

The “Doula” in accompanying the end-of-life

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Abstract. Since time immemorial, the occurrence of death and adjoined burial ceremonies have been at the core of critical anthropological challenges that have depicted and proved the social-cultural value of this topic moment throughout the ages. Recently, several social factors, along with the development of biomedical techniques and the increasing medicalization of man in his life course, have changed the appearance of death. In the industrialized and urbanized areas of contemporary society, death has progressively shed the ‘naturalness’ of a difficult moment that always has concerned the inner circle of family, to further has been frequently relegated to medical or, at least medicalized, context in which the demise takes place long gone from the gazes and affections of kin and beloved ones. Against a context in which the medical technique becomes increasingly intrusive, the innermost anguish of the dying individual is consumed: that of being abandoned to a solitary confrontation with life’s most tormented event, at a time when according to medical science “there is nothing left to act”. Therefore, these contingencies oblige contemporary bio-medical ethics to rethink the moral and accompanying rules at the end of life that validly regulated this arena in the past, but which at present appear outdated and insufficient. To this end, the authors analyze the figure of the “End-of-Life Doula”, a figure who can intercept the social need revolving around the subject of death, by offering the dying person and family members support, comfort, and a meaningful response to the ordeal of death.

Keywords. Death doula, death, terminal assistance, end of life, health care assistant, accompanying death, mortuary rites, vulnerable people, rites of passage.

Reflection on death: for end-of-life ethics

In the ingravescence illness, characterized by haste plummet of those events which foreground the person’s encounter with the limit of existence, as well as elderly ages, it is of particular importance to activate support and sustaining measures from which the suffering person and his affective references could benefit by giving every moment of life an intensity of meaning, capable of alleviating pains and worries (1).

The present technicalization of medicine, the meagerness of the healthcare system’s resources, the affirmation of entrepreneurial models of assistance, as well as other manifold social factors (the crisis of the family organization, the simplification of family units with the decrease in the average number of its members, the drop in fertility, the fragility of ties, ...) risk to result in care contexts entailing separations and up-

rooting from affective points of reference and the usual and safe spaces of everyday life (2).

On closer inspection, death should not be regarded as a medical event or merely a clinical dimension that revolves solely around science. Instead, albeit is an experience that, first and foremost, belongs to man.

The hurdle of contemporary society in offering the dying that assistance and care of a non-exclusively medical nature, and that is of pivotal nature to overcome the distress of the last moments, is thoroughly conveyed by the words of the sociologist Norbert Elias “Never before have men died so silently and hygienically and never before have, they been so alone” (written long before Covid and having become prophetic (3).

At nearly ninety years of age, Elias addresses how today’s society has lost the ability to talk about death, emphasizing how the isolation of the dying and the

suppression of the idea of death are expressions of the exaggerated control of emotions characterizing our contemporary world.

Thus, very often, the reality of advanced industrial societies is that people grow old and die in solitude, hidden from the rest of the human consortium by a sort of aseptic curtain and within healthcare facilities that, although providing advanced medical treatments, are not able to tackle the feelings and loneliness of those approaching the end of their lives. Still not too seldom, the presence, contact, words, and gazes with sentimentally significant people who could offer great comfort and 'care' while passing away are considered a nuisance that interferes with the rational treatment of the patient (4).

On the contrary, since past civilizations were characterized by a strong belief in being part of a community that transcended the individual and would survive him, the ultimate moment would fall within normality, nature, and man and be experienced as such (5).

The current context appears very far from the one described by Foucault, in which the family was entrusted with "the sweetness of spontaneous care, the testimony of affection and the common desire for healing, [and where] everything contributed to aiding nature in its struggle against evil in order to bring evil itself to the truth" (6). Today, death has almost vanished from our existential horizon and is deprived of that very cultural and relational dimension that could make it acceptable by assigning it a meaning.

