

## Doctor's responsibility and end of life: the right to negotiate "time"

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*When you left  
I felt  
how much I missed you  
but not for how long.  
... All the rest of my days  
without the rest of your days  
All the rest of me  
without the rest of you...  
(Pier Mario Giovannone)*

### Time in the care relationship

The recent Italian law on consent (Law 219/2017 "Rules on informed consent and advance treatment provisions") has valued time as a central aspect of communication by stating that this time is a time of care, capable of supporting the acceptance and effectiveness of therapies (1,2).

This is certainly an important affirmation that urges the various health professionals to regain possession, despite the moment of strong dominance of technical and scientific skills, of that role that has always been theirs, characterized by a very close nearness with the suffering person (3).

Law 219/2017 has also enhanced the dimension of time in the choice of care, through the advance treatment provisions that offers the possibility of planning one's own therapeutic path in accordance with one's own convictions and existential instances.

The importance, the value and, at the same time, the critical issues of time thus assume in the context of care essential aspects of the entire process of taking charge (4-7).

Entering a path of illness also means measuring oneself with the dimension of temporality and finiteness, with the quality of time that remains and belongs to us, with the possible projects, with waiting, with memory and with memories (8,9).

Making, designing and occupying time, choosing according to one's priorities, allows the sick person to remain anchored to himself, to experience himself as a subject, as an individual, rather than as a mere patient.

The correct and truthful communication to the patient (who does not consciously renounce information) finds and allows, in this context, respect for the autonomy and integrity of the person in all his different and multiple existential dimensions (10-12).

It belongs to the problems related to the management of time also the possibility of deciding to limit the cycle of illness and pain.

The right to choose to die has been the subject of numerous and heated debates for years, today further nourished by the recent decision of the Constitutional Court which provided for the possibility in certain and stringent conditions to avail themselves of aid to carry out one's suicidal intentions (13, 14).

How to live and how to spend one's life and one's end of life is a recognized right that is confronted with complex and heterogeneous problems, not always fully investigated in the different aspects (freedom from pain, the right to accompaniment, the right to prepare freely in one's end-of-life path).

An aspect of great importance on the ethical level concerns the right of the person to live the end of life by planning his being a person in accordance with his own demands.

This right is closely related to the problems of a communication that is sometimes lacking, difficult and/or untruthful (15-17).

For years, the growing attention to respect for the dignity and rights of the assisted subject-person has been promoting full information for the patient about the disease, the course and the therapy. However, the doctor's practice of remaining silent or "manipulating" the truth in the hypothesis of a serious or poor prognosis is still widespread.

And indeed, communication in medicine knows several critical aspects in relation to the truth and confidentiality of information with respect to third parties who may have an interest in their knowledge (18,19).

### **The dignity of time and the claim for compensation for delayed diagnosis**

The recent decision no. 10424 of April 15th, 2019 of the Civil Cassation (sec III) offered significant elements of reflection on the problem of communicating diseases with a poor prognosis and on the remaining time of the person (20).

To grasp the profound meaning, as well as the innovative scope of the principle affirmed by the ruling, it is essential to move from the peculiarities of the concrete case, also in order to appreciate the obvious profiles of difference, compared to the much better known figure of the damage from loss of chance (21).

In the case discussed by the Supreme Court, a hypothesis of delayed diagnosis of a disease with a certainly inauspicious outcome comes to the fore.

The story concerned a young woman undergoing a total hysterectomy in which the histological examination reported the presence of a benign fibroid.

After the surgery, however, the lady continued to experience the same pains that forced her to a new hospitalization. It was renewed the evaluation of the previous histological examination, following which doctors diagnosed a smooth muscle tissue sarcoma. After a short time, the woman died.

The diagnostic error was ascribed to the medical staff who had performed the histological examination. The relatives of the woman denounced the doctors, claiming that the delay in the diagnosis of the tumor

had subtracted chances of greater and better survival from the woman.

The judges assessed, however, that even a correct and timely diagnosis would have been free of therapeutic consequences, both in terms of healing and in terms of the possibility of treatment capable of affecting the quality of life of the patient herself.

According to the judges, in fact, the intervention concretely carried out on the woman, consisting in the total hysterectomy with bilateral annexectomy, would have been, in the opinion of the technical consultants, completely similar to that to be performed in the event that the presence of a malignant sarcoma had been promptly detected. Consequently, even the correct diagnosis would have had no influence on the therapy.

From this consideration the judges of merit brought forth the impossibility of recognizing a harmful event, both in terms of the loss of chance of recovery and under that, distinct from the first, of a more lasting survival of the patient.

The woman's family members, censuring the findings of the judges of first instance, appealed to the Court of Cassation. In particular, the relatives pointed out that the judgment under appeal did not consider that, in the presence of a timely diagnosis, significant consequences would have arisen in terms of the patient's quality of life, even from a strictly existential point of view, regardless of the possibility of recovery, or of a more lasting survival.

In particular, the family members referred to a previous decision of 2008 of the Third Section of the Court of Cassation itself (22), in which relevance was also attributed to the fact that the error in the diagnosis could have prevented the patient not only from choosing the most suitable solution among the various alternatives offered by medical science, but also from the faculty of consciously approaching the end of life, preparing himself for this event in the way considered to be in conformity with his own sensitivity.

On the basis of these arguments, the Court of Cassation accepted the reasons of the woman's family members. According to the Supreme Court, the delay in the diagnosis of pathology, although certainly an unfortunate outcome, can determine legally appreciable harmful consequences, especially in relation to the

deprivation of the patient's ability "to plan his being a person" and "to determine oneself freely in the choice of one's own existential paths in a condition of life affected by pathologies with a certainly inauspicious outcome" (20).

