

To live with dignity, to die recognized¹

Miguel Ángel Pastorino, ORCID 0000-0002-6433-0223

Universidad Católica del Uruguay, Uruguay

For a long time, suffering and death have been confined to the medical realm, reduced to a biological fact, neglecting other dimensions of human existence that give meaning to life, suffering, and death. Dying is more than a biological event; it is a relational process intertwined with others, a biographical fact, a profoundly human experience for those who are aware of their mortality and for their closest companions. There is an increasing call to reexamine life and death more deeply, expanding the cultural and spiritual horizon to embrace death in a truly human manner.

A sociocultural problem arises as death becomes a taboo subject, hastily dismissed to avoid contemplating its significance. This cultural evasion of death results in forgetfulness and dehumanization of this inevitable aspect of life. ⁽¹⁾

However, there are those who are progressively transforming the relationships among healthcare professionals, patients, and families, whether dealing with chronic or life-threatening illnesses. These are the palliative care teams, which, more than a specialty, constitute a new paradigm in the interaction with patients, healthcare personnel, and families. This entails a new anthropological and ethical perspective that denounces the materialistic and mechanistic reductionisms that have long dominated the approach in health sciences.

Behind every ethical standpoint lies an anthropological view, an assessment of life, and an understanding of the inherent dignity of the human condition. A fresh appreciation and acceptance of our vulnerability and dependence, constitutive aspects of human beings, deconstruct the modern individualistic myth portraying humans as naturally autonomous and self-sufficient. Reality and empirical evidence challenge an anthropological model that forgets what defines us: our relational, interdependent, and vulnerable nature, reliant on others. Caring humanizes both the care and the caregiver, extending this humanization to the entire society.

The ethics of care

The ethical dimension of palliative care is tied to a broader concept of how we should treat one another, reflecting a deeper interpretation of human dignity. "It is intricately connected to the ethical notion of acknowledging the other in all their breadth and depth". ⁽²⁾ The shift in mentality regarding the patient's perspective, stemming from the acknowledgment of their intrinsic dignity, implies that it is not accurate to assert that "nothing more can be done" when a cure is no longer possible. Because there is always something that can be done for the other: caring for them, alleviating their suffering, accompanying them. Moreover, recognizing the other's value as a person is not contingent on their condition or situation, not even on the loss of their autonomy. To die with dignity is to pass away acknowledged and respected in one's dignity as a human person, a status that persists until the moment of death.

¹ This editorial is based on the article "Caring for and recognizing the other: Leaving no one behind", published by the author in *Semanario Voces* on October 7, 2021.

Recognizing the other implies accepting that we all possess an inherent value that cannot diminish, a value that remains unchanged; we refer to this value of every human life as dignity. Respecting the autonomy of others is one way to acknowledge their dignity, but it is neither the only nor the most significant way. Even if someone requests it, we cannot abandon them or cause harm; we cannot violate their dignity. If someone were to express feeling like a burden and undeserving of care, if we care, we would continue to provide support and make them feel valuable, unique, and irreplaceable, dedicating our time to them.

We often perceive ourselves through the eyes of others, and in a society dominated by values of profitability, productivity, and efficiency, a condition that limits life's possibilities is experienced as a devaluation of life, leading individuals to depreciate themselves as if they were a "burden" to others.

Only the gaze of the other, which recognizes, respects, and values, can restore self-esteem and acknowledgment of dignity. Only a gaze capable of accepting one's own vulnerability can compassionately embrace the other.

The hypertrophy of autonomy

In bioethics, the importance of the principle of autonomy and the recognition of the patient's freedom has been emphasized, manifested through informed consent, advance directives, and even living wills. Laws have progressively enshrined patient rights, respecting their autonomy and acknowledging their dignity. This marks a significant advancement from medical paternalism, which, in the name of the principle of beneficence, could infringe upon the freedom of the afflicted.

However, there is a current trend towards tilting the balance to the other extreme, fostering an hypertrophy of autonomy that transforms healthcare professionals into mere service providers. This shift weakens the therapeutic alliance and may lead to abandoning the patient, rationalized under the notion that it is "their decision."

There exists today an idealized overvaluation of individual autonomy, with a tendency to believe that if someone requests something, one must comply with their request without further inquiry, as the individual is deemed the master of their decision. This poses risks, especially when dealing with vulnerable individuals who are experiencing significant suffering and are surrounded by social and emotional pressures, or who perceive themselves as burdens to others. "Respecting their decision" can be a subtle form of patient abandonment if there is not a profound understanding of what lies behind the desire to die or resist certain forms of care.

From Plato to the present day, we understand that not all modes of action are ethically equally valid, and some actions can be judged as commendable or condemnable. Facilitating autonomy ensures individuals are free to act, but it does not guarantee the goodness of their actions. The fact that decisions are made freely does not automatically make them good, humanizing, or necessarily desirable.

Affirming that a decision was made freely says nothing about its goodness; it merely indicates that the decision was made without coercion. Therefore, the most crucial foundation for ethical discernment is respect for the inherent dignity of every person, a dignity that does not diminish or become relative based on their situation or subjective feelings of unworthiness. One's lack of self-valuation does not diminish their inherent worth. If dignity were subjective, respect for human rights would depend on individual feelings or beliefs about whether one deserves to be well-treated.

Being more dependent does not make us less human or less dignified. We have the experience that even when someone has lost physical and psychological autonomy, we can love, respect, and value them for their human dignity, regardless of whether they are aware of our care. This is because they are intrinsically valuable, not based on their state or quality of life.

Helping to live and die with meaning

In a society where there is not always time or space for compassion or reflection on death, but rather for the swift disappearance of anything that detracts from a pleasurable and self-sufficient life, it is not uncommon for "dignity" to be confused with "quality of life" and for happiness to be reduced to "well-being."

In 2021, experts in human rights from the United Nations expressed their alarm at the growing trend of enacting laws that allow access to medically assisted death based on having a disability or conditions of disability. ⁽³⁾

In this nihilistic context in which we live, there is also an avoidance of suffering, as if it were not a part of life. In recent years, more analgesics have emerged than in all the rest of the history of pharmacology combined. Currently, the threshold for declaring suffering "unbearable" is becoming increasingly lower, and it is a highly subjective reality. What is lacking today are sources of meaning, values, and narratives that give purpose to existence and to inevitable suffering. As Nietzsche expressed in the *Genealogy of Morals*, the worst suffering is that which lacks meaning. ⁽⁴⁾

The psychiatrist and Jewish philosopher Viktor Frankl, who survived Nazi concentration camps during World War II and developed Logotherapy, discovered that the lack of meaning, described as an "existential vacuum," is one of the primary causes of neurosis. Speaking on this matter at an International Congress in 1971, he asserted, "Doctors today are faced with some questions that are not of a medical nature but rather philosophical, and for which they are hardly prepared. Patients come to the psychiatrist because they doubt the meaning of their lives or despair of finding it." Regarding this issue, he quotes Professor Farnsworth and states, "Medicine is now confronted with the task of expanding its function. In a period of crisis like the one we are currently experiencing, doctors must cultivate philosophy. The great malady of our time is the lack of objectives, boredom, and the absence of meaning and purpose." ⁽⁵⁾

When I reread Frankl's text, I recalled and appreciated the significant contributions made to our society by professionals dedicated to palliative care. Each human life treated with respect, relieved in its suffering, and acknowledged in its dignity is a testament to their essential work. This goes beyond the expertise of technical specialists; it requires professionals who assist in living and dying with dignity, meaning, in any circumstance of life. Those individuals in the field of palliative care serve as a poignant reminder of what it truly means to be human.

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