It is, hence, needed to give further depth to this difficult existential moment by retrieving the relational, affective dimension of care and an ethic of communication based on proximity, hospitality, empathy, respect, authenticity, and on the awareness of others' fear and pain, along with vulnerabilities so that detachment from the world does not occur in the utter solitude.

In the dramatic setting of chronicity and the end of life, where the singularity of the mournful event and its imminence can evoke something obscure, desecrating, and frightening, there is an urgent need not to leave unaided, neither the patient, family members, nor the healthcare professionals, favoring a multidisciplinary undertaking of the 'ponder over' of death and its significances, as well as the management of the emotionality, anxiety, dread and not infrequently the

anguish that can result from it. Likewise, such a commitment is essential since those who provide care assume a serious ethical responsibility toward those close to death.

Beyond and over, more than assistance inspired by sheer technical rigidity, it is a matter of thinking and acting in cross-disciplinary collaboration, offering support and therapies according to the patient's necessities. The attitude of getting close to, attentive perception, observation, listening, involvement of dear ones, empathy, closeness, and willingness to dialogue are decisive factors capable of reassuring, infusing consolation, and even hope, inasmuch they are rooted in the dignity of the caregiver at this specific time of the end of life (7).

The Confrontation of Man with Death: rituals and representations

In the past, in numerous cultures, specific well-recognized figures have played a guiding role in various significant events in human life, ritualizing and easing the physical and spiritual pain of these difficult transitions, thus making them more comprehensible and acceptable.

Already in 1909, the anthropologist Van Gennep described and analyzed many rites of passage that have accompanied the various stages and changes in life, with specific ceremonies, rituals, and taboos aimed at facilitating a person's path "from one determined situation to another also defined" (8).

The rites of passages' structure reproduced, in symbolic terms, a sequentiality of moments that Van Gennep has identified and differentiated into three different phases: separation or preliminary rites that facilitate the individual's detachment from an early situation; marginal or liminal rituals that place the individual in a state of abeyance; and aggregation or post-liminal rites that indulge the individual's introduction into the new territory, group or social category.

Of the three phases, the intermediate provides an authentic 'enlightenment' on the centrality of the notion of margin, spatially and functionally. According to Van Gennep, the liminal experience is, in fact, the one that eliminates from the transition that immediacy

that would provoke turmoil in both social and individual life; it is the margin that slows down the shift and introduces the gradualness typical of the ritual; it is the margin, in other words, that prevents the coincidence of the movement of separation (from A) and the movement of aggregation (to B): without the margin, the estrangement from A would be tantamount approaching B in the absence of the necessary adequate adaptation times (8).

This concept is perchance the most fruitful in the French anthropologist's intuition, for its ability to grasp in the less traumatic phase the natural keystone upon which rites of passages are organized.

In the past, such practices were used as rich metaphors for each crucial moment of life: birth, entry into adult life, childbirth, death, and the acquisition of the basic skills of survival (hunting, the art of fighting, treatment of diseases...).

The ubiquitous diffusion in all cultures of rites of passages, rituals that support the various disengagement processes, from the family of origin, from the peer group, and from life itself..., is indicative of their importance in the economy of active and conscious involvement of the individual and society (9).

Nowadays, the lack of the opportunity to collectively deal with pain and suffering through the use of rituals of strong symbolic characterization might be one of the reasons for people's growing condition of adaptive discomfort and the increasing prevalence of more or less manifest forms of emotional suffering in the face of life's inescapable events (10).

Many phenomena, death is undoubtedly among them, appear scarcely comprehensible if not contextualized in their deep, ontological, archetypal meanings.

The ongoing attempts to remove the significance and thought of death fail to conceal the importance, for individuals and society as a whole, of mortuary rites, of those cultural forms that encircle death, whereby a community huddles around the bereaved, helping them to overcome the void that opens up before them.

