

EDITORIAL

I IN SEARCH OF THE LOST RIGHTS

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The Numbers of Cancer in Italy (latest available data) estimate over 390 thousand new diagnoses of all cancers in 2022. Cancer deaths in 2021 were over 181 thousand, a figure substantially similar to the forecast of about 175 thousand deaths in 2022. COVID pandemic deaths were, in Italy, about 190 thousand in 3 years, so an average of 60 thousand per year. These data show how cancer mortality is still a major problem, to the point that, often, we refer to cancer (which is not one but a collection of different diseases) as “the evil of the century”, “the ugly evil”, a disease that cannot be named because “cancer equals death” and, often, equals “death with pain”. We often speak of a battle against cancer from which only a few survivors emerge victorious (always the warlike simile, the necessity of the fight, a warlike language that patients, first, dislike). However, little mathematical knowledge should make us realize that 180 thousand is less than half of 390 thousand and, therefore, at least 50 percent survive diagnosis. Nonetheless, one could think that they will die from cancer sooner or later, but the reality is different.

The prevalence of cancer, that is, the number of people who are alive after a cancer diagnosis affects, in fact, a significant number of people, almost 6 percent of the Italian population. In 2006, there were 2.5 million people, a number that increased to about 3.6 million in 2020, or 5.7 percent of the Italian population. Interesting to note that

the increase was particularly marked for those living more than 10 or 15 years after diagnosis. In 2020, about 2.4 million, 65% of the total and 3.8% of the population, have been diagnosed for more than 5 years, while 1.4 million, or 39% of the total, have been diagnosed for more than 10 years. At least 1 million of this multitude of individuals have the characteristics to be considered cured.

Within these 3.6 million patients, there are different types: patients in the acute phase, at the beginning of their history or after the appearance of a recurrence; patients in the chronic phase with disease present but controlled in its course by drug treatments; long-surviving patients without disease but with a time since diagnosis still too short to assume a cure; and cured patients without a recurrence of disease in the absence of active treatment and with an interval free from the last treatment such that it is possible to imagine that the disease is no longer present.

Therefore, can one be cured of cancer? The term “cured” in Oncology has been, often, underused, preferring terms such as long-survivor or, even, survivor. In fact, it has long been known that there are patients who can, with reasonable probability, be considered cured. It is assumed that a patient who has had a previous oncologic disease is to be considered cured when his or her risk of death is comparable to the risk of death of subjects of equal age and equal sex, with the oncologic disease no longer causing an excess mortality with

respect to the general population. Obviously, this is a statistical concept, and it is not possible with absolute certainty to define that the individual cannot, in fact, die from the oncological pathology but, with statistical certainty, his or her probability of dying from any cause, including the oncological one, is no greater than that of anyone else.

There are two tools that can be useful in identifying potential healers: the fraction of healing, that is, the number of patients with that pathology who will not die from the pathology, and the time to healing, that is, the time required so that, in the average person with a previous diagnosis, the oncologic pathology does not result in additional risk of death. Both elements are different among different types of tumors. The age of the patient also plays a role in this assessment. In an older individual, the causes of mortality determined by other diseases typical of advancing age are so numerous that they outweigh the risk of cancer mortality. Differently may be the case of a subject at a younger age. There are, however, diseases in which the percentage of cure is so high and the time to cure so short that, beyond reasonable doubt, the patient can be considered cured some time after diagnosis, the risk of additional mortality being so low that it is not relevant even in the absence of competitive mortality. In addition, the risk of death from an oncological pathology is influenced not only by the type of neoplasm but also by the stage at diagnosis and the availability of curative treatments. Thus, for each cancer pathology completely different time-scales should be specified to define a cured subject but, in most cases, a subject who is free of disease beyond ten years after the end of treatment can, in the absence of recurrence, be considered truly cured. For many cancer patients, the excess risk of death has become the same as in the general population within 5-10 years after diagnosis. Exceptions to this rule are some neoplasms in which the time to cure is longer and all neoplasms arising in childhood and adolescence in which this time can be reasonably reduced to five years.

