2010). The need to make ethical decisions (e.g. end of life decisions, communication about difficult issues such as life-threatening diagnoses and limited prognoses, 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 (Dijxhoorn et al. 2021; Harrison et al. 2017; Hernández-Marrero et al. 2016; Moss et al. 2016; Teixeira et al. 2014; St Ledger et al. 2013; Pereira et al. 2011; Martins Pereira et al. 2014; Martins Pereira et al. 2016). 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 (Dijxhoorn et al. 2021; Harrison et al. 2017; Hernández-Marrero et al. 2016; Martins Pereira 2011; Pereira et al. 2011; Martins Pereira et al. 2014, 2016). 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 (Hernández-Marrero et al. 2016; Martins Pereira 2011).

Clinical judgement and effective communication among healthcare professionals, patients, families, and care partners, as well as within healthcare teams, are essential ingredients in the ethics of care (McCabe and Coyle 2014). Illness with long trajectories provide both the opportunity and the obligation for healthcare professionals to have ongoing conversations

Table 13.1 Main ethical challenges in palliative and end of life 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

Main ethical challenges	Ethical principles and values
Work related problems (e.g. moral distress, burnout, compassion fatigue, post-traumatic stress disorder)	Professionals' Vulnerability, Responsibility

Sources: Based on Akdeniz et al. (2021); Cherny et al. (2015); Chung et al. (2016); Dolan et al. (2021); Emanuel and Scandrett (2010); Garani-Papadatos et al. (2022); Guevara-López et al. (2015); Guo and Jacelon (2014); Hernández-Marrero et al. (2020); Hernández-Marrero et al. (2019); Hernández-Marrero et al. (2016); Martins Pereira (2011); Martins Pereira et al. (2018); Martins Pereira et al. (2015); Martins Pereira and Hernández-Marrero (2023); Meyerheim et al. (2021); Pereira et al. (2011); Philip et al. (2019); Quill and Miller (2016); Schofield et al. (2021); Shaw and Battin (2015); Surges et al. (2024); ten Have and Welie (2014); Twycross (2019); Watson (2019); Worthington and Thorns (2005).

with patients and families about their values, preferences, and wishes for present and future healthcare. In palliative care, the ethics of care is paramount to ensure the implementation of an effective ethical decision-making process (Pereira et al. 2012).

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 (De Panfilis et al. 2019). In practical terms, this translates to tangible actions, such as telling the truth while keeping hope alive, respecting as much as possible patient autonomy, and meeting patients' needs, particularly at the end of life (De Panfilis et al. 2019; Fotaki 2015; Fredriksson et al. 2003; Olsman et al. 2016).

In the context of palliative and end of life care, disputed issues may occur. A disputed issue refers to an important ethical issue or a decision that people argue and disagree about. By their nature, disputed issues are controversial and divisive (Wilkinson and Savulescu 2019; Ruck Keene and Lee 2019). 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* by the Council of Europe (2014), various disputed and controversial issues exist in palliative and end of life care. For example, the legal status and binding force of advance directives (ADs), the limits and contents of ADs, the question of forgoing 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 each presented as disputed issues that warrant further debate, discussion, and careful consideration (Council of Europe 2014).

On another note, the controversies surrounding euthanasia and (physician) assisted suicide are so strong that, in its *Guide*, the Council of Europe (2014) deliberately chose not to include these end of life decisions. 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 nowadays (Radbruch et al. 2016). Table 13.2 systematises the definitions of euthanasia, (physician-)assisted suicide, and non-treatment decisions.

Based on these internationally consensualised definitions provided by international associations such as the EAPC (Radbruch et al. 2016) and the International Association for Hospice and Palliative Care, IAHPC (De Lima et al. 2017), decisions about euthanasia and (physician) assisted suicide clearly differ from other decisions, such as non-treatment decisions

Table 13.2 *Definition of euthanasia, (physician-)assisted suicide and non-treatment decisions*

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 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.

Source: Based on Radbruch et al. (2016) and De Lima et al. (2017).

(withholding and/or withdrawing), voluntary cessation of eating and drinking, and palliative sedation (De Lima et al. 2017; Radbruch et al. 2016).

