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Exploring Volunteers' Perspectives on Medically Assisted Dying: A Qualitative Study

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Alla mia nonna Elena,

con tutto il mio cuore

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INTRODUCTION

It is the fate […] of every human being to be a unique individual, to find his own path, to live his own life, to die his own death. - Oliver Sacks

Death, just like life, is a deeply personal and unique experience for every human being. The way a person chooses to live and also the way one chooses to die are expressions of this uniqueness. This explains why the debate surrounding end-of-life is so complex: by confronting individuals with their own finitude, it inevitably leads them to question who they are and what truly matters to them. Medically assisted dying arises from the need to allow each individual to make their own decisions and to exercise self-determination even in the final stage of life. However, the exercise of individual autonomy takes place in a broader social and cultural context, that has profoundly transformed over time.

In Western societies, in fact, the increasing medicalisation of the dying process, contributed to leave people to confront death more and more in isolation.

It is in this context that volunteers play a crucial role: through their presence, they help make-up for the absence of a community capable of gathering around the dying person, as in the past. The present thesis stems from the need to investigate volunteers' perspectives on the issue of medically assisted dying. Despite their important contribution, significant gaps remain in the existing literature regarding the role of volunteers and their place within the end-of-life (EOL) debate.

The thesis is structured into three chapters. The first chapter explores the social and psychological dimensions of death, explaining how death has changed over time, with a focus on the role of volunteers in palliative care. The second chapter traces the evolution of the EOL debate and outlines the Italian legal framework, with particular attention to the principles of self-determination, dignity and the right to health on which it is based. Finally, the third chapter presents the findings of qualitative research conducted on 15 volunteers, through semi-structured interviews. The study aims to explore volunteers' perspectives on medically assisted dying and their representations of death, examining how their lived experiences in volunteering shape their views on self-determination, dignity and EOL care.

CHAPTER 1

SOCIAL AND PSYCHOLOGICAL DIMENSIONS OF DYING AND THE ROLE OF VOLUNTEERS

1.1 The social transformation of death

Throughout history, the way in which human interface with death has changed significantly, especially from the Middle Ages to the present (Aries, 1974; Elias, 1982/2001; Gorer, 1955, Kastenbaum, 1995; Morin, 1951/2002). In earlier times, people had greater familiarity with death, which was a socially embedded part of everyday life (Aries, 1974). Dying commonly occurred at home and therefore it was a visible and collectively experienced event, integrated in the routines of individuals, families and the community as a whole (Fulton & Owen, 1988). According to Elias (1982/2001), what comforted the dying and their relatives was exactly being able to share the experience with others. Unlike today, death was not perceived as a frightening and lonely experience, but there was a strong community component. Religion also played a major role in shaping attitudes toward death, by providing various rituals, practices and explanations, through which believers could interpret and make sense of death (Parkes et al., 1997); these rituals have themselves undergone important transformations over the centuries. However, the greatest change between the past and the contemporary western societies is the transition between death being managed as a familial matter and it being carried out by professionals (Aries, 1974; Morin, 1951/2002; Sozzi, 2009). Near the end of the 19th century, in fact, the progressive medicalisation of death began, i.e. the experience of dying was gradually displaced from the home to the hospital: previously functioning exclusively as places of healing, hospitals came to serve the secondary function of receiving the dying. The institutionalisation of death then resulted in the gradual loss of much of its ritual and ceremonial dimensions, that were formerly used to acknowledge and integrate death into everyday experience (Aries, 1974, Testoni et al., 2018). This separation of death from everyday social life is further reflected in the relocation of cemeteries from areas within the urban communities to the outskirts of the city: an aspect that, although introduced for sanitary reasons, contributed to the physical and symbolic distancing of death from ordinary social spaces (Sozzi, 2009). Moreover, these transformations were

reinforced by advances in science, technology and medicine, which greatly extended life expectancy and allowed individuals not only to postpone the event of dying but also to ignore, to some extent, the very idea of their own mortality (Kovács, 2003a). The development of modern secular societies, meaning societies where religion is less dominant, particularly impacted the interpretation of death, by weakening the traditional frameworks for understanding mortality (Walter, 1997). According to Kastenbaum (1995), moreover, after the Industrial Revolution, death has increasingly become more embedded within a medical-technological system, in which the human body is conceptualised almost as a machine, that can be sustained, monitored and repaired. It is a new way of representing death, which has progressively shifted from being understood as a natural and socially shared event to an experience subject to professional expertise and institutional management. The growing dominance of medical institutions in the dying process displaced to a considerable extent the family and the community from their previously central role, contributing to individuals social distancing from death (Clark, 2002; Boros, 2020). A direct consequence of this shift is the growing isolation of the dying person from their social environment (Elias, 1982/2001): whereas, in the past, social death used to follow the physical event, in modern Western societies, the chronology of death is being inverted and social death now often precedes the biological fact (Sweeting & Gilhooly, 1992). Indeed, the social transformation of death from a familiar, intrinsic aspect of life into an increasingly medicalised, institutionalised and socially marginalised experience provides the context in which individuals form their own perceptions, emotions and responses toward death, having important consequences on their psychological experience of death and dying.

1.2 Psychological dimensions of death and dying

Death is not a merely biological and social event, but also, and perhaps most importantly, a fundamental aspect of human experience with which individuals must come to terms and makes sense of, thereby giving rise to profound psychological implications. Dying is a deeply subjective experience in which individuals must confront the idea of their own finitude. Mortality awareness can elicit a diverse range of psychological responses, from fear, anxiety and avoidance to acceptance and the pursuit of meaning. One of the most

prominent theoretical perspectives in this sense is Terror Management Theory, developed by Greenberg, Solomon and Pyszczynski (1986; 2015) building on the ideas expressed by Becker in his book The Denial of Death (1973). According to TMT, the human desire for life (i.e. self-preservation) combined with the cognitive awareness of one's own mortality can generate a specific form of existential anxiety or terror, commonly referred to as *death anxiety* (Abdel-Khalek, 2005). The theory proposes that people defend against this threat using two main protective psychological mechanisms: *cultural worldviews* and *self-esteem*. The former are humanly constructed beliefs about the nature of reality that people use to find a sense of meaning, value and permanence: this can include the adherence to a religion, a country, a sports team and so on. The ladder instead is based on the perception of living in accordance with the rules and standards defined by one's cultural context and therefore perceiving oneself as a valuable and worthy individual. These systems allow people to access some forms of immortality, either literal (afterlife, reincarnation, heaven) or symbolic (such as writing a book or having offspring), that help them alleviating their existential anxiety. Moreover, according to Lehto & Stain (2009) death anxiety is not a unitary concept, but rather a multidimensional construct encompassing emotional, cognitive and motivational components, that vary depending on individuals' developmental stages and sociocultural contexts. In fact, responses to death and dying are not universal, but they are shaped by a complex interplay of personal and contextual factors, including life experiences, personal beliefs, emotional resources and their broader cultural and relational environment (Neymer et al., 2004). In this respect, Testoni et al. (2015) distinguish two different ontological representations of death: annihilation, i.e. the complete and irreversible cessation of existence, and transition, conceived as a process of transformation and continuity beyond death. These different conceptualisations profoundly affect individuals' attitudes, emotional and decision-making when facing terminal illness and EOL circumstances. Fundamental is also the concept of *death preparedness,* conceived as a process of cognitive awareness, emotional preparedness and reflection on one's finitude (Hebert et al., 2006; Durepos et al., 2018; Wen et al., 2022). Preparedness is considered to involve much more than the mere understanding of one's medical condition: it implies reflection and meaning making. This can be achieved by situating death in a shared cultural framework, that shapes how death is approached and experienced, and by facing it in accordance with one's own

values and beliefs (Martìnez et al., 2023). Ultimately, anthropological perspectives show that death has an important cultural component: culture seeks to domesticate dying through rituals, symbols and narratives, thus transforming a terrifying biological phenomenon into a meaningful experience and enabling individuals and communities to face their death anxiety within a shared social order (Boros, 2020). However, following the societal changes that we explored in the previous paragraph, this social and cultural framework has partially eroded and a growing psychological tendency to avoid confronting mortality has been observed. In his influential essay The Pornography of Death (1955), Gorer argued that death has progressively become a socially unmentionable subject, often completely displaced from everyday discourse (Gorer, 1955; Sozzi, 2009). As previously explained, death is now something to be concealed, avoided and confined into specific institutional settings. Thus, the cultural avoidance can reinforce the existing individual difficulties in confronting mortality. Within a context of growing medicalisation, diffused death anxiety and avoidance, palliative care and volunteers play a crucial role in creating a space where death can be acknowledge and in which all the needs of the patient and their family are addressed, including psychological and social concerns.

