

Ethics in end-of-life care: The first doula course in Italy

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Abstract. *Background:* Although the role of the end-of-life doula is not yet officially recognized in Italy, the inaugural two-year training program organized in Genoa by the Genoese Society for Cremation (“So.Crem”) marks a significant step toward introducing this innovative and ethical approach aimed at humanizing the dying process. *Methodology:* Twenty participants in Italy’s first two-year end-of-life doula training program, conducted in Genoa by So.Crem, were recruited and interviewed. This qualitative research adopted a narratological approach, using thematic analysis for data processing. *Objectives:* To explore the ethical role of the end-of-life doula and examine how this figure contributes to a cultural shift in how death is experienced and addressed in society. *Results:* The testimonies underline how the doula creates a space for deep listening and acceptance, offering an accompaniment that restores value and dignity to the dying person. The training, which integrates theory and practical experience, prepares students to support the person and the family in this delicate transition, promoting an ethical approach based on closeness and respect. *Conclusions:* The end-of-life doula emerges as a vital figure in promoting a cultural transformation that restores humanity and dignity to the dying process. This ethical practice challenges the prevailing tendencies toward detachment and distance increasingly observed in modern society. To enable this role to fully realize its potential, it is crucial to establish official recognition, including in Italy, to accredit its training, integrate its activities into care services, and enhance its effectiveness.

Key words: death doula, end of life, So.Crem, end-of-life training, consciousness, death care, dying

Introduction

End-of-life accompaniment transcends mere physical care, aiming instead to foster a profound and respectful understanding of the emotional, spiritual, and psychological dimensions of the individual (1, 2). In this delicate transition, end-of-life experiences intertwine with deep and universal questions: the passage of time, the meaning of existence, the awareness of human limitations. These moments also involve confronting loss and solitude, reflecting on our sense of otherness in relation to others, and the commitment to leaving behind a legacy of connection and solidarity that extends beyond one’s individual life (3, 4). In the face of death, each individual responds based on their ability to deal with illness and loneliness, drawing on the emotional bonds and resources built up over the course of life.

These bonds, often rooted in early relationships with parents or caregivers and strengthened through subsequent significant relationships, play a pivotal role in offering support, in promoting adaptation and in promoting resilient responses during moments of greater vulnerability (5-7). In this context, it is essential that individuals navigating the end of life feel embraced in a safe space, accompanied by an authentic interlocutor capable of attentive and engaging presence (8). In this process, the figure of the end-of-life doula can play a crucial role, offering an empathetic and conscious presence that accompanies the person and their loved ones on a journey of inner transformation, in full respect of individual dignity and autonomy (9, 10). Building on scientific contributions that recognize consciousness as an essential and unifying dimension of life, the doula embodies an ethical approach that celebrates the

uniqueness of each person and their experiences. The doula's work is grounded in deep listening and the creation of an authentic caregiving space, fostering greater self-awareness and a more profound understanding of life (11). In Genoa, thanks to So.Crem, a third-sector organization active since the 19th century, Italy's first innovative two-year training program for end-of-life doulas was established. This program, rigorously designed with a balanced combination of theoretical and practical components, addresses a growing need in contemporary society: reclaiming human roots and bridging the gap left by technology that, while prolonging life, has often made it harder to confront suffering and death with authenticity. The program's structure is preceded and supported by an analysis of the motivations of the participants, explored through personal narratives aimed at illuminating their lived experiences, values, and goals. By understanding the motivations behind this challenging yet meaningful path, the program ensures targeted training and fosters the development of a community of professionals who share an ethical and humanistic vision of end-of-life care (12). This approach contributes to a broader cultural shift, reclaiming the humanity and dignity inherent in life's final moments (13-15).

Toward a more human and integrated vision of the dying process: The doula as a guide in transition

The concept of the 'end-of-life doula,' although known and practiced in other countries, is entirely new to Italy, where only maternity doula services exist, supported by very limited literature (16, 17).

This figure represents a significant step towards a more holistic and integrated vision of end-of-life care, promoting the humanization of care and respect for the fundamental rights of the individual. The doula aims to provide comprehensive, compassionate support to terminally ill individuals, considering their emotional and relational networks. By collaborating closely with healthcare providers, the doula seeks to make the dying process less painful, isolating, and distressing (18).

Although not a healthcare professional in the strict sense, the end-of-life doula plays a crucial role in creating a network of emotional, relational, and

psychological support for the person undergoing the final stages of life, recognizing and valuing the individual's uniqueness, life story, and deepest needs (9). In a context where death remains a taboo and healthcare tends to prioritize the prolongation of life, the doula helps to restore balance, ensuring that the final phase of life is experienced with dignity (19). This accompaniment represents an approach, an act of listening and understanding that allows the individual to experience the end of life with serenity, dignity, and awareness. In this process, listening becomes a fundamental element. The doula refrains from judgment or offering prepackaged solutions, instead serving as a discreet witness to the person's life journey, establishing a meaningful and supportive relationship that enables the individual to explore their most intimate feelings. This listening space thus becomes the foundation upon which the individual can process their experiences, even in the most challenging moments. The doula's ability to create a welcoming and respectful environment allows the patient to rediscover a vitality rooted in human connection and the relationships they have built throughout their life. Through deep listening, the individual can face the end of life with greater dignity and serenity, finding meaning not tied to the physical body but to the strength of relationships, which continues to live in the hearts of those they leave behind (20).

