Sickness, Pain, and Suffering: Reflections on Doctors Dealing With Painful Diseases and the Death of Their Patients

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Medicine consists first of all in taking care, also in those cases when it is impossible to cure the patients and to restore their good health. In fact, healthcare workers and doctors are increasingly faced with painful diseases and end-of-life situations. In these difficult circumstances, it becomes necessary for the doctor to recover a more global vision of the person of the patient, and to understand that the present illness can be read as a metaphor of his/her own existence—since the experience of an entire life manifests and redefines itself in the disease. Empathy and compassion constitute a guide to authentic and effective caring that manifests itself in the language used and in attitudes that become externalized as appropriate behaviours. The doctor must do all he/she can in order to alleviate the patient’s physical and psychological pain, using the tools of caregiving and palliative care.

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Suffering constitutes a thematic area that often creates a dark horizon—permeated with painful and sadly difficult situations to be coped with. This is even more true in the field of medical practice, since the doctor is constantly in contact with patients who are suffering and, in certain cases, reaching the end of their days. When faced with (physical) pain, (psychological) suffering and (psycho-physical) death, the involvement that opens up can become emotional as well as ethical and spiritual. For this reason, every doctor, even when he (or she) relies on long professional experience and is well aware of the truthfulness of the Hippocratic aphorism according to which “it is impossible to cure all patients; it would be an even more difficult result than predicting the future” (Hippocrates & Others, 1978, p. 170), may be forced to rethink his position in the face of the suffering and dying patient, to ask himself what he must do in order for his behaviour to be correct and suited to individual and specific circumstances.

When faced with this question, which is also of a deontological nature: “What should be done (déon in ancient Greek)?”, an extremely complex multifactorial sense horizon opens up, involving at the same time personal (interior) and social (exterior) aspects; the latter of a relational nature and therefore characterised by more or less conscious communicative components, such as the use of verbal and non-verbal language, and the activation of behaviours that are expressed in concrete actions addressed to the patient (which actions are not limited to the medical examination or the administration of drugs, but which consist instead of a general attitude of kindness, which may be expressed in a look, a word, a gesture, etc.).

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The personal dimension (*interiority*) is involved herein because every doctor brings with him his own personal experience, in the form of mental attitudes (either positive or negative, as is the case for internalised prejudices) and value schemes that developed following the education received, the path of life undertaken and possible significant encounters with other people whose influence he has suffered, which he applies more or less consciously (in fact often unconsciously) to the situations that arise during his working life. This interiority is also composed of living or latent memories, together with the emotional implications related thereto, which can re-emerge under particularly stressful situations, all the more so if identification processes are also involved, such as when the doctor sees in the patient and those around him (*caregivers*) a reflection of his own past life situations, of his loved ones and, in some cases, even of himself. He must therefore be aware of these interior processes, which are not necessarily negative, in fact often positive.

According to several scholars (Mortari, 2015, pp. 195-206; Pulcini & Bourgault, 2018; Pagliacci, 2019, pp. 173-205) the doctor will be all the more skilled in managing difficult situations, even of unimaginable suffering, to the extent that he himself is endowed with empathy and ability to feel compassion, even if this puts him at risk of incurring excessive personal involvement:

The care work is exhausting. It requires a lot of cognitive, emotional, and in some cases also physical and organisational energy. The reason lies in the fact that it not only makes you more vulnerable, but requires you to operate in a context of great uncertainty. / There can be no care as long as there is no sensitivity to the feeling of the other. However, sensitivity involves exposing yourself to the other, and being exposed increases the vulnerability rate that is inherent in us precisely as beings who are dependent on each other. Precisely because being sensitive exposes and, in turn, exposing puts you at stake, “those-who-care” happen to wonder about the meaning of being sensitive to the other. And yet it is an unavoidable risk for the care to be actualised. (Mortari, 2015, p. 213, my translation)

Moreover, the doctor’s task can be facilitated by a previously gained personal background with the wealth of life experiences that forced him to deal directly with pain and suffering. As clearly pointed out by the historian of ancient philosophy Giovanni Reale, one can indeed “learn through pain”, since “suffering does not teach man to take care of himself only, *but to take care of others as well*” (Reale, 1999, p. 321), modifying the person’s soul (*psuké*) and inwardness in an appropriate way. According to Plato’s theories in particular, “to become a good doctor and heal the sufferings of others, a doctor needs to have endured the same sufferings himself first”, because “the body is not healed with the body but with the soul—not only the patient’s but the doctor’s as well” (Reale, 1999, pp. 321-322).

