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Building a culture of social responsibility: the challenge of palliative care

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I would like to thank Dr. Caraceni for promoting this study day; I would like to thank the Rectors for accepting such an important institutional and cultural challenge as that of committing to the development of palliative care in medical education and other health professions. Now that the population pyramid is a real issue and the economic situation has become more critical, the issues concerning the chronically ill patients, whether in an advanced stage of the disease or terminally ill, are no longer confined to clinical practice, but have reached a social dimension. And it is through this far-reaching vision, involving our common feeling and acting towards the weakening and dying life, that we must deal with palliative care.

Certainly palliative care constitutes a responsibility for medicine. I would say: a revolution and a responsibility. Palliative care is an innovative aspect of clinical medicine - even though it is actually its very soul - first of all because its main focus is the pain relief of the incurable patient. That is a very different target - perhaps even opposite - from the target of the dominant medical mainstream, which is focused on curative surgery in "curable" patients and considers everything that does not achieve this goal a failure, believing that the control of physical symptoms is a marginal aspect and treating any other form of patient suffering as not really relevant to the professional context. Moreover, if the prevailing approach of the dominant evidence-based medicine (EBM) is the fragmentation of knowledge into numerous sub-specialties, palliative care endeavors to restore the unity of the person (bringing back the so-called holistic approach), and to this end it implements an interdisciplinary method that combats the epistemic reductionism and fragmentation of many medical branches.

The delay in spreading palliative care among patients is undoubtedly due to a still insufficient medical training in palliative care and to the ways of incorporating it into a patient’s medical history;

above all, however, that delay is due to a medical cultural attitude that sees patient care as a way to cure the patient, but doesn’t really take care of the patient, unless as plan B when the treatments fail. To cure a patient and to care for a patient seem to be two (logical and cultural) attitudes that are apparently irreconcilable in contemporary medicine. Or perhaps, the logic of caring for a patient has been abandoned because of the prevailing logic of curing a patient which medicine has come to embrace. Today’s medicine focuses primarily on the perspective of treating patients. To care for a patient is seen only as a last resort when healing a patient has proved impossible. No wonder then that hospices are perceived as “ghettos” where you die. According to the medicine dominated by that kind of logic, palliative care is the branch that deals with terminally ill and dying patients. Palliative care puts things right and reminds that the person is a person - alive, with all their needs and all their dignity - until the last moment. Palliative care deals with people and their needs, always respecting human dignity. Palliative care focuses on the perspective of caring for patients.

A perspective that should never be neglected, not just in the last days or when treatment fails. But implementing this in practice requires a cultural revolution in medicine and society as a whole. First and foremost, it means giving value to the caring for patients, it means giving value and recognizing the preciousness of other dimensions of the person that always come into play when we fall ill, such as existential suffering, psychological and social distress. It means acknowledging the intrinsic value (the virtues) of human action beyond the category of usefulness, it means looking at medical knowledge and technique not only as a professional (bureaucratized) performance, but as a service to the person. Medicine will overcome the fragmentation from which it is suffering - and that sometimes causes considerable damage to patients and gives little satisfaction/gratification to doctors themselves - only if it succeeds in combining again, in real clinical models, the treatment and the holistic patient care.

Behind concrete clinical models there are not only medical reasons but also cultural reasons (a certain vision of human being and his/her needs, of medicine and its identity, of human action and its value) that form our contemporary civilization and, as such, have permeated also medicine, changing its paradigm. The reality is that, whereas the treatments can fail, caring for patients never fails, because its effectiveness does not depend on the results it can get, but on its very human meaning and ethical value. Being there, being present, not turning away, watching over the sick has intrinsic value, even when it does not produce any measurable result in the patient (those who have experienced this understand!).