1.3 Palliative care and volunteering

According to the World Health Organization (WHO)'s most recent definition, palliative care is an approach that improves the quality of life for patients (adults and children) and their families who are struggling with life-threatening illnesses. It seeks to prevent and alleviate suffering through the early identification, proper assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (WHO, 2020). The term palliative care has been used with different meanings over time and several organisations sought to broaden and refine its definition (WHO, 1990; EAPC, 1998; WHO, 2002; EAPC, 2008; IAHPC, 2020). However, the origins of modern palliative care can be traced back to Dame Cicely Saunders, a British nurse, physician and social worker who founded St. Christopher's Hospice in London in 1967, giving rise to the Hospice Movement. The term *hospice* suggests a place of care in which a sense of familiarity and intimacy are preserved. The Movement's underlying principle is that of taking care of the

person, and their family, as a whole: the patient must not be considered merely as the bearer of a disease but as an individual whose dignity, relationships, values and needs must remain at the centre of care (Orsi, 2011, pp. 605-606). Therefore, it is a holistic approach, that provides a person-centred care with the goal of improving or optimising a person's quality of life, while offering appropriate treatment for any distressing symptoms (Dzierzanowski, 2021). A key principle of this approach is that of *total pain*, which recognises that suffering is not exclusively physical but also includes psychological, social and spiritual dimensions: fear, loss of autonomy, social isolation and existential concerns deeply contribute to the subjective experience of suffering (Rattner, 2023). Particularly relevant is then the Calman Gap Theory (1984), which states that quality of life can be understood in terms of the gap between a person's expectations and hopes and their actual experience at a given time. Palliative care therefore aims at reducing this gap, or discrepancy, by controlling symptoms and providing support in all the aforementioned areas and by helping patients redefine their priorities as illness progresses (Davis & Hui, 2017). This person-centred approach has significantly contributed to the shift from traditional medical paternalism, where healthcare professionals often were the sole decision-makers in patients' health, toward a system in which patients are actively involved and their autonomy and preferences are respected, through honest communication and shared decision-making (Kuosmanen et al., 2021). In Italy, these principles were formally acknowledged with the enactment of Law No. 38 of 15 March 2010, "Provisions to Guarantee Access to Palliative Care and Pain Therapy". This law explicitly recognises access to palliative care and pain therapy, i.e. the systematic assessment and treatment of pain, as a right of every citizen and places at the protection of human dignity, autonomy, and equity of access at the centre of care. It underlines the importance of integrating the psychological, spiritual and social needs in care and provides the establishment of national healthcare networks, requiring the annual monitoring of their implementation (Ministry of Health, 2024). In this sense, Law No. 38/2010 represents a crucial step in the institutional recognition of the holistic approach underlying palliative care. It's the fundamental difference between to paradigms: *to care* and *to cure*. The former is concerned with the complexity of the individual and never reduces the patient to a passive object of intervention, while the ladder aims primarily at the eradication of the disease, treating the body as a biological matter rather than a person

(Kassaye, 2020; Pellegrino & Thomasma, 1981). The risk of dehumanization is consistent; a review by Testoni et al. (2023) highlights how the predominance of biomedical priorities can erode the patient-clinician relationship, resulting in a progressive loss of personhood in care. In light of this considerations, it can be argued that a holistic perspective of care extends far beyond the professional healthcare team: as proposed by the compassionate community approach, aging, dying, caregiving and grieving are not exclusively medical or familiar matters, but shared actual processes embedded in the daily life of communities (Kellehear, 2005, 2013). From a psychosocial perspective, this paradigm constitutes a decisive shift away from individualistic and biomedical models of care toward a more relational one. It understands suffering as multidimensional, rather than only physical, and impossible to properly adress through medical interventions alone (Kelley, 2023): since illness and dying affect individuals' identity, social roles and relationships, responses to these experiences must also involve their wider social context. Moreover, Knaul et al. (2018) explain that community engagement and social participation significantly help reducing suffering in EOL care. In this context, volunteers play a valuable role: they respond to broad individual needs and address the gaps arising from social changes in EOL care. Volunteers provide a form of support that is distinct from professional healthcare and predominantly social and relational in nature: they offer social, emotional and practical support to patients and families, contributing to their overall wellbeing, and often act as mediators between the family and the hospital (Burbeck et al., 2014; Candy et al., 2015). Furthermore, volunteers are capable of fostering trust, dialogue and shared responsibility, aspects considered fundamental for the meaningful exercise of rights such as the right to health, dignity and self-determination, that could not be exercised to an equal extent in isolation. Notably, community psychology has demonstrated that supportive social environments, characterised by participation, empowerment and mutual recognition, are essential for the effective exercise of rights as well as for individual and collective wellbeing (Kloos et al., 2012). Thus, caring communities should not be considered as an optional complement to professional care, but as a necessary condition for its effectiveness (Sallnow et al., 2022). In Italy, the SICP (Italian Society of Palliative Care) and the FCP (Palliative Care Federation) expressed their commitment to promoting the collaboration with non-profit organisations and voluntary associations operating in the field and, at present, they count

more than 245 non-profit organisations active in palliative care and about 3560 volunteers (SICP, 2026). Palliative Care and the role of volunteers are introduced to guide a better understanding of the current end-of-life debate. In fact, the relationship between palliative care and medically assisted dying remains ethically contested. Two main perspectives can be identified: while some scholars conceptualise palliative care and medically assisted dying as lying on a continuum, others still regard medically assisted dying as completely incompatible with palliative care and argue that the two should be clearly distinguished (SICP, 2026).

CHAPTER 2
MEDICALLY ASSISTED DYING: ETHICAL AND LEGAL FRAMEWORK

2.1 The evolution of the end-of-life debate

Having explored the nature of palliative care and the role of volunteers, it is now possible to examine the evolving debate surrounding end-of-life (EOL) care, which has become particularly salient within this context. In order to understand thoroughly the evolution of this debate, it is crucial to recognise and differentiate between euthanasia and medically assisted dying, each characterised by a specific meaning, regulation and implications. Euthanasia refers to the act, carried out by a physician or another individual, of intentionally ending a person's life at their explicit and voluntary request, in order to relieve suffering associated with a serious or incurable medical condition. However, certain specific cases, such as death resulting from the suspension of life-sustaining treatment at the request of a competent and conscious patient or premature death that occurs as an adverse outcome of appropriate palliative care, do not fall under euthanasia. Medically assisted dying, instead, provides that a physician intentionally aids another person in ending their own life, by supplying them with the necessary means to carry out a freely, autonomous and explicit request: for instance, death resulting from ingesting a pill prescribed by the physician falls within this category (Ciliberti et al., 2025). Across the European context, a small yet meaningful number of countries – the Netherlands, Belgium, Luxembourg, Spain, Portugal, Austria and Switzerland – have legalised forms of euthanasia or medically assisted dying, each with their own legal instruments and ethical safeguards. For instance, the Netherlands were at the forefront of this development, becoming the first European country to decriminalise euthanasia and medically assisted dying, through the Termination of Life on Request and Assisted Suicide Act (2001/2002). Another intriguing example is Switzerland, which permits assisted suicide but not euthanasia, provided that the act follows the principle of altruistic motivation, i.e. it is not motivated by selfish interests (Art.115, Penal Code). In Italy euthanasia is considered illegal and a comprehensive legal framework governing medically assisted dying is not yet available; however, in recent years, a number of cases attracted significant media attention, stimulating considerable public and institutional