The recent pandemic, with its ban provisions on celebrations of mourning and farewell rites, has revealed how significant the lack of a collective mourning ritual is for processing a detachment that requires gradualness, time, and continuity. Such rituals constitute, in fact, a moment of sociality of great relevance

during which people's bodies would touch, comfort, and embrace each other as a way of fostering separation between the living and the dead.

Speculating on an evolution of customs towards a recovery of rituals to sanction universally difficult moments of passage in the life cycle could help restore a feeling of collectivity, solidarity, and belonging to the human race.

Perhaps the young 19th-century anthropologist, Robert Hertz, was justified in limning funeral rituals and mourning as an attempt to defeat death and make life endure, not only that of the community member but especially that of the social group which, by ritually confronting the end of the individual, defends its collective identity, affirming over the death its vitality and resilience (11).

Ritually consecrating the death of an individual within the community is, hence, a fundamental moment to overcome the liminal phase, accept death and loss on an individual and collective level, and return to life.

Death education and the "Doula"

The so-called marginal or liminal rites phase is of particular significance when addressing the issue of accompanying the person into the terminal stages of life. It suggests an awareness of how the suffering preceding death could represent a valuable transitional period that, however excruciating it may be, is necessary to prepare for detachment and to be able to bargain in the relationship the meaning of the past experience.

Despite being called upon to integrate the idea of death into his life experience, each man may react by developing forms of removal, sometimes dysfunctional and maladaptive. Max Scheler, in particular, singles out two forms of defense (12). The first is related to the survival instinct and represents a kind of ontological inclination, a positive vocation towards duration. The second denotes the result of an impulse of omnipotence, a failure to recognize the limit. This protective model is a peculiar modern man's dimension, who is no longer capable of acknowledging that death is an inherent in nature necessity, but rather, as a fact that in principle can be modified, that cannot be postponed,

and easily attributable to medical professionals who have failed to transform the successes of technology and science into guarantees of immortality.

These considerations show the necessity of developing an ethics of accompaniment as an adequate strategy concerning the sick person and those close to him, aimed at preparing patients, relatives, and healthcare personnel for the theme of death, through paths of death education, of a psycho-pedagogy of farewell and of accompanying.

At the end of life, the relational aspect takes on peculiar features. Since it encounters the deepest and most inalienable pasts of those who feel threatened both from an inner side due to their growing weakness, and from an outer side, given the fragility and precariousness of interpersonal relationships, it requires specific training.

New professional figures are already operating in this domain to assist people in consciously participating in their death process, preserving the right to be protagonists both of their own time and of all the existential choices to undertake medical, personal, family, emotional, and organizational.

It is a matter of social professionals, technicians of listening, of relations, of accompanying, capable of guaranteeing the ill individual and his or her beloved ones an intimate and personalized presence, constant listening, support, and help in daily life oriented at furthering the humanization of the 'death' event and feasible the individual's choices of how to terminate one's life, in moments of greatest vulnerability.

These are figures that, in a particular manner, reclaim what in archaic societies at moments of life's passage was the role played by the family, the ritual, and the community.

The word Doula, in ancient Greece, was used to refer to a woman expert in helping other women. In the 20th century, the anthropologist Dana Raphael employed the term to indicate the female figure who supported mothers in the puerperium and breastfeeding phase (13).

The term is still used today in many countries to define a woman experienced in childbirth who continuously provides physical, emotional, and informational support to the mother before, during, or immediately after delivery (14-16).

As pointed out by Simonds et al. (17), the professional is concerned not only with delivering babies but also with helping their mothers, in the sense of paying attention, focused emotional support, and providing practical childcare to the mother-woman so that childbirth becomes a transitory identity experience.

Even in Italy, some first experiences in mothers' helping have been experimented on and have characterized the Doula as a non-healthcare figure who eases the finding of information and encourages the woman to reflect, to express desires, fears, expectations, and choices, a figure who can accompany the mother to healthcare visits and check-ups, who can share practical activities of recreational or artistic nature, or various others, relating to family management and domestic organization of the post-partum period (18, 19).