Here is the passage that the scholar makes reference to, taken from the *Republic* (III, 408 C-E), i.e. the Platonic dialogue on justice *in interior homine* and in the ideal city:

> Don’t we need to have good doctors in our city? And the best will surely be those who have handled the greatest number of sick and of healthy people.[…]. The cleverest doctors are those who, in addition to learning their craft, have had contact with the greatest number of very sick bodies from childhood on, have themselves experienced every illness, and aren’t very healthy by nature, for they don’t treat bodies with their bodies, I suppose—if they did, we wouldn’t allow their bodies to be or become bad. Rather they treat the body with their souls, and it isn’t possible for the soul to treat anything well, if it is or has been bad itself. (Plato, 1997, pp. 1044-1045)

The doctor does not heal the patient with the body but with the soul, and the more his soul has experienced suffering on himself the more he will be able to recognise suffering, “feel” it, and manage and alleviate it in others (at least as far as he reasonably can).
Plato identified the doctor’s emotional involvement, made possible by the suffering felt upon himself before the encounter with the patient, as the true medicine capable of healing; and this is because (as can be deduced from the final negative affirmation: the soul cannot successfully heal something if it is—or has become—bad itself) the soul that learned to suffer is necessarily a good soul and only a good soul can recognise, practice and do good (Lombard, 2016, p. 83; Mortari, 2015, pp. 96-100).

The Greek philosopher obviously did not consider it possible, nor desirable, for all doctors to fall ill; the sense of the hyperbolic statement that he puts in Socrates’ mouth is the following: the doctor’s inwardness meets the patient’s in a profitable way only when he is able to feel the patient’s suffering on himself and therefore to fully understand it; once he has understood it, he will consequently know how to act properly and work with a view to doing good.

In so doing, the cure becomes “caregiving” that can help heal what is curable and make what is not curable bearable.

As is known, a relationship of cure (to cure) that actually also implies taking care (to care) was described by Sir Thomas More as one of the characteristic features of the ideal State on the island of Utopia, in which he imagined the existence of well-kept hospitals equipped with everything needed to treat patients, who are cared for with tenderness and with a watchful eye, where highly skilled doctors are constantly looking after them:

In distributing food, first consideration goes to the sick, who are cared for in public hospitals. Every city has four of these, built at the city limits, slightly outside the walls, and spacious enough to appear like little towns. The hospitals are large for two reasons: so that the sick, however numerous they may be, will not be packed closely and uncomfortably together, and also so that those who have a contagious disease, such as might pass from one to the other, may be isolated. The hospitals are well ordered and supplied with everything needed to cure the patients, who are nursed with tender and watchful care. Highly skilled physicians are in constant attendance. Consequently, though nobody is sent there against his will, there is hardly anyone in the city who would not rather be treated for an illness at the hospital than at home. (More, 1992, p. 42; emphasis mine)

In contemporary society this utopian vision of health has in part been achieved, with the emergence of large well-kept hospitals equipped with everything needed to treat patients and provided with increasingly advanced technologies: from high-precision diagnostic machinery to the most sophisticated lab instruments, in-house pharmacies and hyper-technological intensive care units. Nevertheless, two questions arise: Are patients cared for with tenderness and with a watchful eye? Are highly skilled doctors constantly looking after them?