discussion on the issue. Particularly relevant were the cases of Piergiorgio Welby, Eluana Englaro and Fabiano Antoniani (also known as DJ Fabo), which contributed to the progressive development and clarification of central questions surrounding EOL care: respectively, the refusal or withdrawal of life-sustaining medical treatment, the reconstruction of the presumed wishes of an incapacitated patient, and ultimately requests for assistance in suicide. Diagnosed during childhood with muscular dystrophy, a progressive and irreversible degenerative disease of the skeletal muscles, Piergiorgio Welby had gradually lost his autonomy and eventually became entirely dependent on mechanical ventilation. In September 2006, he addressed an open letter to the President of the Italian Republic, Giorgio Napolitano, requesting the withdrawal of the ventilation that was keeping him alive and describing his condition as mere "biological survival" (Associazione Luca Coscioni, 2019b). However, given the absence of legislation on the matter, The Civil Court of Rome held that Welby's request could not be authorised (Bock et al., 2007). On 20 December 2006, anaesthesiologist Mario Riccio decided to take action and administered Welby deep sedation, while interrupting mechanical ventilation. In 2007, eventually, the Rome Preliminary Investigations Judge (GUP) acquitted Riccio, holding that his conduct did not constitute a criminal offence, but rather gave effect to the patient's expressed wishes. His case is important because it paved the way for the recognition of the legitimacy of refusing medical treatment, even when their withdrawal may foreseeably result in the applicant's death. Thereby it contributed to establishing the principle that medical treatment cannot be imposed against the patient's will, highlighting the significance of the exercise of self-determination. Another highly relevant case is that of Eluana Englaro. Following a terrible car accident in 1992, Eluana entered a permanent vegetative state (PVS), requiring artificial nutrition and hydration. For several years, Eluana's father fought a legal battle to uphold what he considered to be his daughter's wish, namely, to discontinue life-prolonging treatment: in fact, he believed that a life in PVS undermined Eluana's dignity and was contrary to her wishes preceding the accident (Luchetti, 2010). Eluana had been in that state for 15 years, when the judgment No. 21748/2007 of the Italian Supreme Court of Cassation established that the withdrawal of medical treatment can be carried out when the vegetative state is irreversible and the withdrawal reflects the patient's wishes, as inferred from their previous life and expressed preferences. As a consequence of this judgment, in 2009, the suspension of treatments for

Eluana Englaro was finally authorised. This case represented a pivotal moment in the Italian EOL debate, since it drew attention to those situations in which an individual is unable to understand and make decisions, raising the question of the implementation of their presumed wishes. Lastly, the case of Fabiano Antoniani must be addressed, given that it brought the issue of medically assisted dying in situations of severe clinical deterioration to public attention, highlighting the lack of a structured legal framework on the matter. In June 2014, Fabiano Antoniani, known by his stage name Dj Fabo, was involved in a serious car accident that left him tetraplegic, blind and unable to breathe or eat independently. After trying several unsuccessful treatments and in light of the irreversible nature of his condition, Antoniani expressed the desire to undergo medically assisted suicide in Switzerland. He found support in the Luca Coscioni Association and particularly the figure of Marco Cappato, who, in February 2017, decided to accompany him to the Swiss clinic. Subsequently, Cappato reported himself to the authorities for the offence of proving help in suicide, although prohibited by Article 580 of the Italian Criminal Code. His actions and the public resonance that followed brought the Italian legislation to consider the existence of an area of non-liability in the context of assistance in dying and, eventually, he was acquitted by the Milan Court of Assizes in 2019. The Court, in fact, questioned the constitutional legitimacy of Article 580 of the Criminal Code stating that it appears to be incompatible with the principles of self-determination and liberty enshrined in the Italian Constitution. It was therefore issued ruling No. 242/2019, that placed medically assisted dying within an exceptional framework, which aims to safeguard these fundamental rights (Italian Constitutional Court, 2018/2019).

2.2 Self-determination, dignity and the right to health

Before undertaking a more in-depth analysis of the current Italian legal framework concerning medically assisted dying, it is important to examine the three inalienable rights that form its foundation: self-determination, dignity and the right to health. These rights are articulated in the Universal Declaration of Human Rights (UDHR), in the Charter of Fundamental Rights of the European Union (CFREU) and the Italian Constitution. Particularly, articles 2, 13 and 32 recognise the individual as an inviolable and autonomous subject who may not be compelled to undergo any medical treatment

against their will, except in cases provided for by law and always in accordance with respect for human dignity (Baldini, 2018). The right to health was first recognised internationally in the Constitution of the World Health Organization (WHO, 1946), as an essential condition for personal dignity and self-realisation, and subsequently grounded in Article 25 of the UDHR (1948) and Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR, 1966) that explicitly states "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health". The concept of health, that in the past was equated with the mere absence of illness, has gradually moved towards a broader, more holistic interpretation, which comprises physical, psychological and social well-being. This broader understanding of health has shifted the medical model from a disease-centred approach, oriented only towards symptoms control, to one that places at its centre the person as a whole (Rietjens et al., 2017; Radbruch at al., 2020). The intrinsic value of the person is also explicitly safeguarded in Article 3 of the Italian Constitution, which posits the equal social dignity of all citizens. The right to dignity, enshrined in Article 1 of the UDHR (1948) and Article 1 of the CFREU (2000), is another inviolable right and constitutes the basis of freedom and equality (Lebech, 2004). It establishes that individuals must be protected not only against illness but also against any form of objectification or dehumanisation. In healthcare, as in the EOL debate, this translates into the importance of always treating patients as individuals endowed with intrinsic value rather than passive objects of medical intervention. Moreover, it implies that no one should be subjected to inhuman or degrading treatments (ICCPR,1966) and medical interventions must respect the dignity and identity of the human being (Oviedo Convention on Human Rights and Biomedicine, 1997). In fact, it was demonstrated that the perception of dignity is strongly correlated with psychological well-being and sense of identity (Chochinov et al., 1995; Chochinov, 2002, 2015). Despite its recognised importance for individual well-being however, the concept of dignity remains somewhat difficult to define (Horn & Kerasidou, 2016), Sulmasy refers to dignity as being formed by an *intrinsic component* (i.e. worth, stature, or value that human beings have simply because they are human) and an *attributed component* (or social dignity or created dignity), also explained as dignity-of-self (i.e. the dignity we attach to ourselves as integrated and autonomous persons) and dignity-in-relation (the dignity that the individual perceives or does not perceive in the eyes of others

within interpersonal relationships), which highlights the importance of recognising and protecting other's dignity (Grassi et al., 2024). Finally, the right to self-determination, or *therapeutic self-determination*, translates these principles into the patient's right to participate meaningfully in decisions concerning their body and healthcare and to refuse any medical treatment, including life-sustaining interventions such as artificial nutrition and hydration (Viganò, 2023). This right, just like the right to dignity, cannot be realised in isolation but rather find its full expression and is sustained by psychosocial, relational and community condition (Chochinov, 2007; Chirkov et al., 2003). As proposed by Deci & Ryan in their Self Determination Theory (1985, 2000, 2012), human wellbeing depends on the satisfaction of three psychological basic needs: autonomy, competence and relatedness. In the healthcare context, autonomy regards the possibility of making informed choices rather than achieving complete independence, while competence concerns the ability to understand and manage one's health condition, and relatedness refers to the support provided through caring and trustworthy relationships (Ryan & Deci, 2000). In this framework, feeling that one's action is self-directed is not, in itself, sufficient; autonomy should be accompanied by a sense of competence and efficacy, as well as by meaningful social connections and a sense of support and care from others. When these needs are fulfilled, individuals are more likely to experience agency, dignity, and psychological well-being. In conclusion, therefore, the right to self-determination, dignity and health establish that patients are considered not merely as recipients of medical decisions, but rather as persons with intrinsic worth, whose preferences, choices and overall well-being must be recognised and respected. Taken together, these principles provide the necessary foundation to help explain the current Italian legal system concerning medically assisted dying.