Awareness of mortality and consciousness in end-of-life care

End-of-life care is a process intrinsically linked to a profound reflection on death and consciousness that runs through every moment of this final phase of existence (21). Death is not only a biological event, but significantly involves the conscious and spiritual dimension of the individual. In this delicate context, the central theme can only be awareness, in particular self-awareness: the individual's ability to reflect on himself, to be aware of his own existence, his own life path and its inevitable conclusion. The fundamental question that emerges in this process concerns the meaning of being alive and what death represents, both for those who are about to leave us and for those who accompany them. Consciousness is not limited to the

perception of one's own body, but embraces a deeper reflection on personal identity, on the meaning of one's own experience and on the meaning of being and being there. Physicist and philosopher Federico Faggin challenges the materialist view of consciousness, arguing that it is not a mere product of the brain, but an autonomous phenomenon that transcends the materiality of the body. Consciousness, for him, is what gives meaning to life and is expressed through a constant internal dialogue (22). In this context, end-of-life accompaniment becomes an act of great responsibility. The end-of-life doula enters a relationship with the individual's inner world, often silent or difficult to articulate. Her attentive and sensitive presence provides a space for the dying person to explore emotions, fears, desires, and reflections, accompanying them in the process of reconciliation and detachment from life. It is the dying person's consciousness, heightened and intensified in these final moments, that guides them and imbues even this last phase of life with meaning. The theoretical physicist Carlo Rovelli enriches this vision by intertwining consciousness and death, proposing a reality composed of relationships and processes in which every part dynamically interacts with the other (23). This approach invites us to view death not as a mere causal event, but as part of a continuous flow of experiences and relationships. Every gesture, word, and silence during end-of-life accompaniment becomes a relational act that helps the dying person experience death not as an end, but as a profound and authentic opening toward others. In this perspective, end-of-life accompaniment represents a genuine relational practice that acknowledges and respects the individual's consciousness. The doula thus becomes a silent witness, helping the individual confront their most intimate emotions and their awareness of finitude, through attentiveness to silences, glances, and gestures, often difficult to endure. The awareness of human finiteness introduces a painful aspect of suffering but can also provide an opportunity to reclaim the meaning of one's life and reassess choices and relationships. In this process of reconciling with one's own story, end-of-life accompaniment becomes an act of care, nourished by a profound human connection, creating a space for reflection and serenity. In a culture that tends to treat death as a taboo, the doula works

to normalize the dying process, viewing it as a natural phase of life, on same level as birth and growth (24, 25). This approach frees the dying person from the isolation and abandonment often exacerbated by modern medicine and technology, which can make their condition distressing and alienating. In an era marked by frenzy and emotional detachment, the end-of-life doula enables a return to slowness and provides the "extra time," as Freud wrote in *Mourning and Melancholia*, necessary for the elaboration of thought and for the shared journey with others (26-28).

A process of mutual growth

Closeness to suffering, immersion in vulnerability, and confrontation with death prove to be transformative moments of personal and human growth, both for those who are accompanied and for those who accompany them. The doula becomes a respectful witness to life, capable of creating a safe and welcoming space in which every existence is honored, even in its final journey. In Genoa, the two-year advanced training course for the "End-of-Life doula," established by So.Crem, has emerged as a response to the growing need for professional preparation. This training program, distinguished by its integration of theoretical learning and quality internships, is based on the awareness that advancements in medicine and technology, while extending life and treating numerous illnesses, have distanced us from the deeper roots of our humanity. In reality, the adequate transmission of theoretical knowledge alone does not seem sufficient; it is equally important to emphasize the development of empathic skills, deep listening, and inner awareness, all of which are essential for navigating one of life's most delicate experiences. The testimonies of those who have chosen to undertake this training path show how this experience not only enhances professional skills but also fosters profound personal growth. A first-year participant, who has worked in healthcare for many years, describes their journey as follows: "I was looking for an opportunity to both enhance my professional experience and give meaning to this phase of my life by being of service to others. When I saw the course advertisement, it immediately caught my attention. I had