The fact that a person who has had a cancer disease could be considered cured represents a radical paradigm shift: from "cancer incurable disease" to "cancer chronic disease" from which one can be cured. One is not always cured, this is unfortunately not yet possible and unlikely to be absolutely possible in the future, but rather one can be cured. This paradigm shift can also become a motivator for adherence to screening, once it is understood

that healing is easier the earlier it is diagnosed. The definition of a cured cancer patient can thus also have a public health role.

Although the cancer patient may therefore reach a point where he or she can be considered medically cured, this often does not correspond to legal and social healing. In essence, a cancer patient, even when his or her illness no longer involves excess additional mortality is considered a "cured sick person" and is likely to encounter difficulties in his or her daily life when, for example, he or she tries to take out life insurance or applies for a mortgage or bank loan to start a business. Fewer difficulties, or at least not explicit difficulties, he/she encounters in the world of re-employment, but the professional situation of people diagnosed with cancer has been shown to deteriorate considerably two years after diagnosis. He or she may also have a more challenging path when deciding to begin an adoption journey, although there is no rule against adoption even for patients who cannot be declared cured in the absence of immediate death risk. The issue thus has some cultural aspects that require the need for information for all citizens and, often, for the medical profession as well, and training for certain practitioners, such as magistrates, on the problem, but it can have real impacts in the insurance and banking world. Indeed, a previous cancer diagnosis is still considered equivalent to a poorer life expectancy, and the stigma remains, regardless of the actual conditions of treatment or to the criticism of the chronic disease.

Several European states have enacted ad hoc laws to define the terms under which insurance companies can request information about a prior cancer condition, starting with France, followed by the Netherlands, Belgium, Luxembourg, Portugal, and Romania. These legislations exclude the possibility of requesting information about the oncological past of disease-free patients for 10 years, if the disease had arisen in adulthood, or 5 years in the case of disease arising in minor individuals.

Thus, in February 2022, the European Commission in the context of the European Oncology Plan called for all member states to have a law on the "Right to Oncological Oblivion"; and by not merely making this concept explicit, it hopes that this will happen by 2025.

In Italy, the issue has been raised for years and has involved many different actors, from scientific societies to patient associations. On this basis, the Italian Association of Medical Oncology

(AIOM) Foundation decided to launch, in January 2022, a campaign to collect signatures in support of the proposal for a law on the Right to Oncological Oblivion, accompanied by a social campaign to spread awareness of the problem of discrimination of cured cancer patients to the entire citizenry *#iononsonoilmiotumore* (*#Iamnotmycancer*). Several scientific societies, patient and citizens' associations joined this campaign, and more than 107,000 signatures were collected. Meanwhile, during 2022, at least 4 law proposals were submitted by parties of all political orientations but the end of the legislature in July 2022 caused them to lapse. In the new legislature, additional drafts have been submitted, by all political forces and the Consiglio Nazionale dell'Economia e del Lavoro (CNEL), and the single text drafted by the Parliamentary Commission it was discussed and approved on 28 July 2023 by the "Camera dei Deputati" and will have to pass to the vote in the "Senato" of the republic in the coming months.

The law on the Right to Oncological Oblivion would make it possible to no longer have to declare an oncological pathology 5 years after the end of treatments in the case of a cancer diagnosed before the age of 18 and 10 years in the case of a cancer diagnosed after the age of 18 years, in the absence of recurrences. But as it is already the case in France, over time we could achieve further reductions, because there are oncological diseases found in early stages for which it is possible to speak of a cure as early as one year after diagnosis. Therefore, once the law is passed, we will then have to create tables to make the necessary distinctions.

This law does not aim at the deletion of personal health data, which must continue to be present and available in public information systems, be-

cause they serve to monitor the evolution of one's clinical picture, but also to be able to continue to take advantage of any concessions or exemptions from co-payments, they serve the evaluation of the performance of the Health System, and they serve research.

The "Right to Oncological Oblivion" is an ethical law and is the first stage of a path that AIOM Foundation with *#iononsonoilmiotumore* will continue for other rights denied to cancer patients.

There is life after cancer.

COMPLIANCE WITH ETHICAL STANDARDS

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