There is no univocal answer to these questions. Whether this occurs or not depends on many variables, either social or economic, political, etc. There can be hospitals in the same city that meet, in whole or in part, the objective set out by Sir Thomas More and others that deviate greatly from it. Furthermore, there may be different situations in the various wards of the same hospital in which the ethos that is established can be either convergent with the idea of caring expounded by the English philosopher or clearly divergent from it. In addition to the general ethos of the ward, the individual operators also count, bringing with them their individuality (personal experience) and personality (character, disposition towards the other—whether in terms of openness or closure—and mentality, be it intercultural or not) that underlie the establishment of positive and effective relationships with patients.

The relationship, in actual fact, is expressed as communication: explicit and implicit, verbal and non-verbal. Doctors often use an allusive and metaphorical type of language (it should be noted that metaphors involve a dislocation and extension of the meaning of words which they import into speech) (Ricoeur, 2004)
which seems to be consubstantial with medicine. Indeed, if on the one hand it is true that “since its Hippocratic origins medicine has been nourished on metaphors and it has nourished [other fields] of metaphors”—and “in the former case, they are not medical metaphors but metaphors drawn from other fields, such as the economic, military, culinary, domestic, architectural, political, animal or vegetable ones, metaphors aimed above all at staging pathologies” (Maquelin, 2004, p. 743)—on the other hand, it is also true that in the latter case these are used to translate concepts (otherwise difficult to understand) into accessible terms, as well as to establish the specific roles of the social actors involved (doctor-patient) (Tomelleri, 2009, p. 163).

Thus, in the communication that characterises the social relationship that is established between doctor and patient, medical science is turned into an art (in the Hippocratic language referred to as: iatrikétêkne) which irremediably meets the rhetorical art (in the Platonic language referred to as: retorikétêkne) creating a fruitful combination that actually lays the foundations for care and caring.

As the sociologist Tomelleri (2009) puts it:

> Paradoxically, the more the cultural model of Evidence Based Medicine becomes established and consolidated within medical practices, the more the inescapable narrative, creative and artistic values of the care professions emerge. The richness and far-reaching scope of the metaphorical registers that are used in the course of conversations, relating to illness and the interactive context, social roles, therapeutic paths, etc. demonstrates that the metaphor is an act whereby care is provided with specific effects on therapeutic practices. The importance of the metaphor reveals the downsizing of certainties based on the current technical and scientific development of medicine and a renewed centrality of the transversal skills (negotiating, mediating, dissuading, solving problems) of health professionals as social actors. (p. 164; my translation)

When it comes to illness itself, that afflicts a person in a serious and sometimes even irreversible and deadly way, it can be understood as a metaphor: an existential metaphor, which expresses the patient’s personal experience by condensing it into a nucleus of meaning with indefinite margins, and yet still identifiable in its essence by an attentive and vigilant eye.

When the American writer Susan Sontag fell ill with breast cancer, she had the idea of writing a book about her illness, which she entitled precisely Illness as a Metaphor (Sontag, 2009). The author represented and interpreted the drama that she was going through also based on her own intellectual experience, sifting through her human story and considering illness as a metaphor for her own existence. This book thus provides an important interpretative tool, as it actually teaches that illness can be understood as a metaphorical symbol (from the Greek sunballo, meaning “I put (ballo) together (sun)”, “I condense”), according to which it is not just a physiological, biological, and psychophysical question... but something more: the patient lives an experience that is at the same time existential, anthropological, and philosophical.

In order to understand all this and to act accordingly and appropriately with respect to the specific treatment situation, the doctor who is faced with the sick person (and the disease that the latter is afflicted with in her whole being) cannot rely only on medical science strictusensu, whose role, however, remains essential, but it is to be hoped that he also acquires a whole set of notions and skills deriving from the human sciences.