The terms '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 'euthanasia' and 'assisted suicide' with 'softer' ones, such as MAID, corresponds to the use of euphemisms (Jones 2021; National Academies of Sciences, Engineering, and Medicine 2018; Sams and Jaggard 2024). A recent article pinpoints the fact that this trend is deleterious because proponents of MAID 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 (Sams and Jaggard 2024). 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 (Sams and Jaggard 2024). Unambiguous language and clear definitions should always be provided when referring to end of life decisions, including the 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 (Martins Pereira and Hernández-Marrero 2018; Seale 2009; Zenz et al. 2014, 2015). However, there seems to be a trend towards a broader acceptance and societal normalisation of the practices of euthanasia and assisted suicide, even in persons with advanced dementia or psychiatric conditions and in children or minors (Bolt et al. 2017; Brinkman-Stoppelenburg et al. 2020; Cohen et al. 2014; Evenblij et al. 2019; Lerma-García et al. 2024; Singh et al. 2020). One of the basic principles of palliative care is that it neither hastens nor postpones death. Therefore, international associations (e.g. the EAPC and the IAHPC) have been expressing and reinforcing their opposition to these practices (De Lima et al. 2017; Finlay 2018; Radbruch et al. 2016). 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 (Finlay 2018). However, with the growth in the number of countries legalising 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 (Radbruch et al. 2016).

A common denominator between those in favour 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 (Blaschke et al. 2019; Preston 2019). 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 (Finlay 2018; Radbruch et al. 2016).

THE ROLE OF BIOETHICS IN END OF LIFE CARE: THE 'WISH TO HASTEN DEATH' AS A BIOETHICAL CHALLENGE

The role of bioethics in end of life care is associated with providing essential insights into the ethical challenges faced by healthcare professionals, patients, and families when making decisions about care at the end of life. Patient autonomy is a cornerstone principle in both bioethics and palliative care (Borges et al. 2024; Hernández-Marrero et al. 2019; Kalsi et al. 2020; Martins Pereira et al. 2018). This underscores the importance of respecting patients' rights to make informed choices about care, including treatment options, palliative care, and ADs (Endacott et al. 2016; Gómez-Vírseda et al. 2019; Hetzler et al. 2018; Hold 2017).

Healthcare professionals, family members, and care partners also play a crucial role in guiding and promoting patient autonomy and shared decision-making processes, providing relief from suffering, and support that addresses physical, emotional, and spiritual needs. In fact, shared decision-making in palliative care can be considered a process in which patients navigate the balance between autonomy and reliance on healthcare professionals (Edwards et al. 2023; Svendsen et al. 2024). Yet, the main responsibility for successful patient participation in shared decision-making lies with the healthcare professionals and the organisations providing palliative care (Kuosmanen et al. 2021). Promoting dignity, comfort, and peace is crucial to ensuring that decision-making processes are truly shared and end of life care aligns with the cultural beliefs, values, wishes, and end of life preferences of patients (Borges et al. 2024; Cain et al. 2018; Hernández-Marrero et al. 2019; Kennedy 2016; Martins Pereira et al. 2018; Murali 2020; Sailian et al. 2024).

Focusing on patients' needs in end of life situations includes having open and honest conversations with patients about their goals of care, treatment options, and advanced care planning (Borges et al. 2024; Edwards et al. 2023; Hernández-Marrero et al. 2019; Kalsi et al. 2020; Martins Pereira et al. 2018; Svendsen et al. 2024). Effective communication is crucial for ethical decision-making and requires healthcare professionals, patients, families, and care partners to navigate complex ethical dilemmas with sensitivity, compassion, and respect for patients' autonomy. Balancing beneficence and non-maleficence while considering patients' family-centric society is essential to resolving ethical conflicts (Cain et al. 2018; Güell et al. 2015; Varkey 2021), ensuring the significance of prioritising the quality of life over the length of life through aggressive medical interventions.