It is no accident that "visiting the sick" is one of the seven corporal works of mercy. But even in a more secular experience, simply being close to the sick expresses a transcendence that goes beyond the profession itself. It is not by chance that some doctors have spoken of the "privilege of being close to the sick". But even if we look at the data in the scientific literature, the degree of burnout and moral distress is much lower in palliative care teams than in other branches of medicine (like intensive care, neonatology, etc.); a cultural paradox if we think that palliative care workers deal daily with what for most people is a taboo that should not even be mentioned (the incurable or dying patient).

The essential vocation to "take care" of people needs to be given new life by medicine. 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.

A further and crucial innovative element concerns the social dimension of care, so strongly felt and represented in palliative care, but often ignored in other branches of medicine. Medicine has an intrinsic social dimension, by virtue of the doctor-patient relationship on which clinical activity is based. Now, it is probably true that this relationship has become more technical (i.e. reduced to a material work performance), more bureaucratized (i.e. reduced to a series of set procedures) to the detriment of the ethical value and human essence of clinical practice, but this should be read as a limitation and not as a necessity of contemporary medicine. Palliative care brings our attention back to a key element for the human being: the relationship with the other.

And palliative care looks at this relationship, once again, not in a merely pragmatic-utilitarian way (i.e. as an instrument to achieve other objectives regulated by set procedures), but in an ethical way, i.e. as the privileged and essential place for the personal fulfilment of those who interact with one another. It is in the ethically-based relationship with the patient that healthcare professionals find the crowning achievement of their career. It is in the ethically-based relationship with the healthcare professional that the dignity of the patients is recognized. It is in the relationship with a patient's family that the healthcare professional starts building a network of social solidarity. It is in the community of the palliative care team that healthcare professionals exercise those relational virtues that cannot fail to find expression in other spheres of their human and social life.

The impoverishment of the social dimension, in fact, is not a peculiarity of medicine, but of contemporary culture and is present in many other human contexts. All human communities - family, business, university and education in general, neighborhood, etc... - are now permeated by a technical and contractual conception, exemplified by the fact that the most common terminology is related to law and privacy (which goes far beyond the legitimate respect and protection of the intimacy of the person, of the family). Privacy today means individualism and self-referentiality, absolute impenetrability and incommunicability that allow room for libertinism. In some contexts, however, privacy results in isolation and abandonment. It is in the name of privacy protection that the physician does not interfere with the patient's choices.

What actually happens is that the patient is left alone, without that support, that wise advice, that point of reference that every healthcare professional must be for their patients, as well as parents are for their children, brothers and sisters for each other, and likewise friends, neighbors and all human communities. That is not to say that the doctor-patient relationship should fall back into the old paternalistic pattern, which has been highly contested in recent decades; it is more about reaffirming that there is a social responsibility, which is primarily a duty of mutual care. We are called to care for each other. The other is not a stumbling block or a tool. The other - whoever he or she may be - is not only a means, but also an end for each of us. It is clear that what is in play here is the deepest vision of human beings, the vision of society as a group of men and women and only secondarily the vision of medicine as an area of human endeavor.

Palliative care recognizes the importance of the social dimension of health or suffering not just by supporting the patient's meaningful relationships, that is, by allowing others to reach the patient, but also by allowing the patient to reach others. Others are a significant resource of strength for the patient. But the patient is also a treasure for the community and a responsibility, since not only medicine, not only palliative care specialists, but society as a whole is called upon to take care of them. This is the challenge that palliative care today poses to all of us, first of all to the medical culture and then to the whole of society. Palliative care sees medicine as a scientific community, but also as a human community. This is why palliative care does not limit itself to procedures and technical acts, but is very open to cooperation and values. Actually, all clinical medicine - not just palliative care - has enormous ethic potential, and consequently a great capacity to ethically transform society and culture.

For all these reasons, we believe that palliative care can change modern healthcare systems and society as a whole. Besides, our perspective is in line with what Pope Francis wrote in the Apostolic Exhortation *Evangelii Gaudium* on the proclamation of the Gospel in today's world: *I especially ask Christians in communities throughout the world to offer a radiant and attractive witness of fraternal communion. Let everyone admire how you care for one another, and how you encourage and accompany one another* (EG, 99).