2.3 The Italian legal framework

In Italy, the first fundamental step toward the legislation of medically assisted dying was Law No. 219 of 22 December 2017, "Provisions on informed consent and advance treatment directives", which came into full effect in 2018. It asserts the patients' right to informed consent, regulates advance treatment directives (ADT), introduces shared care

planning and decision making (SCPDM) and prohibits futile treatments (Montanari Vergallo & Spagnolo, 2019). Informed consent, regulated by article 1, is the process through which a competent individual, having received and understood adequate information concerning a proposed intervention, including its risks, benefits and alternatives, voluntarily authorises or refuses it (Beauchamp, 2011); informed consent constitutes the first space in which patients can actively exercise their right to self-determination. Advance treatment directives (ADT), regulated by article 4, are legal documents that allow any capable adults to express in advance their wishes regarding medical treatment and EOL care, in anticipation of a future inability to articulate them. ADT therefore guide healthcare professional and family members in respecting the person's will and values. The patients may also appoint a trusted representative to act on their behalf in relations with healthcare professionals and facilities, thus providing further safeguards for their previously expressed wishes. ADT appear as another expression, different only for its temporal collocation, of that consensus between patient and healthcare professionals established with informed consent. Hence, their function is to preserve the will of the informed patients also in the future, should they not be in a position to decide it anymore (Di Paolo et al., 2019). Alongside ADT, shared planning and decision making (SCPDM) develops in Article 5; it regards situations in which a patient is already affected by a chronic or disabling condition, or a disease with irreversible progression and unfavourable prognosis. It is a dynamic process involving the patient, the medical équipe and, when appropriate, family members, that communicate in order to plan in advance therapeutic decisions, in light of the foreseeable progression of the patient's condition. SCPDM aims at ensuring patient engagement in healthcare trajectory across time and practice settings (Di Paolo et al., 2019). Treatment goals and care preferences are in fact defined on the basis of patient's clinical condition, personal values and quality-of-life expectations. Through SCPDM, the law redefines medical decision-making as a shared moral space, where the physician's duty to care meets the patient's right to decide (Aprà et al., 2025). Altogether, Law 219/2017 thereby gives concrete legal expression to the aforementioned principles of self-determination, autonomy and dignity, while safeguarding the individual right to health. Despite the broadening of the legal instruments aimed at protecting therapeutic self-determination, however, Law 219/2017 did not regulated either euthanasia or assisted suicide (Baldini,

2018). Following the Antoniani-Cappato case, a further step was taken in this direction. Constitutional Court Judgment No. 242/2019 questioned the constitutionality of Article 580 of the Italian Criminal Code, regarding aiding and abetting suicide, and identified a limited set of circumstances in which assisting suicide may not result in criminal liability. Strict requirements were defined: the person must suffer from an irreversible condition causing intolerable physical or psychological suffering, must be dependent on life-sustaining treatment and must have full capacity to make free and informed decisions (Constitutional Court, 2019; Razzano, 2020). Moreover, the patient's conditions and the methods of execution must be verified by a public structure of the National Health Service, upon approval of the territorial ethics committee. However, the lack of a comprehensive national legal framework leaves considerable room for uncertainty regarding the practical application of the Judgment, that remains uneven across the country. EOL requests are, in fact, entrusted to the different regions, which exhibit great variability in their approaches, presence and functioning of local ethical committees and the access to palliative care. As of August 2026, Tuscany, Sardinia and (recently) Emilia-Romagna are the only regions that have enacted legislation on medically assisted dying. Tuscany was the first to take legislative action: through Regional Law No. 16, adopted on 14 March 2025, *Organisational Modalities for the Implementation of the Constitutional Court Rulings Nos. 242/219 and 135/2024*, Tuscany established precise procedural and organisational rules governing access to medically assisted suicide within the Regional Health Service (Regione Toscana, 2025; Blandi et al., 2025). The law entails several steps, establishes a multidisciplinary commission to assess patient's eligibility and the specific protocol for the implementation of the practice. Sardinia, then, approved the Regional Law No. 26 on 18 September 2025, *Procedures and timeframes for regional healthcare assistance in medically assisted suicide pursuant to and as a consequence of Constitutional Court Judgment No. 242/2019.* Similarly to the Tuscan Law, Sardinia defines the procedural framework and timeframes for the provision of medically assisted suicide, in compliance with Law No. 219/2017 and Judgment No. 242/2019 (Regione Autonoma della Sardegna, 2025). Lastly, Emilia-Romagna very recently followed the two aforementioned regions with the approval of Law, *Organisational procedures for the implementation of Constitutional Court Judgments No. 242/2019 and No. 135/2024* (i.e. *concerning medically assisted suicide,* on 27 July 2026. With respect to the other regions,

some have initiated different measures on the matter while others have seen their proposals firmly rejected. In conclusion, therefore, it can be stated that the issues extend far beyond the sphere of individual rights but also encompass questions on heath-care organization: the effective exercise of patients' right of self-determination depends on the system's capability of ensuring that their choices can be actually implemented. Furthermore, the lack of structured end-of-life training and systematic Death Education programmes, both for healthcare professionals and people in general, constitute an additional barrier to the development of a shared culture of therapeutic self-determination and EOL rights (Testoni et al., 2023; Ordine degli Psicologi del Lazio, 2023).

CHAPTER 3

THE PRESENT STUDY

3.1 Research Objectives

The present study is a qualitative research that aims to explore participants' understanding and perspectives on medically assisted dying and their representations of death within the broader context of palliative care. Particularly, it intends to investigate the role of volunteers and how the experience in volunteering may influence these positions, as well as meanings attributed to dignity, care and end-of-life decisions. This research also seeks to understand the extent to which conversations about death take place with patients and their families.