Bioethics research in end of life care examines ethical challenges, such as balancing the goals of prolonging life and ensuring the quality of life, navigating cultural and religious beliefs, and managing conflicts among stakeholders (Akdeniz et al. 2021; Hernández-Marrero et al. 2019; Karnik and Kanekar 2016; Kalsi et al. 2020; Martins Pereira et al. 2018). It also plays a crucial role in establishing legal frameworks, codes of ethics, and healthcare policies that regulate ethical standards and guidelines for providing compassionate care and making ethical decisions in palliative and end of life care (Akdeniz et al. 2021; Cain et al. 2018; Quill and Miller 2016). Evidence suggests that developing ethical competencies, including ethical sensitivity and cultural sensitivity through education among healthcare professionals is crucial when navigating these challenges with integrity and ethics (Boström et al. 2022; Lechasseur et al. 2018; Tang et al. 2023; Weaver et al. 2008). This underpins care delivery, upholds ethical standards, and respects patients' dignity at the end of life (Cain et al. 2018; De Panfilis et al. 2020; Hemberg and Bergdahl 2020; Hernández-Marrero et al. 2019). The role of bioethics in end of life care highlights the importance of interdisciplinary collaboration among healthcare professionals, such as nurses, physicians, social workers, ethicists, policymakers, and researchers. This approach can help address complex ethical challenges and provide holistic care to patients and their families (Akdeniz et al. 2021; Alanazi et al. 2024; Fornehed et al. 2020).

BIOETHICAL DECISION-MAKING PROCESSES: MODELS AND FRAMEWORKS

Various bioethical models and frameworks can be identified to aid healthcare professionals when navigating through complex decision-making processes, particularly at the end of life (Grill and Dawson 2017; Suarez et al. 2022; van Bruchem-Visser et al. 2020). 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 (Khizar and Harwood 2017). A recent review identified at least seventeen different frameworks for complex decision-making in older patients, which could be divided into two categories: with or without a step-by-step plan (van Bruchem-Visser et al. 2020). Another study expanded the use of frameworks or models to other healthcare specialties, identifying a total of 55 ethical decision-making models across seven healthcare professional groups and 22 sub-fields (Suarez et al. 2022).

A selection of five different frameworks that can be used in complex ethical decision-making processes in palliative and end of life care is provided in this chapter. The choice of these five frameworks is based on the fact that they represent best practice in the interprofessional resolution of ethical problems in clinical practice, with a focus on the tools needed for all team members to communicate with each other. All five models embrace an interdisciplinary, collective, dialogical, communicative, and thought-provocative approach that makes them useful both in clinical contexts and in education.

The first model refers to the seminal work entitled 'The Anatomy and Physiology of Ethical Decision Making in Oncology' developed by Amy M. Haddad (1993). Haddad proposes a five-step normative decision-making model to help healthcare professionals arrive at sound ethical judgements. 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 as follows: first, respond to the 'sense' or feeling that something is wrong; second, gather information and conduct an in-depth assessment of the situation; third, identify the ethical problem and/or establish a moral diagnosis of the situation; fourth, seek a solution; and fifth, work with others to determine a course of action (Haddad 1993). These steps outline a process, a way of making judgements about what ought to be done in a particular ethically complex situation (Haddad 1993, 1994, 1996). Although this model embraces a stepwise approach, ethical decision-making is more than following steps. In fact, there are multiple and complex questions inherent in each step. The decision-making process 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 (Veatch et al. 2015). This framework includes ethical principles to systematically analyse and resolve ethical problems in particular cases. This normative model for ethical decision-making provides a guideline for systematic reflection that will lead to a clear articulation of an ethical problem and a justifiable resolution (Haddad 1993, 1994, 1996; Veatch et al. 2015).

The second model is Moral Case Deliberation (MCD), a process in which everyone concerned with 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 (Gracia 2003). The goal of this process is not to reach a consensus but to enrich points of view with others, increasing the maturity of the decision to make it wiser or more prudent (Gracia 2003). MCD provides group-wise, structured reflection on dilemmas from practice (Abma et al. 2009; Haan et al. 2018; Svantesson et al. 2014; Weidema et al. 2013; Weidema et al. 2012).