a moment of doubt, thinking that my age might be an obstacle. But once I started, I realized that it was not an issue at all. This first year has been incredibly enriching, not only because of the content, but also due to the personal growth it demands. It challenges you deeply as a person and, step by step, helps you gain a clearer understanding of the role you are meant to play". These words illustrate how the work of the doula can represent a journey of growth that involves both parties. Deep listening, unconditional acceptance, and the ability to forge connections become the key tools for creating meaningful support (29). Being a doula means transforming relationships into spaces of mutual enrichment, where fragility becomes the starting point for rediscovering the strength of human connection. Another testimony, given by a participant who is a psychologist, emphasizes the importance of emotional and cultural preparation in approaching death as a natural passage, rather than a tragic event to be feared. The participant shares her experience of losing her mother and expresses the absence of a figure who could support her during such a delicate time: "When I faced the death of loved ones - and even the possibility of my own - I felt the absence of a professional figure who could be there, not as a doctor, nurse, or psychologist, but as a human presence, ready to help me confront my mortality. Someone who could support me in organizing what I wanted to accomplish in the time I had left and help me express my fears without judgment. I realized that people often avoid discussing death, encouraging optimism or overlooking the need to address fears and uncertainties. Yet death is neither a punishment nor a fault; it is a natural reality that deserves to be acknowledged and openly discussed. The responses collected highlight that, in most cases, the desire to approach the topic of death with awareness and without social taboos or reluctance is one of the central motivations that drive individuals to become end-of-life doulas. Being a doula means not only supporting those nearing the end of life but also contributing to a cultural shift. It is an ethical commitment that emphasizes the need to humanize the dying process, reminding everyone that dignity remains intact even in the final moments. The relationships formed become spaces of exchange and meaning, where the presence of another offers comfort and opportunities

for reconciliation. In another interview, a participant, a woman working in a caregiving profession, shared that she approached the course after her mother's death three years ago. She described experiencing her mother's death not as an event, but as a passage. In her view, the role of the doula is fundamental: providing a presence that embraces and accompanies the entire end-of-life journey, offering support and care during the most delicate moments. Through their empathetic and human role, the doula helps transform the dying process into a more serene and dignified experience, providing support that goes beyond physical care and deeply touching the emotional and relational aspects of both the dying person and their loved ones. The testimonies of other participants, including doctors, nurses, and healthcare professionals, emphasize how the doula can fill a significant gap in the care system, particularly for those facing the end of life without adequate emotional and human support. Central to these responses is the recognition that the doula does not simply provide material assistance but represents an empathetic presence, creating a space of proximity, listening, and awareness. In doing so, the doula restores dignity and respect to individuals at every stage of their existence. These testimonies further illustrate that this type of support for the dying offers an opportunity to promote a cultural shift, returning humanity and dignity to the moment of death. It becomes a space of mutual growth, where fragility and strength intertwine, enriching both parties and giving new meaning to the journey towards the end of life. For all these reasons, the official recognition of the End-of-Life doula in Italy is considered a fundamental step in enhancing their role and ensuring their effective integration into social and healthcare services. The role of the death doula remains inadequately defined, even in many international contexts, and is marked by critical challenges stemming from the lack of formal training programs and the absence of a standardized registration system (30). Formalizing this profession means guaranteeing structured, high-quality training to prepare doulas to support individuals with competence and sensitivity during the delicate end-of-life stage. Clear regulation would also define the relationship with other roles in the healthcare and social systems, promoting a collaborative and synergistic care model. This institutional

recognition would not only provide ethical and professional guarantees but also address the growing need for a personalized and human approach to the final stages of life (29). In a society that often prioritizes efficiency and emotional detachment, the formal recognition of this professional role would signify an important cultural shift, bringing values such as listening, presence, and respect back to the heart of care. Recognizing the End-of-Life doula would thus expand the care network and offer communities a concrete opportunity to approach the topic of death with greater awareness and sensitivity (31).

Conclusions

The role of the End-of-Life doula represents an innovative and profoundly human approach to the moment of death. It goes beyond providing practical support, immersing itself in the most intimate aspects of human existence, emotions, meaning, and relationships.

The accompaniment provided by the doula is an act of moral solidarity, empathetic listening, and presence that recognizes the value of life even in its final phase, transforming death into a natural, dignified, and meaningful transition. Through solid training and valuable practical experience, the End-of-Life doula emerges as a key figure in promoting cultural change.

End-of-life care becomes an opportunity to rediscover a form of vitality that transcends the physical dimension of life, encompassing self-awareness and the strength of human relationships. In this context, death is not merely an event to fear but a final moment of life that can be approached with dignity, facilitated by a conscious and respectful presence that fosters intimate reflection, reconciliation, and profound connection.

In a culture where death is often treated as a taboo to be avoided, the doula helps restore the recognition of death as an integral and natural part of life.

Testimonies from course participants, including those who have lost loved ones or work in caregiving professions, emphasize how accompanying the dying also provides an opportunity to rediscover the value of human relationships. These relationships - concrete, sensory, warm, and co-constructed through

communication with others - form the foundation of the empathetic function of the mind and the ability for emotional regulation and mentalization. Recognizing an additional caregiver with shared responsibilities should not be seen as a luxury but as a fundamental step toward a society that prioritizes emotional care, the continuity of relationships, and the stability of bonds. These elements serve as a secure foundation for protecting life and health.

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