3.2 Methodology

In order to explore volunteers' perspectives on medically assisted dying a qualitative research approach was deemed appropriate. This method in fact allows participants to share their lived experience and opinions freely, without requiring the quantitative measurements of variables (Creswell, 2017). Moreover, qualitative research uses an ideographic perspective, i.e. it focuses on understanding the unique experience of each participant and the contextual factors that shaped it. This approach is particularly well-suited to investigate personal experiences since it enables an in-depth exploration of the subjective interpretation that individuals attribute to their own experience (Testoni et al., 2023). Within this framework, the researcher is not a mere collector of data but plays an active role in the interpretative process, identifying and developing patterns of meaning embedded in participants' narratives (Aspers and Corte, 2017). Data were collected through semi-structured interviews, based on a flexible set of guiding questions. Unlike structured interviews, that are based on a fixed set of questions, and unstructured interviews, that use general discussion prompts, semi-structured interviews include predetermined topics while contemporarily allowing participants to elaborate on their experience and researchers to explore interesting emerging themes. This approach is considered particularly suitable for addressing death and EOL issues, since it enables

individuals to express their views in a personal and spontaneous way, while ensuring a reasonable level of consistency and comparability across interviews (Kallio et al., 2016). The interviews explored a diverse number of key thematic areas: participants' experiences related to EOL care, suffering and death; the role of faith and their personal representations of what happens after death; the meanings attributed to dignity and self-determination; the role of volunteers; perspectives, doubts and reflexions on medically assisted dying and the EOL debate. The study was approved by the Ethical Committee for Psychological Research of the University of Padua, Area 17, with the unique identification code 1690-A. All the participants received and signed an informed consent containing information regarding the aim of the study, the interviews procedures, the recording of the interviews for analytical purposes, and all the measures adopted to ensure participants' anonymity and the confidentiality of the data collected. The interviews were conducted either in person, in a private room suitable for conversation, or remotely via an online platform and lasted 45 minutes, on average. With participants' prior consent, the interviews were audio-recorded and subsequently transcribed verbatim. The transcripts were then analysed using Reflexive Thematic Analysis, accordingly to the model proposed by Braun and Clarke (2006). This method makes it possible to identify recurring themes through a six-phase process: familiarisation with the data, generation of initial codes, searching for themes, reviewing themes, defining and naming themes and producing the final report.

3.3 Participants

The research involved 15 participants, which are volunteers in the context of palliative care. 9 are females (60%) and 6 are males (40%). The age of participants ranged from 35 to 86, the participants' mean age is 67,53 years with standard deviation of 13,68.
The years of volunteering ranged from 2.5 to almost 40, the participant's mean years of volunteer service is 12,1 years with standard deviation of 10,31. The participants come from several regions in Italy, with the majority being from Brescia (8 out of 15); 10 are retired, 1 is a housewife and 4 are still working; most identify as Catholics (9 out of 15), 4 hold spiritual beliefs of different nature, 1 is an atheist and 1 didn't share it. They exhibit

diverse personal, educational and professional backgrounds: this heterogeneity allowed us to collect different perspectives with respect to the topics investigated in the study.

A brief description of the participants is provided below: pseudonyms are used and any potentially identifying information have been modified in order to protect participants anonymity.

Laura, 77 years old, she's from Padua. She has as professional qualification and worked as a corporate secretary. She's now retired. She's been volunteering for more than 30 years now. She didn't share her religious beliefs.

Claudio, 70 years old, he's originally from Cremona but lives in Brescia. He has a technical diploma and worked as an administrative employee. In 2007 he was diagnosed with a tumor with a 30% chance of survival and he recovered. He became a volunteer 9 years ago, after retirement, following his wife. He's Catholic.

Roberta, 59 years old, she's from Brescia. She graduated middle school and then worked in a factory. She's now retired. She's been a volunteer since 2009. She started volunteering after her husband recovered from a tumor. She's Catholic.

Filippo, 35 years old, he's from Brescia. He works as a Religious Education Teacher at an elementary school. He's been volunteering for 6 years. He's Catholic.

Matteo, 74 years old, he lives in Brescia. He worked in a bank and is now retired. He became a volunteer in 2013. He's Catholic.

Ettore, 71 years old, he's originally from near Mantua but lives in Brescia. He has a Master's Degree. He worked in the IT sector, in finance and in the family business until retiring. He started volunteering in 2023. He holds some kind of spirituality.

Giustino, 86 years old, he's from the Garda Lake but moved to Brescia. He graduated from a commercial school and became a corporate manager. He's been volunteering for almost 40 years. He's Catholic.

Silvia, 45 years old, she's from Sicily but lives in Florence. She has a bachelor's degree and she's working in administration. She's also attending a master at the University of Padua. She's been volunteering for almost 3 years. She's a believer.

Clelia, 79 years old, she's from Brescia. She worked for 25 years and then she's been a housewife. She's been volunteering for about 12 years. She holds some kind of spirituality.

Marina, 59 years old, she's from Brescia. She has a bachelor's degree. She owned an association focused on holistic wellbeing. She's been volunteering for 3 years now. She holds some kind of spirituality.

Giacomo, 73 years old, he's from the countryside near Brescia. He had been a workman until 38 years old, then felt the need to change his life. He attended evening classes, became a counsellor specialised in bioenergetic and also a massage teacher. He's been volunteering for about 4 years. He holds some kind of spirituality.

Rossana, 82 years old, she's from Sicily but lived in Rome and then moved to Brescia. She was a teacher, then worked as an employee until retirement. She's been volunteering since 2010. She's Catholic.

Fiorella, 71 years old, she's from Reggio Emilia. She was an administrative employee and is now retired. She's been a volunteer for 12 years. She entered this reality right after retiring, following a reflection on the use of her time. She's Catholic.

Maria, 70 years old, she's from Brescia. She's been a nurse and is now retired. She started volunteering 2.5 years ago due to a strong personal need to help others. She's Catholic.

Federica, 62 years old, she's from Brescia. She has a professional diploma, she works as a restorer. She started volunteering in 2015, after the death of a very dear friend. She is not a believer.

3.4 Results

The following section presents the findings that emerged from the thematic analysis of the interviews, conducted according to the approach proposed by Braun and Clarke (2006). The examination of the participants' narratives led to the identification of 5 main thematic areas: 1) Volunteers' motivations and emotional experiences; 2) Beliefs, personal representations and attitudes towards death; 3) Communication and avoidance of death; 4) Self-determination and perspectives on medically assisted dying; 5) Lived experiences and the role of volunteers in medically assisted dying.

3.4.1 First thematic area: Volunteers' motivations and emotional experiences

The first thematic area explores the motivations that led participants to become volunteers, as well as their emotional experiences when faced with illness, suffering and death. The three main motivations that emerged from the interviews are: a personal drive to help others or live more meaningfully; the illness and death of loved ones, often described as extremely painful; and a personal experience of illness or close contact with death. The majority of volunteers report having begun this journey out of a personal desire to help others or to give new meaning to their lives.

For instance, Maria, who worked as a nurse for many years, explains:

"I felt the need to remain involved in social activities, to help others."

Likewise Filippo stated: "My desire was to do something for others and therefore to engage in some form of volunteering".

For Fiorella, instead, it was a feeling that emerged over the years, after a reflection on the use of her time:

"I used to feel a strange sensation when I closed the office window… I had spent the whole day within those walls. Once I retired, I devoted myself entirely, in this newly found space of freedom, to listening to myself […] and that's when a strong need emerged from within, an inner drive to dedicate some of my time to others. And so I connected this need […] to the question I had asked myself earlier about the meaning of my time."

It is also through the most painful experiences that people feel drawn to volunteering.

Federica, who lost both her best friend and her partner to cancer, explains: "My best friend was diagnosed with cancer […] so I did it for him, and it is as if I'm still doing it for him. I've been through two very painful personal experiences. I came to volunteering almost by chance, but I decided to stay."

Similarly, Matteo recounts: "My experience here is because my wife died here. She had pancreatic cancer."

Two participants, then, report having personally experienced illness and death.

Ettore reveals: "Life led me, at a certain point in 2019, to confront death directly, in the sense that I died. Without any warning, I had ventricular fibrillation. […] I was at work during my lunch break and I collapsed to the ground, dead. They brought me back; they performed CPR on me until the ambulance arrived with a defibrillator. So, basically, I

was without a heartbeat for an unknown number of minutes. As soon as I retired, I applied to become a volunteer."

However, even before that episode, Ettore had already developed an interest in the subject of death: "Around the age of 40, I attended some psychology courses. […] During one of the many meetings we had with this group, I encountered the topic of death and dying for the first time. It really fascinated me, if I can use that term, and so I went on to read many books on the subject."