If (as asserted by Georges Canguilhlem):

> The patient is a Subject capable of expressing himself, who recognises himself as a Subject in all that he is able to indicate through possessive expressions: his pain and the representation he makes thereof; his anguish, his hopes and his dreams. In short, it is impossible to cancel the subjectivity of the patient’s experience in the objectivity of medical knowledge. (quoted in Gaillle, 2011, p. 157; my translation; Canguilhlem, 2011)
Then as explained by Todorov (2011):

Understanding the individual, as well as the community, is essential for the doctor to succeed in identifying the appropriate reaction. It is too risky to ask him to rely solely on his personal intuition. It is in his best interest to profit from the knowledge gained over the centuries, concerning the psychic and social life of human beings, as well as the principles that govern actions relating to knowing and judging. In the past, this knowledge was contained in the works of philosophy and morals, history and politics; these still remain a living source of light. A particular place must be reserved for the arts and literature: images and, even more, literary works constitute the first human science. (p. 7; my translation)

Knowing human anatomy and the most advanced drug therapies is not enough for the doctor; he also needs spirituality, that is the spiritual dimension meant in the most general (non-confessional) sense possible. “Medicines” are not enough for him, he needs “medicine” in its original meaning of therapeutic art. As a matter of fact, “therapy” etymologically means “to put oneself at the service [of someone]”, that is to worry about and take care of someone: in ancient Greek a “Thérapon is the one who assumes an overall disposition, placing himself at the service of the other, though not necessarily turning this concern into concrete interventions” (Curi, 2017, p. 55).

Contrary to this original setting, the following often happens today:

Also—but not only—because he is physically unable to worry at the same time for many hundreds of individuals, the doctor transfers and objectifies his concern in a plurality of concrete acts, inevitably neutral from the emotional point of view, whose effectiveness therefore depends solely on a measurable incidence in quantitative terms, on the success they achieve above all from the point of view of the disappearance—or reduction—of the morbid symptoms. A real reversal therefore occurs with respect to the original approach. (Curi, 2017, p. 59; my translation)

It is thus a question of reversing again what was mistakenly overturned. Actually, the more we move in a hyper-technological context, immersed in the suffocating digital bureaucracy—and here, “in a medical world which is increasingly bureaucratic and technology-driven, the Hyppocratic personal touch seems in danger of being lost” (Porter, 2002, p. 45)—the more it becomes necessary for the doctor to recover a more global vision of the person, to the point of overcoming the exiguity of the anamnesis and prognosis, identifying (in Sontag’s words) the metaphor in which the specific experience he has in front of him is inscribed.

In the words of the French professors of human and social sciences in the medical area:

The carer must be sensitive to the fact that language cannot be confined to a simple communication tool. Speaking is being. It means going beyond the simple manipulation of symbols; it involves delving into the depth of a language crossed by the feelings and history—both intimate and social - of the subject. […] For the carer, communicating does not mean so much imposing his own speech (whether medical, informative or prescriptive) as rather sharing, building a bond with the person of the other in order to foster solidarity; in other words, understanding is the social and human meaning of medicine. (Collège des enseignants de sciences humaines et sociaux en médecine et santé, 2011, p. 426; my translation)

The value of care has been highlighted and explained in all its subtest implications—with references, in addition to the classics of philosophical thought, from Plato to Heidegger, to important contemporary female authors such as Stein, Murdoch, Zambrano, and Pulcini—by the scholar Mortari (2015) in her book The Philosophy of Care, a work of absolute theoretical relevance and conceptual clarity:

Care is a practice driven by the intention of providing benefit to the other; the principle of benevolence identifies the generative matrix of care. The orientation to seek what is good is actualised in some postures of being there: the assumption of responsibility towards the being of the other, which is oriented by concern for the other, feeling reverence for the other, nourishing the willingness to share what is essential and the courage to undertake initiatives. (p. 177; my translation)
You need to immerse yourself in the representation of human existence, which is limited, transient, fragile, and imperfect, as thoroughly described by Pascal, but recovering its greatness in the infinite and irreducible dimension of thought. *The doctor must be aware of the fact that the experience of an entire existence manifests and redefines itself in the disease.*

Sometimes the onset of disease is like the reflection in the mirror of a life at the time when its existence is being threatened, when it seems to be about to come (or is actually on the verge of coming) to an end. This term is configured as natural and unnatural at the same time: *natural* because the human being is biologically designed like this, to be born, grow up, and die; *unnatural* because the human being himself would like to escape his fate and avoid death (Bauman, 2013).