In practical terms, MCD is organised through collaborative meetings where a group of healthcare professionals jointly reflect on a concrete moral question, issue, or dilemma (Abma et al. 2009; Haan et al. 2018; Janssens et al. 2015; Rasoal et al. 2017; Stolper et al. 2016; Svantesson et al. 2014; Weidema et al. 2012, 2013; Widdershoven and Molewijk 2010). 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 (Abma et al. 2009; Gracia 2003; Haan et al. 2018; Janssens et al. 2015; Stolper et al. 2016; Svantesson et al. 2014; van Bruchem-Visser et al. 2020; Weidema et al. 2012, 2013; Widdershoven and Molewijk 2010). 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?' (Abma et al. 2009; Gracia 2003; Haan et al. 2018; Janssens et al. 2015; Rasoal et al. 2017; Stolper et al. 2016; Svantesson et al. 2014; van Bruchem-Visser et al. 2020; Weidema et al. 2013; Weidema et al. 2012; Widdershoven and Molewijk 2010). Moreover, in these meetings, three central, often co-existing, goals of MCD 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 professionals' moral competencies, (iii) to reflect on institutional or organisational issues and improve the moral quality of care at that level (Abma et al. 2009; Gracia 2003; Haan et al. 2018; Janssens et al. 2015; Stolper et al. 2016; Svantesson et al. 2014; van Bruchem-Visser et al. 2020; Weidema et al. 2013; Weidema et al. 2012; Widdershoven and Molewijk 2010).

Various examples of MCD 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 in the moral case deliberations, plus the conclusions deriving from 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 emerge, fleshed out in learning by doing (Stolper et al. 2016; Widdershoven and Molewijk 2010). In simple terms, MCD is based on the assumption that group reflection increases insight into ethical issues (Gracia 2003; Rasoal et al. 2017).

A more simplified MCD model has been developed by Widdershoven and colleagues (Abma et al. 2009; Janssens et al. 2015; Stolper et al. 2016; Svantesson et al. 2014; Weidema et al. 2012, 2013; Widdershoven and Molewijk 2010). This is a four-step, low-threshold instrument that fosters ethical reflection for professionals working in palliative care (van Schaik et al. 2022). These four steps are an acronym of the name of the instrument, ‘CURA’ (Metselaar et al. 2022; van Schaik et al. 2022). 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 understanding what is of value to those involved in the situation. The fourth step, ‘Act’, focuses on relating moral judgement to concrete action (Metselaar et al. 2022). 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 (van Schaik et al. 2022).

MCD has been applied in various clinical settings, adopting slightly different versions and steps. Regardless of the specific model or the number of steps implemented in practice, MCD follows an inductive learning approach through a dialogical moral inquiry in which participants develop not only knowledge but also skills, attitudes, and character (Haan et al. 2018; Stolper et al. 2016). The dilemma method, which is a specific conversation method used in MCD, is useful for supporting healthcare professionals and helping them reflect on their own moral issues in clinical practice (Stolper et al. 2016). Evidence suggests that MCD can indeed be useful for healthcare professionals to better recognise the moral dimension of their daily clinical practice, to become more able to distinguish various perspectives, to increase team cohesion and mutual understanding, to reason in a systematic manner, and to improve care (Abma et al. 2009; Gracia 2003; Haan et al. 2018; Janssens et al. 2015; Rasoal et al. 2017; Stolper et al. 2016; Svantesson et al. 2014; van Bruchem-Visser et al. 2020; Weidema et al. 2012, 2013; Widdershoven and Molewijk 2010)

The third framework for ethical decision-making that we consider particularly useful is the one developed by the Markkula Centre for Applied Ethics at Santa Clara University (2021). This is intended to serve as a practical tool for exploring ethical dilemmas and identifying ethical courses of action. According to this framework, making good ethical decisions requires a trained sensitivity to ethical issues and a practised method for exploring the ethical aspects of a decision and weighing the considerations that should impact the choice of a course of action. Having a method for ethical decision-making is therefore essential. When practised 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 (Markkula Centre for Applied Ethics 2021).

This framework for ethical decision-making is composed of five dimensions, each divided into multiple questions that can facilitate self-reflection, collective discussions, and decision-making processes. In this framework, multiple ethical lenses can be mobilised to help answer some core questions when making complex ethical decisions. Each of these questions and approaches can help healthcare professionals and teams determine what standards of behaviour can be considered ethical. However, using these ethical lenses is not without challenges. 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 even on what constitutes a 'good' or a 'bad' action. The apparently basic question of '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 (Markkula Centre for Applied Ethics 2021).