By contrast, Claudio, who survived rectal cancer, recounts how his illness changed the way he approached suffering and allowed him to start volunteering:

"Before my illness, you couldn't even take me to the hospital because the smell alone would make me run away. After going through the illness, […] all of that had gone. And after seeing my wife volunteer, I said, *When I retire, I'll give it a try too*".

His wife, Roberta, in fact, became a volunteer shortly after Claudio recovered in fulfilment of a promise made to God:

"After my husband's illness […] they had given him a 30% chance of making it. But within nine months, he became ill and recovered; he was a miracle. I remember that when he went for chemotherapy, I would accompany him and then go to the chapel. I would pray and cry in front of the crucifix […]. I had made a promise to God that if he recovered, I would dedicate myself to helping others too, just as others had helped us during that time." Helping others is a key aspect of volunteering, but the interviews clearly show that volunteers themselves derive great benefit from this experience.

"[Volunteering] is truly special. I have to say that at first I had some concerns, but now it really feels as though, the moment I enter the room, everything else disappears. I have this feeling that, when I enter a room, there is an empty space for me and the other person to inhabit. It certainly enriches you and makes you feel more connected to your humanity. I feel that, deep down, I am never there solely for the other person; I am also there for… absolutely… for myself." (Giacomo)

"You realise that you're doing something useful for the person, but also for yourself, because you're spending your time on something meaningful, and that time also gives you a sense of peace." (Matteo)

"[…] and the patients give me so much—it's not me who gives to them." (Claudio)

Matteo stated, “it is not an easy experience, of course” and many volunteers used the word *intense,* but all the participants described their experience as overall positive and enriching, highlighting the opportunity to learn valuable life lessons from it.

“Every time I am welcomed into a patient’s room, I truly feel privileged […] The uniqueness of these encounters, which transcend social class, age, and all other differences, and the stories and narratives they share, are a life lesson for me.” (Fiorella)

“It’s definitely intense, and truly enriching. It is a deeply personal experience, confronting this dimension, embracing this silence, this uncertainty, this mystery that… I mean, the person who is approaching death experiences it, but you don’t have any certainty about these things either. So when you are there, there is an intensity in the way you look at each other, in that closeness, which is truly beautiful, because that is when all the masks fall away.” (Marina)

“An intense, deeply human and humanising experience. You really learn that many of the things we take for granted are, in fact, not guaranteed. Even something as simple as being able to go for a walk or carry out certain activities independently can be very important. This is something you learn here.” (Filippo)

Moreover, some volunteers particularly emphasised the concept that the hospice is not all about death, but it is fundamentally about life.

Silvia shares: “It is always a new and intense experience, one that gives me a strong sense of the meaning and fullness of life. What is strange is that you might think that going to a hospice means being surrounded by the smell of death, whereas I actually feel a concentration of life, because it is the very final stage, when everything somehow becomes more meaningful. It is an environment in which I somehow become a container for people’s stories and lives.”

Giustino confirms: “We are volunteers who accompany people not in dying, but in living the final part of their lives.”

Volunteering appears therefore to be approached for a variety of reasons, but eventually it is chosen for the lessons and emotions it leaves with those who experience it.

3.4.2 Second thematic area: Beliefs, personal representations and attitudes towards death

The second thematic area examines how participants represent death and what are their attitudes towards it, in relations to their beliefs. The majority of participants identifies with the Christian faith; however, the analysis revealed a variety of perspectives and diverse representations of death and the afterlife.

Filippo, in line with his religious beliefs, firmly states: "For me, after death, there is certainly the Kingdom of Heaven. I fully identify with the Catholic view. [The people here] are preparing themselves for what, from a Catholic perspective, is a passage from this life to a fuller life, which is, of course, life in the Kingdom of Heaven."

Claudio, who rediscovered his faith only after recovering from cancer, recounts:

"[I used to say] *Pray? Why should I pray? I die, they dig a hole, put me in, and that's it.'* But now I believe in it; I believe there is another life after this one. And there we will all be equal, we will all be brothers and sisters, and we will be in joy. I'm no longer afraid of death."

Both men express a conception of death as passage, that is also found among other participants, regardless of their religious beliefs.

Marina for instance affirms: "I do not identify with any particular religious faith. [...] I have my own spirituality, as asking myself profound questions about life and exploring them. I read about all kinds of things, but I don't take a particular side. And after death? Yes, I only see positive things. I see death as a passage. I therefore don't consider death to be an end, except for the death of this physical body. Rather, I see it as the beautiful part—the beginning of a return home and the possibility of freeing oneself from the duality and conditioning we have experienced in this life. For me, true life begins after death."

Similarly, Silvia explains: "I believe in this idea of a threshold, of a passage, because I believe there is something beyond what is visible. But I don't think it necessarily has to be identified with something Christian, Buddhist, or anything else."

For others, the answer lies in some form of reincarnation or permanence of matter.

Clelia for instance says: "I have my own beliefs, although I'm not a practicing believer. Sometimes, simply appreciating what surrounds us, the way the world is, is also a form of prayer, a form of gratitude. I don't believe in heaven or hell… no, I don't think so. I

also don't believe that we simply cease to exist. I believe that, in some way, we return to something, because we are matter. I hope that a small part of me will become part of a plant, perhaps a caterpillar…yes, maybe in a second life I'll be a butterfly."

Giacomo agrees: "I really identify with this kind of perspective […] which essentially teaches that we are not born and we do not die. In other words, there is another dimension beyond time and space."

Ettore instead shares his doubts on the topic:

"I have a lot of doubts. I have attended Buddhist meditation retreats […] I would like reincarnation to be possible. But rationally I find it difficult to believe that it is possible […] so, I don't know."

Federica then has a more resolute view of death, which however accompany with the idea that one can continue to live in the memories of their loved ones.

"I don't have such a Christian view; I find it something rather funereal. But I believe that people live on very much in the memory of those who remain. I also make an effort to talk about my loved ones who are no longer with us, to keep them alive, to remember them."

Laura, finally, having acknowledge that death is inevitable, shifts the focus on how people die, rather than what awaits them after death: "Over the years, perhaps because I have seen so many people die, I have come to accept that we all have to die eventually. Therefore, I believe it is the way we die that makes the difference."

Many participants regard death as a part of life and in light of this reflection they report not fearing death.

"Death does not frighten me anymore. Death is something that is part of life, just like being born, so is dying" (Roberta)

"My whole perception of death has changed. For me… it's not just a cliché; death is truly part of life." (Fiorella)

And lastly Silvia underlines how the experience in volunteering led her to reflect on death but also extensively on life:

"I have very few certainties and more and more questions. I am not afraid of death, but I reflect a lot on my own life. I think that being in contact with dying makes us give more meaning to life."

3.4.3 Third thematic area: Communication and avoidance of death

The third thematic area examines the extent to which death is discussed or avoided in both hospice care and in participants' personal experience. In most of the participants' accounts conversations about death appear to be widely avoided in their private life.

Matteo shares with commotion that, when his wife was dying, the two of them never openly talked about what was inevitably going to happen:

"I think this is a phenomenon that exists more generally, but neither of us has ever said to the other, '*I am going to die'* and *'I know that you are going to die.'* There was this kind of situation where neither of us spoke about it directly."

A diffused fear surrounding the topic of death was also identified by Ettore:

"I became aware of how, around us, people seem to be terrified not only of talking about death, but even of thinking about it. For example, I remember going on a trip with two friends in 1998; we were heading to Mexico. It was a very long flight, which I wasn't used to at all, so while we were on the plane, I told my friend that I had written my will before leaving. He looked at me as if I was crazy. He started making the sign of the horns and knocking on wood."