And yet death is an inseparable companion of our days; it dwells within life, in the inextricable intertwining of beginning and ending that makes up human history and is an unmistakable feature of the human condition of mortality. This is precisely the intolerable paradox of dying, which is at the same time the natural epilogue of existence and the violent subtraction of will and freedom, a physiological and at the same time radical traumatic event, an experience of the limit but also a reference to a possible “ulteriority”.

Death has always been one of the constituent objects of medicine, as are health and illness, as well as its opposite: life; we also find it in the definition of “medicine” that appears in the 10th volume (pp. 260-275) of the monumental work edited by Diderot and d’Alembert: the *Encyclopédie* (Barroux, 2017, pp. 94-103).

From the point of view of modern philosophy of medicine it is necessary to distinguish between the *biology of death*, whereby death coincides with the cessation of the functioning of vital organs (La Marne, 2004) and the *metaphysics of death*, whereby the more general concept of “person” (*personhood*) and the more particular concept of “consciousness” are inserted in the definition of death (Stegenga, 2018, pp. 37-38) and specifically:

> Death of the organism occurs when the relevant bodily processes cease to function. Death of the person occurs when the relevant moral-status-conferring processes cease to function. [...] The death of a person occurs when there is an irreversible cessation of the capacity for personhood. But what is that? (Stegenga, 2018, p. 39)

The answer to this question is controversial and has given rise to extensive debates in the field of bioethics, whose countless implications cannot be discussed here for the sake of brevity. One fact is that, due to the ever increasing number of people dying in hospitals or other socio-medical institutions (i.e. hospices, care homes, and retirement homes), healthcare workers are increasingly faced with end-of-life, carrying out also the *spiritual* role that was historically entrusted to religious figures or to relatives and friends of the dying person (Fagot-Largeault, 2010, pp. 200-201; on the nearly “sacerdotal” role of doctors see Minois, 2015, pp. 390-391; see also Stanworth, 2004).

What dignity, then, can be recognised in the suffering of the last days in an “institutionalised” environment? Can we perhaps speak of a *dignity of dying* (just as we can speak of a dignity of living)? How do we deal with that living in which the margins of operational and functional autonomy are now reduced to zero? The extreme responses to these questions—euthanasia on the one hand and excess of futile medical care on the other—emerge on the uncertain and problematic field of the ordinary encounter with death, sometimes humiliated by physical degradation and the inefficiency of health facilities, as well as by existential *loneliness* of the typically human *anguish* in the face of the imminence of the approaching end (Alici, D’Agostino, & Santeusanio, 1998).
In view of the limits of science and of the risks entailed of a progressive medicalisation of life, a close
collaboration between families and health structures is highly needed, while the legitimate claim of the patient’s
right to autonomy requires searching for a new balance in the medical profession (Alici et al., 1998, p. 6).
Hence there is a need for a complete professional and ethical training of the doctor, to give a new substantial
boost to the culture of solidarity and help and therefore to “an accompanying practice (pratiqued’accompagnement) that, in addition to the medical dimension, also makes room for psychological
and social aspects, for instance by fully integrating the patient’s entourage” (Lombard & Vandewalle, 2010, p.
104; my translation).

In response to the widespread repression and trivialisation of death, it is necessary to overcome the
impersonal point of view so as to become able to look at death firsthand through the hard training in providing
assistance to the dying person. Indeed, when healing is impossible, caring remains a task that goes less and less
through the cold and invasive procedures of technique and more and more through the warm and discreet
gestures of the tenderness of solicitude. In this way, in the gratuitousness of a relationship with the other—who
is a loser only in belonging—we discover a way to build a horizon of responsibility that goes beyond the
inexorable laws of biology.

Suffering is, in part, enduring what happens, feeling a certain degree of passivity; sometimes, however, it can also
bring with it something constructive. Although manifesting itself aggressively, as something destructive, suffering also
manages to positively question the subject about the possibility of a re-construction. (Collège des en seignants de sciences
humaines et sociales en médecine et santé, 2011, p. 413; my translation)

Death teaches people to recognise themselves as “entrusted to their own body, without completely trusting
in it; death is the outrage of the limit as hope for the ulterior” and it is important to make fear evolve in a
rational way, to grasp the meaning of the extraordinary fact that is happening (Alici et al., 1998, p. 7).