The fourth framework refers to the one developed by The W. Maurice Young Centre for Applied Ethics at the University of British Columbia. This centre uses a specific framework for ethical decision-making (McDonald 2014), which was further elaborated and applied in clinical practice (McDonald 2019). One of the key features in the practical application of this model in clinical practice is its deep consideration of the context of decision-making processes. The model provides a stepwise structured reflection on ethical issues, questions, and challenges that arise 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 and therefore puts emphasis on both the rational and emotional aspects of the decision-making process. A series of questions is raised to increase ethical awareness.

Finally, the *Guide on the Decision-Making Process Regarding Medical Treatment in End of Life Situations* (hereinafter *Guide*) elaborated by the Council of Europe (2014) is another relevant framework that was developed with the aim of improving decision-making processes and empowering professionals in making end of life decisions. 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, for instance, healthcare professionals, patients, families, and associations (Council of Europe 2014).

In terms of structure, the *Guide* is organised 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 centre 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; 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 (Council of Europe 2014).

The *Guide* summarises 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 (Council of Europe 2014). It recognises that, in those situations, the main purpose is to provide palliative care, focusing on the quality of life (Council of Europe 2014; Finlay 2018; Hui and Bruera 2020; Hui et al. 2013, 2022; Miccinesi et al. 2020; Radbruch et al. 2020; Watson 2014). The *Guide* calls attention to the need to take patients' wishes into consideration, actively involving patients in decision-making processes (Council of Europe 2014). 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 (Council of Europe 2014; Watson 2014).

In a series of Portuguese studies (Hernández-Marrero et al. 2019; Martins Pereira et al. 2018, 2024), evidence suggests that end of life decision-making processes made by palliative care teams seem to be consistent with the *Guide* of the Council of Europe (2014). Our research showed that the following parties were commonly involved in the decision-making process: the patient, family members, and the healthcare team. Other stakeholders (e.g. clinical ethics committees) were involved on 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 characterised by collective and interprofessional approaches (Martins Pereira et al. 2018). As recommended in the *Guide*, autonomy is a highly valued ethical principle in end of life care and decision-making processes in palliative care (Hernández-Marrero et al. 2019; Martins Pereira et al. 2018, 2024). Nurses, in particular, expressed major concerns in assessing patients' preferences and wishes and promoting advance care planning (Hernández-Marrero et al. 2019). According to our research, and although the *Guide* does not explicitly mention the role and involvement of nurses in end of life decision-making, nurses working in palliative care in Portugal are highly involved in end of life decision-making (Hernández-Marrero et al. 2019).

In another recent Portuguese study, a collective decision-making process with the patient at the centre was valued by most participants, although they recognised the need for a more inclusive approach. For example, involving clinical ethics committees or clinical ethics advisors as part of the decision-making process was considered helpful, albeit not implemented in daily clinical practice (Martins Pereira et al. 2024). This reinforces the collective and inclusive approach recommended in the *Guide* (Council of Europe 2014). This latter study also found that, although healthcare professionals rated the *Guide* as being very important, applicable, and transferrable to their clinical practice, they do not use it in their day-to-day practice (Martins Pereira et al. 2024). 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. This might be related to the fact that the latter require advanced ethical knowledge, competencies, team effort, time, and true embeddedness into daily clinical practice (Martins Pereira et al. 2024).

In sum, these five frameworks are only a few examples of existing normative models and frameworks for ethical decision-making in complex situations, such as those that occur at the end of life. In fact, these five frameworks are deeply culturally rooted and reflect the concerns, conceptualisations, and practices of societies and healthcare professionals in the Global North. More bioethical models and frameworks for ethical decision-making exist. What is paramount is to ensure ethical sensitivity and the development of ethical competencies, including ethical attitude (personal desire to do good), ethical basis (the best for the patient as a common goal), and ethical culture (the establishment of common goals and values within the interdisciplinary team). These competencies can be strengthened by reflection, time for talking and discussing ethically complex situations, and interdisciplinary teamwork and leadership, with the establishment and recognition of an ethical role model and support (Boström et al. 2022; Cain et al. 2018; De Panfilis et al. 2020; Hemberg and Bergdahl 2020; Hernández-Marrero et al. 2019; Koskinen et al. 2022; Lechasseur et al. 2018; Tang et al. 2023; Weaver et al. 2008).