He then added: "Outside of this setting, I have tried to talk about my volunteering experience, but it is difficult. When I tell my friends that I volunteer at a hospice, 90% of them look at me as if I was an alien or completely crazy. They just end the conversation there; they rarely ask me any further questions."

The same experience is reported by Fiorella: "Death is still a topic that everyone shies away from. I see this in both my family and my circle of friends: no one wants to talk about it."

With regard to the hospice context, however, participants' views fall into two distinct groups: those who perceive that death is discussed openly with volunteers and those who perceive it still an avoided topic. Some argue:

"I have never had patients talk to me about death, no. It has never happened with relatives, either." (Maria)

"It has happened to me only very rarely. They simply don't talk about it." (Marina)

"It is rare for people to ask you, '*What will it be like on the other side?*' More often, they just ask whether they will see their husband, wife, or children again. We see death as something frightening; it has been ingrained in us since we were children." (Clelia)

“Those who suffer, they feel the need to talk […] they talk to us a lot. But death is mentioned very rarely, extremely rarely. Only one patient, the day before she died, told me in a barely audible voice, ‘I’m afraid. I’m really afraid of death.” (Rossana)

While, for instance, Silvia reported a different experience:

“Generally we talk about it, people do talk about it, but […] it is just one of the topics. Not always, there are people who avoid it, but if I had to give a percentage, I would say that it is definitely not a taboo subject, although it is not the main topic either.”

Moreover, Laura found that conversations between family members appear more rare and difficult than conversation with volunteers:

“People, I don’t know why, don’t want to confront the issue of death; I talk about it openly. There are these silences, I call it the ‘conspiracy of silence’ […] They don’t want to confront the issue because they don’t want [the patient] to know. It is more difficult among family members […] We are able to address it, both with the patient and with their relatives. It is often between family members themselves that the end of life is not discussed.”

Finally, Filippo, who’s an elementary school teacher, explained:

“Death is not discussed much at school either. In religious education, it may be discussed a little more, for example when talking about the death of Jesus […] the topic is touched upon, and many children in fact ask questions and talk about experiences they have had in their families. […] So, in my view, children have a need to address this topic. I notice that here, when families come to visit a deceased person, they often leave their children upstairs and do not take them down to the mortuary; in other words, they try to prevent their children from having direct contact with the deceased person. And I think this is somewhat problematic, because children also have the right to be exposed to this part of life, because death is, after all, a part of life.”

Thus, he found that the topic of death is rarely addressed in schools and there is an increasing avoidance of discussion also between parents and children.

3.4.4 Fourth thematic area: Self-determination and perspectives on medically assisted dying

The fourth thematic area concerns participants' views on medically assisted dying, with particular attention to self-determination in EOL care. The interviews reveal that the majority of participants expressed views in favour of medically assisted dying, although the topic gave rise to a wide range of different reflections and concerns. A recurring theme across most of the interviews is the concept of self-determination, alongside freedom of choice and respect.

Maria stated: "It is a personal choice. I don't judge, and I believe there should be the possibility for someone who can no longer cope [with his condition] to choose to die. With assistance. Yes, I would say so."

Laura is also favourable: "It is right. When there is nothing more that can be done, when people are bedridden and completely unable to move, I would want them to be allowed to die. I mean, if someone has a terminal illness and can no longer eat, drink, sleep, or do anything… I agree. What is the point of keeping someone alive in such a condition? I wouldn't want that for myself… I wouldn't even want a feeding tube through my nose."

Fiorella then states: "I maintain an open and non-judgmental position, because I realise that there are complex situations involving suffering in which the request to die is a strong and deeply considered request, arising from full awareness, even when other forms of support have been provided."

Ettore, reflecting on what he would want for himself and recalling a famous case, affirms: "I wouldn't want to be in certain conditions. I strongly believe that a person has the right to express their wishes. I also remember the case of Eluana Englaro, To me, it was unacceptable that anyone should question her father's wishes […] I mean, in cases where a person has been unable to express their wishes, I believe that those who love them have every right to say, '*Enough*.'"

Federica adds to the discussion the concepts of autonomy and dignity:

"I find it somewhat inhumane to force people to witness this kind of decline, this betrayal of their own bodies. […] The idea of no longer being autonomous, of living in such a vegetative state in bed and depending on everyone else… I don't know, it doesn't seem like a life to me. So, if a person consciously asks for it, I agree. If it were to happen to

me, at a certain point I wouldn't want to be a burden to anyone, to my daughter, or to myself. At that point, it would no longer be dignity."

In addition to this, Silvia reflects on the importance of receiving adequate information in order to make an informed decision.

"I understand it, because it is also a matter of human dignity. One thing is to live, that is, to receive palliative care while watching your condition deteriorate and becoming increasingly unconscious; another is to choose to access assisted suicide at a stage when you are still fully aware of yourself and able to say goodbye to your family. I think that is, to some extent, the difference. But I also think it is highly subjective (…) I am absolutely in favour of assisted suicide, but also of euthanasia (…) Everyone should have the opportunity to access information and be fully informed, so that they can make the choice that is right for them as freely as possible."

A group of participants instead express their opposition to medically assisted dying. For instance Rossana asserted:

"I wouldn't feel comfortable with it, because life is a gift from God, and since God has given it to us, we cannot reject it."

The same view was expressed by Filippo:

"I am clearly and absolutely opposed to both euthanasia and assisted suicide, in line with my Catholic beliefs. For me, life is sacred and should be protected from conception to natural death. Therefore, I believe that society should not help a person to die, but rather accompany them with dignity through the final stage of life."

Then, Roberta firmly stated:

"I am against it, because it is the Lord who gives life and it is the Lord who takes it away. Accompanying people is fine, to alleviate their suffering. But no, absolutely not. We cannot allow ourselves to take someone's life." But she adds: "Honestly, if it was a family member of mine who decided to die, if it was their choice and they were still fully aware, even though I would suffer greatly, you cannot go against their wishes, because it is their decision. But if I had to be the one to decide, absolutely not."

Moreover, one relevant line of thought, expresses the importance of prioritising and enhancing palliative care, that is considered preferable to medically assisted dying.

Matteo affirms:

"Before euthanasia, there is palliative care, and that is what needs to be strengthened. We must never give up hope. Illness must be lived as a significant time, a time of life."
In line with this view, Giustino explains:
"What I can say is that in almost 40 years, we have never had anyone ask to be helped to die. Of course, if you leave someone in pain, in a situation of abandonment, it is obvious that they might say, '*I want to die*.' That is understandable, and that wish should also be respected. […] I believe, and I strongly advocate, that people need to be cared for and supported. If it is possible to provide proper care and support, in my view, that desire [for medically assisted dying] does not arise, or at least I have never witnessed it." However, he continues: "But if that desire does arise, if the person feels that way and genuinely wants it, then their wish should be respected."
Similarly, Giacomo remarked: "It appears that people whose pain has been effectively managed and who feel that they are being supported and treated with dignity are less likely to reach the point of asking for life-sustaining treatment to be withdrawn. That said, I believe there must be freedom of choice."
Finally, Silvia reflects on the importance of having access to the adequate information in order to make an informed decision.