Illness generates bewilderment, melancholy, loneliness not only for those who are sick and for their
families, but also for health care workers. The heart is frightened, as the current pandemic period has shown us:
images of death, family members who not only cannot mourn their relatives but sometimes not even see them
one last time or even “struggle” to find them with the fear and terror of having lost track of them forever.

Loneliness is the predominant feeling from which everyone would like to flee because it is the experience
of non-relationship, of an I without a YOU. A literary giant can help us in the reading of illness as loneliness:
Dostoevsky. In Crime and Punishment, going through the drama of evil, especially in a moral sense, the great
author lets us touch the noble fruit of the self-in-relationship: love; and this sends us back to the compassion
that guides and leads to true and authentic caring:

When in life you experience good care events, which nourish the soul with trust, then you know how to be in the
presence of pain without it overwhelming you. The absence of care, on the contrary, makes you weaker, more fragile, and
more ready to be annihilated by pain. [...] The ability to take care of the other also lies in this: being there when the other
feels all the fatigue of the business of living, showing the willingness to share what one has to support together the work of
weaving existence without letting the sense of a cold life of loneliness extinguish the vital energy. [...] When care as
therapy takes charge of the person as a whole (mind and body), then it is not just—so to say—a “repair of something that
has jammed” in the body, but in fact a comprehensive care of the being as a whole. (Mortari, 2015, pp. 34-35; my
translation)

The last frontier of care, if you are in the presence of “a serious, degenerative or terminal disease”
(Baszanger & Salamagne, 2004, p. 1058), is represented by palliative care, which shows a rediscovery of the
deepest vocation of medicine. *Medicine consists first of all in taking care:* its task is to cure even if it is not always possible to heal. How? Relieving suffering as much as possible; managing and eliminating physical pain (Baszanger, 2004).

Over the last few decades, palliative care has developed to such an extent that it now represents a new medical discipline, as pain has been by now recognised as a disease and, consequently, the patient’s right to be relieved of it has been lawfully established.

While erroneous conceptions still persist (such as the one expressed by Alex Broadbent in *Philosophy of Medicine*, according to which “pain relief […] is a use of medicine and medical knowledge, but not a goal of medicine per se” (Broadbent, 2019, p. 46) and not even palliative care would prove the opposite) the far more enlightened views that prevail today put human dignity and the quality of life, even in the end-of-life phase, in the foreground (Lombard & Vandewalle, 2010, pp. 102-106, 117-118). Furthermore, many nations have adopted these views, converting them into legislative and regulatory acts; such was the case for national law Number 38 of 2010 in Italy, which establishes the right of citizens to anti-pain therapy and palliative care. Even a transnational religious institution such as the Roman Catholic Church, which has always conceived pain as a form of personal redemption and approach to the divine, in an official document addressed to health workers asserts the legitimacy for doctors and, in the most acute cases, even the duty of “preventing, alleviating and eliminating pain” (Pontifical Council for Pastoral Assistance to Health Care Workers, 2021, Article No. 70; see also Conferenza Episcopale Italiana—Ufficio Nazionale per la Pastorale della Salute, 2020).

Palliative care bears witness, within clinical practice, to the awareness that the limit requires not only to be fought and shifted, but also to be recognised and accepted. When all the resources of “doing” seem to have run out, it is precisely then that the most important aspect in human relationships emerges, which is that of being: being present, being close, being welcoming, following the footsteps of the woman who founded hospices and conceived the idea itself of *palliative care*: Cicely Saunders (Clark, 2018).

When curative treatment (*soin curatif*) fails, it is precisely from this failure (*de ceté chec*) that the other side of the Care—i.e. *palliative care* (*soin palliatif*)—originates (Lombard & Vandewalle, 2010, p. 104). Like a cloak (from the Latin word “pallium”, hence the name) palliative care holds in a warm embrace the chilly torpor of death that tries to take possession of the sick body, enveloping the *humana fragilitas* as much as it can.

References