CONCLUSIONS

In palliative care, it is important to plan for end of life care that considers the physical, emotional, spiritual, and social needs of patients and families. This involves working collaboratively with and within interdisciplinary teams that comprise, among others, palliative care specialists, palliative care nurses, psychologists, social care workers, chaplains/spiritual carers, and other healthcare professionals, to provide comprehensive support and guidance. By having open and honest conversations with patients about dying and death, healthcare professionals can help instil dignity, wisdom, peace, and ethical sensitivity as patients approach the end of their lives. In fact, research has shown that having proactive discussions about care goals and values throughout an illness helps patients make informed healthcare decisions and prepares them for the end of life.

Evidence shows that healthcare professionals often experience moral distress, burnout, and other health-related problems when required to provide treatments or care they believe do not align with the patients' best interests. Ethical decision-making processes play a relevant role in the development or prevention of such problems, either increasing the risk of burnout or acting as protective factors against it.

As shown throughout this chapter, a comprehensive approach to end of life care that is rooted in an ethics of care and prioritises well-being and completeness over merely prolonging life is needed. It is paramount to engage in transparent, open, ethically sensitive, and compassionate communication and education with patients and families about end of life care preferences, objectives, and values. Patients and families need to be involved and have an active role in shared decision-making processes that honour individual and relational autonomy, preferences, and values. By integrating palliative care principles, approaches, and practices in a timely manner in the illness trajectory, healthcare professionals can proactively manage symptoms, offer psychosocial support, and deliver holistic care that prioritises quality of life and comfort.

Healthcare professionals must also prioritise self-care, emotional resilience, and well-being in end of life care, acknowledging the emotional challenges, moral dilemmas, and ethical problems that may arise. Seeking support, supervision, and opportunities for reflection is vital for processing experiences, coping with grief, and maintaining professional boundaries while delivering compassionate care. Embracing a holistic, person-centred approach to end of life care that emphasises health, completeness, and quality of life can significantly enhance the end of life journey for patients and families, upholding their dignity and improving healthcare professionals' well-being.

Palliative and end of life care is not only an ideal aspiration of high-quality care provided to those facing a life-limiting and/or life-threatening disease. It is evidence-based and intrinsically complex and challenging due to the individuality of each human being involved in the care provided: the patient, family members, healthcare professionals, volunteers, communities, and the wider society. Often, high-quality palliative care is not compatible with established and well-defined boundaries between scientific and medical disciplines. This poses additional ethico-clinical challenges that can only be addressed through ethical sensitivity, open communication, flexibility, and shared decision-making processes.

Bioethical frameworks can be particularly useful when healthcare professionals and teams face the need to make complex and difficult ethico-clinical decisions. These bioethical frameworks help to simplify the complexity by providing steps, questions, and reflexive tools that healthcare professionals can integrate into their daily clinical practice. Further research is needed on how to best implement, operationalise, and integrate the use of these frameworks. The ethical and conceptual issues surrounding bioethical challenges in palliative and end of life care might again change the nature of palliative care, requiring ongoing, continuous, and dynamic analysis to respond adequately to the diverse needs of changing societies.

ACKNOWLEDGEMENTS

We acknowledge the financial support from Fundação para a Ciência e Tecnologia (Portugal) through research grants UIDB/00685/2020 and UID/00685 of the Centre of Applied Economics Studies of the Atlantic, School of Business and Economics, University of the Azores and from the Regional Directorate for Science, Innovation and Development. The chapter was partially written during the duration of Sandra Martins Pereira's contract as Principal Investigator funded by the Portuguese Foundation for Science and Technology under the Scientific Employment Stimulus (CEECINST/00137/2018) at the Research Centre in Management and Economics, Ethics and Sustainability Research Area, Universidade Católica Portuguesa.

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