

Technology and the end-of-life: the primacy of accompaniment

by Archbishop Vincenzo Paglia

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The digitalisation of medical assistance and the advancement in technology to support aid where at the centre of the conference organised by the Order of Malta, at the Magistral Villa in Rome, titled “E-Health: from current experiences to future opportunities”. Before the closing remarks, Monsignor Vincenzo Paglia, President of the Pontifical Academy for Life, shared his insight into the primacy of end-of-life specialised care recalling the tragedy of Covid victims dying in solitude and loneliness. Here the full text of the Speech.

Thank you for the invitation and the opportunity to reflect together on very controversial issues in our country, even at this time. As you know there is a bill filed in the Italian Parliament, which aims to transform the decision n. 242/2019 of the Constitutional Court on assisted suicide into legislation, but signatures have also been deposited for a referendum that aims to decriminalize the murder of the consenting person.

It may therefore be useful to dwell for a moment on the reasons that have led us to the current situation. They have to do with a sum of factors that operate together. On the one hand, there have been developments in medicine and new technologies that are increasingly numerous and effective; on the other hand, cultural dynamics that stress the individual dimension of freedom, understood as absolute self-determination. Certainly there are positive elements in this evolution: we have moved away from the Hippocratic “paternalistic” tradition within healthcare, to achieve a more balanced relationship between doctor and patient, in a logic of shared decisions. At the same time, it is not easy to find the right balance between these different elements and to calmly discuss them in the public debate on these issues, which are very delicate.

As Pope Francis pointed out, “the growing therapeutic capabilities of medical science have made it possible to eliminate many diseases, to improve health and to prolong people’s life span. While these developments have proved quite positive, it has also become possible nowadays to extend life by means that were inconceivable in the past. Surgery and other medical interventions have become ever more effective, but they are not always beneficial: they can sustain, or even replace, failing vital functions, but that is not the same as promoting health. Greater wisdom is called for today, because of the temptation to insist on treatments that have powerful effects on the body, yet at times do not serve the integral good of the person.” (Pope Francis, *Address at the World Medical Association European Region Meeting On End-of-Life Questions*, November 17, 2017).

Due proportion in the use of remedies

Pope Francis continued: “Consequently, it is morally licit to decide not to adopt therapeutic measures, or to discontinue them, when their use does not meet that ethical and humanistic standard that would later be called *due proportion in the use of remedies*. The specific element of this criterion is that it considers *the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources*. It thus makes possible a decision that is morally qualified as withdrawal of *overzealous treatment*. Such a decision responsibly acknowledges the limitations of our mortality, once it becomes clear that opposition to it is futile. *Here one does not will to cause death; one’s inability to impede it is merely accepted* (Catechism of the Catholic Church, No. 2278). This difference of perspective restores humanity to the accompaniment of the dying, while not attempting to justify the suppression of the living. It is clear that not adopting, or else suspending, disproportionate measures, means avoiding overzealous treatment; from an ethical standpoint, it is completely different from euthanasia, which is always wrong, in that the intent of euthanasia is to end life and cause death.”

The Magisterium of the Church therefore clearly denies the legitimacy of choices that end life (euthanasia and assisted suicide), but just as clearly it acknowledges the difference between "killing" and "letting die". While the former, in the different forms that it can assume, is always considered wrong, the latter is considered lawful when in the presence of disproportionate remedies. It is therefore worth analyzing more accurately the elements leading us to regard a treatment as proportionate. There are two factors to consider. The first one - which is a sort of premise actually - falls within the competence of physicians and concerns the assessment of the clinical pertinence and efficacy of treatments. The second depends on sick people, without whose assessment no principle of proportionality can be established: they have the final say with regard to their own health and the medical interventions on their own body. Therefore, the fullest possible information, open communication and collaborative dialogue with both the med team and the loved ones accompanying the patient will be necessary.

These considerations allow us to mention also a patient’s prior instructions regarding treatment: a valuable tool for the respect of the patient's will in the proportionality assessment, which is the fundamental criterion that legitimizes the use of therapeutic means in the field of medicine. They find the most useful way of implementation in the shared care planning, provided for in Article 5 of Law 217/2019, also for the teaching of the Church (cf. *Pontifical Council for Health Care Workers, New Charter for Health Care Workers*, LEV, Rome 2016, no. 150).

Palliative care and accompaniment

An adequate use of pain therapy and palliative care, which focus greatly on people and the many dimensions that characterize them, is also very important to provide a response to their physical, psychological, relational and spiritual needs, avoiding the consequences of inadequate care. Nevertheless, the sick people may consider clinically appropriate treatment to be unbearable in their current situation. Dialogue, discussion and ethical advice can help to discern and choose an option shared by the patient, the med team and the family.

I would like to dwell for a moment on the meaning of accompaniment, because the resources offered by e-health and telemedicine can also be of help at this stage to the extent that they follow the logic of accompaniment. This is a logic that has its own clear identity and aims to overcome the logic of death control, which attempts to prolong life at any cost or conversely to hasten death. A careful comparison between these two logics allows one to realize that the alternative is not a choice between therapeutic obstinacy and euthanasia, between absolutizing mere survival and mythologizing self-determination, both of which lead to wrong outcomes, as we have seen. Two more general interpretations of the terminal phase of human life are under discussion here: on the one hand, the one inspired by death control which results in both therapeutic obstinacy and euthanasia, contrary to what one would think; on the other hand, the one inspired by accompaniment itself.