3.4.5 Fifth thematic area: Lived experiences and the role of volunteers in medically assisted dying

The fifth thematic area focuses on participants' lived experiences and opinions on what the role of volunteers should be in relation to medically assisted dying. Few participants reported having had direct contact with a person asking for medically assisted dying, however, they all expressed their views on what the volunteers' role should be in relation to such requests. Clelia for instance stated:
"These are issues that, in my opinion, a volunteer should not presume to address. I think they can be addressed by a religious minister if the person is a believer, in that case, yes. Or by a doctor, because only a doctor can [address them]."
On the contrary, many participants highlighted that volunteers should offer their presence and listening to the patients.
"As a volunteer, I can be available and listen." (Ettore)

“I accept people’s points of view, even when they do not align with my own beliefs. Generally, you simply listen and accept; then, if there is room for it, you talk about it. We talk a lot.” (Silvia)

“When I am there with you, I accept you for who you are. I think that is what dignity means. Dignity always involves seeing and treating someone as a person. And I often see how much people want to still be treated as people, not as patients or as illnesses.” (Giacomo)

Filippo agrees with the aforementioned views: “As a volunteer, I think my role is simply to be there for the person and to care for and support them.” But he also adds: “Clearly, it depends very much on the circumstances and the individual’s condition. If, for example, someone was to speak to me directly about it, I would find it difficult to endorse their views. Instead, in keeping with my own beliefs, I would at least try to show them that there is another possibility, another path.”

Roberta, Ettore and Marina instead reported their direct experience with a patient, a man living with multiple sclerosis.

“There is a patient […] who has multiple sclerosis and has no use of his legs or arms, so we help feed him every day. He told me, ‘I also spoke with the ethicist about assisted dying…’ So he was the one who brought up the subject with me. He said, ‘Because I don’t want to reach a point where I force my daughter to look after me for the rest of her life.’” (Marina)

“So I told him, ‘Look, as a believer, I would never do it.’ But then I told him, ‘At the moment, I’m well and I have no problems, so these are things you can only really talk about once you have experienced them. It’s easy to say these things from the outside; you have to actually be in that situation.’” (Roberta)

“He is completely dependent on others for everything. Even if he has an itch, for example, one day I was feeding him, and he asked me to scratch his nose for him. There are certain questions I would like to ask him, because I feel that he is someone I could talk to. He is very calm. What fascinates me is that he is in such a condition and yet he is serene. […] He spoke to someone at the hospital, a doctor who deals with medical ethics, to get information about what he could do if he were to reach a condition that he considered unacceptable, even though, in my view, he is already living in a condition that goes

beyond that. Being completely dependent on others for everything is something I would not be able to tolerate." (Ettore)

Fiorella also shared a deeply meaningful encounter with a person suffering from ALS: "One day, a patient with ALS told me, with two large tears running down his face, *'It's hard, it's hard. I'm tired. It's hard.*' And I said to him, '*I understand your suffering.*' I hugged him […] and he said to me, '*Thank you, but you can't understand, you can only imagine.'* For me, this is… this is the central point of everything. […] Another important idea that I have come to understand from these situations is precisely this: the person who is actually experiencing the situation should be the one to decide, because only they know what they are going through. Every human being is unique, and I believe that the solution, the choice, and the respect for everything concerning that person should therefore be unique as well."

3.5 Discussion

The present study sought to explore volunteers' perspectives on medically assisted dying and their representations of death. Overall, the objectives set out were achieved: the research explored participants' personal relationship with and representations of death, their lived experiences as volunteers in EOL care and their opinions regarding dignity, self-determination and medically assisted dying. The findings show that participants' views are closely connected to their personal and volunteering experiences, as well as to their representations of death. Most participants reported a representation of death as *passage*, in contrast to the notion of death as *annihilation.* A study by Testoni et al. (2015) showed that representing death as annihilation is associated with greater hopelessness and lower resilience. The interviews corroborate this trend, in that most participants that saw death as a transition to some form of afterlife also reported less fear of death and greater openness towards it. Another key result regards participants' perception of the diffused tendency to avoid discussing death, identified both within their social and relational context and between patients and their family members in the hospice setting. These observations corroborate Kastenbuam's (2018) discussion on the modern tendency to remove death from everyday experience and are consistent with theories of cognitive dissonance (Festinger, 1957), according to which individuals tend to avoid content that

generates emotional discomfort., Testoni et al. (2020) explains that death and dying are perceived as social taboos that prompts individuals to actively avoid emotionally activating stimuli linked to their own finitude.

Moreover death avoidance is then compatible with the Terror Management Theory (Greenberg et al., 1986), according to which, when death becomes salient, individuals must confront their mortality and therefore cope with death anxiety. In several interviews then emerged that patients tend to have more conversations about death with hospice volunteers than with their own families. This observation is supported by existing research, which explains that the concerns about causing negative emotions or placing an emotional burden on the other person are significantly higher in informal context, i.e. with friends or family members (Blanckenburg, 2022). A tendency to particularly exclude children from all aspects of death was then identified, despite their curiosity about the topic. Death appears to be given limited space also in school settings, although the literature highlights the positive implications of talking about death, in order to reduce death anxiety (Testoni et al., 2019). Altogether, these findings underscore the need to enhance Death Education.

Regarding medically assisted dying, the general stance appears to be in favour of this practice, despite some strong opposition coming from highly religious participants.

This confirms the findings in the literature that highlight the influence of religious factors in shaping attitudes towards EOL issues: for instance, strong religiosity and beliefs in an afterlife were found to both increase opposition to euthanasia (Costa & Carvalho, 2026).

Moreover, the interviews place a strong emphasis on the need to enhance palliative care, in order to avoid situations in which the desire to die may arise or be influenced by social isolation or inadequate support or care. This is consistent with the literature, which suggests that the wish to hasten death is a complex, multifactorial phenomenon that may be associated with different factors, including social isolation, loss of autonomy, reduced quality of life and even feeling a burden to others (Rodríguez-Prat et al., 2024).

The reference to the fear of becoming a burden to one's family also emerges from the interviews, further recalling the role of interpersonal relationships in the perception of one's own condition. Particularly significant is also the finding that, however some participants are not in favor of medically assisted dying, they still advocate the need to respect the person's wishes and decisions. This reinforces the importance of self-

determination in the EOL debate, discussed in the second chapter. Many participants emphasise the need to safeguard the right to self-determination, acknowledging the individual's subjective experience and suffering. Moreover, a reflection on the importance of being adequately informed about one's rights and available alternatives was raised. This finds confirmation in the literature, which states that self-determination is not merely the ability to choose, but it requires the ability to understand one's situation, consider the available options and make decisions freely, based on individual values (Baldini et al., 2018). Lastly, the interviews emphasised the central role of dignity, which is considered closely intertwined to self-determination, autonomy and the possibility to maintain meaningful social relationships, as confirmed by the literature.

CONCLUSION

The present study aimed to explore the topic of medically assisted dying, examining it in relation to the participants' perspectives as volunteers.

Overall, the findings suggest that the EOL debate cannot be regarded simply as a legal, institutional and healthcare issue but it is much more complex: it involves lived experiences, cultural backgrounds, personal values, faith and subjective representations of death. Participants' perspectives appear, in fact, deeply related to and shaped by their experiences and backgrounds. Having had close contact with death and illness, as well as culture and personal beliefs influence the positions on medically assisted dying. Although the overall tendency is generally favourable, the interviews reveal a multiplicity of opinions and reflections. Particular emphasis is placed on the principle of respect, considered essential to safeguarding patients' autonomy, self-determination and dignity.

The study presents some limitations, including the relative homogeneity in terms of age, origin and religious background of the participants. In fact, they are mostly over the age of sixty, come from Brescia and profess the Catholic faith. These limitations do not diminish the value of the data collected, as the participants' accounts provide an in-depth qualitative insight into the subjective meanings attributed the EOL issues by a group of volunteers. Future studies could include participants with a more diverse demographic background, for instance expanding the investigation to younger volunteers, coming from different regions and with different religious beliefs.

In conclusion, the findings show a clear need to develop community-based Death Education programmes to increase awareness and provide individuals with greater knowledge of their rights and available choices. At the same time, volunteers should be adequately trained and supported in order to be prepared to address these issues sensitively and effectively.

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