The considerations expressed regarding the enhancement of the boundaries of free determination of the individual with regard to the ways in which to "face the last stretch of one's life path" are extremely incisive, regardless - it must be emphasized - of any claim to judgment on the "dignity of the contents" of those possible choices (20).

From the point of view of the legal classification of the damage in question, the judgment in question points out its difference from that of loss of chance, of which the configurability in the specific case is excluded, highlighting its full conceptual autonomy.

Although, in fact, the culpable diagnostic delay does not affect, in these hypotheses, physical integrity, not being placed in a causal relationship neither with respect to the concrete methods of progression of the disease, nor with respect to the determination of the unfortunate outcome of the same and neither to the duration of survival, it is necessary, on the other hand, to contemplate the possibility that it may negatively affect the "quality and organization of the patient's life". It is precisely this deterioration in the quality of life that would constitute the harmful event liable to give rise to compensation liability.

### **The right to enter death with open eyes**

The decision in question brings to attention an ethical issue of great importance that concerns the recognition of the correctness of the information and the impact that it may have on the quality of life-time available to the patient. A time that belongs to the person and that acquires a particularly significant value when this time is burdened by an illness with an unfortunate outcome.

The premise on which the judgment of the Supreme Court is based is the recognition that the legal system is not at all indifferent to the need of the human being to "freely determine himself in the choice of his own existential paths" (20), once he knows that

he is suffering from a pathology with a certainly inauspicious outcome.

On the basis of this assumption, founded on the right to know, the judge underlines with great ethical sensitivity, an absolutely unprecedented profile that concerns the right of the sick person to consciously approach the end of his life, preparing for this inevitable event in the way deemed most appropriate, both materially and spiritually (23, 24).

Regardless of the fact that the diagnostic delay did not in itself probably influence a shorter survival, the Court identifies the right of the person "to enter death with open eyes". With this effective and learned literary quote, taken from the *Memoirs of Hadrian* by Marguerite Yourcenar, defined by the Italian judge as "one of the highest voices of the literature of the '900", the Court incisively outlines the profound meaning of the nature of the damage in question. It consists in the loss by the woman of the "choice to proceed (as quickly as possible) to the activation of a therapeutic strategy, or the determination for the possible search for alternatives of a merely palliative nature, but also the same decision to live the last stages of her life in the conscious and aware acceptance of suffering and physical pain (without resorting to the aid of any medical intervention) waiting for the end".

The judge's analysis is in tune with a wide-ranging vision of care, which finds its origin in a vision of human being attentive to all the dimensions of his being and which values the importance of combining "care" and "taking care". In this vision, caring does not always and only mean making the person survive at all costs, but rather taking on the shared responsibility of accompanying life to its natural fulfillment, in the awareness of the limits of the human condition and of knowledge.

In recognizing the importance of a non-exclusively material dimension of existence, it is outlined the consequent need to offer protection and meaning also to the possibly metaphysical perspectives to which an individual can adhere and, consequently, to one's determination on how to prepare for the end of life (25).

Recognizing the right of the human being to enter death with open eyes means, in fact, qualifying as a good of life worthy of protection that intimate and decision-making sphere of the person that invests the

choices of a more strictly religious and philosophical nature.

The distinction, although not explicit in the pronouncement, is to some extent implied, since the decision-making space likely to be harmed concerns both, on a material level, the choice of how to live the time that separates from the end, and, perhaps, a fortiori, that of how to prepare oneself for when life will end.

From this point of view, the sentence appears innovative and suggests not obvious reflections on the relationship between law and the most intimate sphere of conscience.

For the particularity of the story and the rigor of the argumentation, the sentence must certainly be counted among the rulings, made on issues of particular importance from an existential and human point of view, which have recently intervened on the delimitation of the scope of the choices relating to the “end of life”.

The Court of Cassation, in fact, does not rule on the contents of possible decisions relating to the end of life, but limits itself to noting how an adequate space of self-determination must be protected and, indeed, underlines that this freedom is relevant in and of itself, regardless of the content of those choices.

In fact, the formation of the Court affirms that “even suffering and pain, where consciously and awar-ely not cured or alleviated, acquire a very different meaning, in terms of quality of life, if accepted as a fact determined by one’s own personal option of value in the perspective of an end that is announces (more or less) imminent, rather than passively experienced, as mysterious signs of an inexplicable, unfathomable and distressing, inevitability of things” (20).

These are, perhaps, precisely the most significant considerations of the judgment, which give back the meaning of the reference to the phrase of Marguerite Yourcenar.

The Court of Cassation, in short, puts us in front of the fundamental importance of the awareness of the end and the need to be able to enter death with open eyes, precisely in order to allow the individual to express his most intimate, as well as last, existential choices.

## Conclusions

Today’s society confronts us with continuous challenges and problems that are not easy to solve.

The availability of increasingly efficient, safe and manageable diagnostic and therapeutic tools is certainly an important milestone that has allowed an improvement in the quality of care. However, alongside a necessary specialization, the loss of global attention to the person is often denounced. Training in the themes of pain, death, solidarity, end of life and the value of conscientious objection is of fundamental importance to the role that the physician and health professional assume within the community (26-28).

The medical school must be the guarantor of the global and permanent training of doctors, favoring the integration of technical-scientific knowledge with the humanistic one. If this combination is not realized, the doctor is destined to remain a mutilated doctor, a body technician able, at best, to cure the disease, but not to take care of the person.

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