The alternative ultimately depends on the different meaning given to the time of dying. The trivialization of the terminal phase, basically underlying therapeutic obstinacy (insofar as this practice reduces human time to biological time), and the devaluation of the terminal phase, in some ways underlying euthanasia (insofar as many of the arguments justifying it reduce human time to a mere duration that can be kept under control), are contrary to the ethics of accompaniment, which is another way of looking at the time of dying.

Faced with the circumstances created by this time of pandemic, everyone knows how many arguments and emotions combine to cause embarrassment and anxiety. And yet one cannot simply dismiss the issue by denying the human particularity of the terminal phase of life. To deny this particularity would be a lie and would lead us to downplay or neglect the individual experiences of those approaching death. On the contrary, valorizing the terminal phase, as in the original instance of Palliative Care, means giving the time of dying a relational nature, to help experience it in the sense that a person intends to give to the ending of their life.

This essential vocation to "take care" of people needs to be given new life by medicine, by recognizing its value. We need to get out from misunderstanding the term "palliative" as "useless" or ineffective. That kind of confusion is evident because of the resistance that actually hinders the practice and dissemination of palliative care, even when its importance is affirmed in principle,

sometimes also with the promulgation of laws, which are often ignored (as is the case, for example, of Law No. 38/2010 in Italy: "Provisions to ensure access to palliative care and pain therapy"). Clinical and training experience shows that few medical and nursing students are willing to devote themselves to the care of dying patients and especially of the elderly, because they find this professional field poorly gratifying compared to more sought-after specialties. Medical and nursing schools focus on preparation for surgery and acute diseases, so it is difficult to deal with a medicine that increasingly extends human lifespan and consequently extends the time of living with a long-term illness. This is where a great need for awareness and training comes to light, so that consideration and skills grow within the medical profession, an area where much can still be explored and researched, also thanks to the continuous evolution of knowledge and possible practices. As the Pontifical Academy for Life we are devoting great efforts to this end, both for the training of physicians in universities and in clinical practice.

Training is very important because it is a question of "going beyond" the approach aimed at restoring the functioning of organs or systems affected by a disease, which is medicine's spontaneous approach in its clinical work. Instead, it is necessary to give space to relationships and to listening to emotions, which are the properly human dimension of dying. Here lies the problem that the culture of Palliative Care is called to address. If it is unable to do so, the risk is that this project, born with the intention of personally and socially enhancing the final phase of earthly life (and the passage to eternal life), will end up being reduced to another form of medicalization of dying. In this respect, telemedicine will have to find its own balance, because its intervention will not be automatically positive, but it will have to be carefully managed.

Usually, the criticism that is made when referring to these aspects of dying questions the very possibility of identifying dimensions of universal scope and value. The very concept of a "good death" is criticized as being "coercive" by some. However, the very situation we have experienced and the emotions aroused by the experience of death at the time of the pandemic can call into question these doubts and this criticism. It is precisely by valuing these emotions, giving ourselves time and ways to allow them to resonate within us - personally and collectively - that we can come to recognize meanings that favor paths of action that always respect the dying person.

The emotions I refer to are those we felt when people affected by the virus were removed from their homes and admitted to intensive care units without being able to see their loved ones. They are those we felt, when we learned that the corpses of deceased patients were put in plastic body bags and immediately placed into the coffins. They are those we felt, when we saw the night scene of trucks loaded with coffins drive away from our cities. They are those we felt, when we saw health workers locked inside their protective suits trying to hug their patients through their gaze to meet their

bewildered eyes and give them comfort. They are those we felt, when we saw the dramatic consequences of isolation and confusion for the elderly hospitalized in nursing homes because of the measures intended to protect them.

Taking these emotions seriously confronts us with situations that we all perceive as contrary to human dignity. This is an approach which, in a pluralistic context such as that of our society, makes it possible to create the conditions for a death that respects the dignity of persons. It is precisely these conditions that Palliative Care aims to foster.

Recognizing these emotions draws our attention to the fundamental value of life in all its phases, including its terminal phase, and to the imperative to overcome the logic of a throwaway culture. Those who are experienced in the terminal phase of life, those who know the special needs of dying people are well aware that some gestures and words take on vitally important meanings in that context.

The harshness with which the recent pandemic struck people, the brutality with which in many cases it brought them to the brink of death, suffocating their voices and stopping their words and gestures, tragically confirm the human depth that characterizes the last days of life. Palliative Care was born precisely from this recognition, to which the new digital technologies must also contribute. We have a great cultural task ahead of us, which involves, on the one hand, taking a public stand against the pressure to reduce the terminally ill patient to a set of inefficient biological functions, to be medicalized or drugged; and, on the other hand, not undervaluing the time of dying, but deepening its meaning for each person and for the entire community.

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