The growing presence of the Doula in Italy constitutes a form of silent social movement expressing awareness of 'unacknowledged spaces' and needs that health and social services are not always able to perceive.

Consistent with this trend, in more recent times, the Doula's realm of action has been broadened in order to respond to accompanying and support needs, also during that phase of the life cycle complementary to birth, namely the labor of death, guaranteeing support to the dying and family members: towards, during and after the moment of parting (20, 21).

Thereon, we may speak of an 'end-of-life doula,' a figure that in Italy still has no institutional recognition but whose evolution and establishment represent a cultural advancement that intercepts the social necessity that revolves around the theme of death.

The Doula, with its care practices and ritual, can encourage an educational path on grief, institutionalization, and farewells, promoting the culture around the theme of death and trying to refill empty spaces left by the progressive and growing unglue between individual experiences and the offer/availability of social and family support, which today is even more limited by the processes of family nuclearization, by the shrinkage of social networks and by a healthcare system reshaped according to the medicalization and corporatization approaches.

The birth of the Doula should consequently be understood in the context of a broader cultural move-

ment as a rejoinder to the current excessive medicalization of society, to the notions of separation, specialization, and technological development that underpin the Western biomedical system.

The Doula is a new figure that takes up the space left vacant by the medical industrialization of death, enriching it with emotional support and presence, i.e., the simplest and most direct form of accompanying (22).

Valuing the terminal phase also means including the dying time within the realm of relationships, dwelling in it with words and through presence, with ever-new accompanying forms (23, 24).

Toward an ethic of accompanying

To all intents and purposes, the death episode constitutes an irreversible, substantial, critical, and meaningful transformative passage, which requires specific forms of accompanying and deciphering. A complex relational experience to explore and that, to be legitimized and thus fully experienced, needs spaces in which what takes place in the body can find expression, be recognizable and become the object of a specific attribution of significance.

Within the current public health context, existing fissures can solicit additional and various spaces for accompanying. Amidst these, the Doula can play a facilitating role in the generation of the meaning of the experience lived by the dying person and his or her loved ones: in a projective sense (through accompanying the exploration of wishes, fears, and expectations) in the “here and now” (by being present and in connection with feelings) and in a retroactive sense (via listening and building of memory).

The literature specifically addressing the figure of the Doula has been developed predominantly through the work of North American authors interested in reproduction.

Several studies have pointed out that Doula’s support for parturient women has yielded favorable results worldwide, but that Doula’s roles are still evolving and remain the most unregulated (25-27).

The literature is nearly absent in Italy, where end-of-life Doula is just beginning to emerge. Nonetheless,

the first testimonies of experiences of accompanying people in hospices, at home, or of the creation of informal support groups, especially for cancer patients in difficulty, are not lacking.

Even in the international context, a professional framework enabling the specific criteria for the training, operation, and protection of these social workers to be defined is absent.

This professional figure’s recognition and required regulatory framework will provide a new step toward holistic and customized assistance to the dying person, offering a valuable additional resource to existing services.

An ethical approach and the ability to relate with others constitute, on par with technical preparation, the foundation of this figure’s professional competence.

Undoubtedly in order to conduct a constructive interdisciplinary and professional comparison capable of enriching the services advocating for the dying person and family members, it is necessary to be committed to mediation processes that may deconstruct those vortexes of self-referentiality that still too frequently characterize the dialogue between ‘adjoining professional categories’, and that curb resources, in a sometimes-rancorous climate of intolerance and rivalry.

A disclosure / conflict of interest statement

None of the authors of this manuscript has a financial or personal relationship with other people or organizations that could inappropriately influence or bias the content of the paper. It is to precisely state that “No Competing interests are at stake and there is No Conflict of Interest” with other people or organizations that could inappropriately influence the content of the paper.

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